

**Digital Storytelling: Towards Epistemic Justice for People with Psychotic Disorders and
Establishing a Line of Communication**

Liquaa Wazni, RN, BScN

Thesis Submitted to the University of Ottawa in partial fulfilment of the requirements for the
Degree of Doctoral in Philosophy in Nursing

Faculty of Health Sciences

School of Nursing

University of Ottawa

© Liquaa Wazni, Ottawa, Canada, 2022

Abstract

People with psychotic disorders die earlier than expected due to physical illnesses such as cardiovascular diseases, diabetes, and cancer. Despite substantial evidence about managing physical health to improve quality of life and reduce morbidity and mortality, there is limited research from the perspectives of people living with psychotic disorders. Since discourses are attached to all areas of knowledge, I situated myself within the critical social paradigm to understand factors that subjugate voices of people with psychotic disorders in research, practices, and policies. I used postcolonial theory as a lens for my research to show power asymmetry that often oppresses and dominates patients based on exclusion. Postcolonial theory in general and Spivak's theory more specifically helped draw the parallel between systems of power such as colonization and patriarchy that silence the subaltern in the context of colonization and people with mental illness in psychiatry. Committing to Spivak's theory of subalternity for self-representation, I chose digital storytelling as a methodological approach for generating transformative knowledge that exposes forces that mediate health and illness. Digital storytelling has an epistemological commitment to self-representation and critical reflection through visual, audio, and other forms of expression that facilitate more accurate articulations of experiences.

The overarching purpose of this thesis was to explore the process of digital storytelling with people with psychotic disorders as a means of expressing their voices and to understand how nurses and healthcare leaders engage with the digital stories and foresee the use of digital stories in healthcare practices and policies. Six short videos capturing personal stories of people with psychotic disorders about their physical health needs and concerns were produced. Digital stories are audio-visual vignettes of approximately 2-5 minutes in length, presenting first-person stories in conjunction with audiovisual material (photos, images, soundtracks, etc.). The digital

stories were presented in 2 focus group sessions to understand their impact on nurses and nursing leaders (n=15). Findings from this research brought forth stories that spoke of deep struggles people with psychotic disorders experience in addressing their physical health concerns within the psychiatric system. Participants talked about their embodied experiences and invisibility in the healthcare system in their digital stories. They expressed that healthcare providers had paternalistic approaches when addressing their physical health problems and revealed how they compensated for their lack of power and loss of identity. Story makers embedded their experiences with notions of powerlessness and despair and the associated negative impact on significant aspects of their lives. By reflecting on the digital stories and placing the content of stories within the larger context of the psychiatric system and current practices, nurses were able to expose power relations and structures such as quantitative approaches to care, stigma, and the biomedical model of care that excluded the experiences of people with psychotic disorders in psychiatry. Meanwhile, reflecting on the stories exposed nurses' passive stance in challenging and resisting the dynamics that exclude patients' voices at every level of care. In this research, Spivak's theory helped highlight the thematic centrality of epistemic violence and the role of the digital stories in overcoming epistemic injustice and opening a line of communication with those in positions of power in psychiatry.

Acknowledgement

This dissertation is dedicated to my husband (Farzad Panahi) and my children (Ali, Cameron, and Adrian) for all the love and support while on my dissertation journey. I could not have completed this process without their consistent and loving encouragement. To my beloved husband of 15 years-my light, my strength, my comforter, my everything-your presence in my life has fostered much of the resiliency required to finish this Ph.D. You have been with me every step of the way. I am forever grateful for your ability to keep me grounded when things get challenging. Without your love, patience, and enduring selflessness, I could never pursue and complete this journey.

I would like to especially thank my dissertation supervisors, Dr. Wendy Gifford and Dr. Amélie Perron, for their continuous encouragement and dedication and for sharing their knowledge, passion and criticality. They have truly been a source of inspiration and strength. I could not imagine a more motivating and inspiring guide accompanying me on this journey. With their guidance, leadership, knowledge, and skills, I was able to advance in my academic endeavours and overcome the difficulties and obstacles of being a doctorate student. Engaging in discussions on the philosophical perspectives that have shaped nursing science helped me re-examine my intentions and motivations as a researcher. They helped me realize my true passion and identify my research direction.

I would like to thank my thesis committee, Dr. Amanda Vandyk and Dr. Ian Graham, for their interest in this project, their ongoing support and immense wealth of knowledge, and for challenging me to examine my work in new and vastly meaningful ways. I want to acknowledge the examiners, Dr. Dave Holmes, Dr. Roanne Thomas, Dr. Sandra Harrisson, and Dr. Ruth Desouza, for their excellent feedback.

To my loving and supportive family and friends, Shahrzad, Mohammad-Ali, Nasreen, Parviz, Alaa, Rida, Laith, Reem, Rania, Ala, Angie, and Chelsy, thank you for believing in me and encouraging me to always push forward. I love you all and I am so lucky to have you in my life.

I would like to thank Dr. Barbara Davies, Dr. Craig Phillips, and Dr. Patrick O’Byrne for believing in me and encouraging me to pursue a doctorate degree. I would like to acknowledge and thank all the participants who bravely shared their narratives; I continue to be humbled by the resiliency they possess to navigate the increasingly complex and challenging realities of the healthcare system.

Acknowledgement of Funding Sources

I am grateful to the following funding sources for financially supporting my doctoral education and this research study:

- University of Ottawa Admission Scholarship
- Ontario Graduate Scholarship
- University of Ottawa Excellence Scholarship
- Nicole Begin-Heick Scholarship

Table of Contents

Abstract	ii
Acknowledgement	iv
Acknowledgement of Funding Sources	vi
Chapter 1: Introduction	1
My Initial Research Plans	1
The Evolution of My Epistemic Stance	5
The Evolution of My Research-New Inquiry and Direction.....	8
Research Objective and Questions.....	11
Chapter 2: Review of the Relevant Literature	11
Definition, Diagnosis and Treatment of Psychotic Disorders.....	11
Poor Physical Health of People with Schizophrenia.....	17
Factors Contributing to Poor Physical Health of People with Schizophrenia.....	19
<i>Antipsychotic Medications Leading to Physical Conditions</i>	19
<i>Social Factors and Their Impact on Physical Health</i>	24
Socio-economic Status.....	25
Networks and Belonging.....	26
<i>Healthcare Disparity Leading to Physical Conditions</i>	27
Voice, Power and Agency of People with Psychotic Disorders in Psychiatry	29
<i>The Antipsychiatry Movement</i>	30
<i>A The Critical Psychiatry Movement</i>	35
<i>The Recovery Movement</i>	37
Art-Based Research-Audiovisual Methods.....	42
<i>Digital Storytelling</i>	44
Digital Storytelling Workshop.....	46
Digital Storytelling in Research, Practice, and Policy	46
Digital Storytelling in Mental Health	47
Chapter 3: Theoretical Framework	50
Postcolonialism	50
The Contribution of the Co-founders of the Postcolonial Theory	51
The Contribution of the Co-founders of the Postcolonial Theory	52

<i>Orientalism by Edward Said</i>	53
<i>Homi Bhabha's Discussion of Cultural Hybridity</i>	55
<i>Subalternity by Gayatri Spivak</i>	57
Controversies Surrounding Postcolonial Theory	58
Use of Postcolonial Theory	61
Spivak's Theory of Subalternity	63
<i>Controversies Surrounding Spivak's Theory of Subalternity</i>	68
<i>Relevance of Spivak's Theory of Subalternity to This Research</i>	69
People with a Mental Illness as Subalterns	71
Opportunities for Resistance Through Radical Approach to Knowledge Creation	76
Chapter 4: Methodological Considerations	83
Digital Storytelling: A Participatory Approach	83
Methods	84
<i>Stage-1: Developing Digital Stories with People with Psychotic Disorders</i>	85
Setting (Stage-1)	85
Sampling Approach (Stage-1)	85
Eligibility Criteria (Stage-1)	86
Recruitment Process (Stage-1)	86
<i>Gaining Access to SSO</i>	87
<i>Strategies to Approach and Recruit Participants</i>	87
<i>Data Collection (Stage-1)</i>	88
Developing the Stories	90
<i>Developing a Narrative</i>	90
<i>Building the Digital Story</i>	91
<i>Recording the Voice-over and Adding Sound</i>	92
<i>Photoshop Tutorial: Adding Emotions and Making the Story Visible</i>	92
<i>Storyboarding</i>	93
<i>Sharing the Story</i>	94
<i>Data Analysis of the Narratives (Stage-1)</i>	94
First Level of Analysis	95
Second Level of Analysis	95
Third Level of Analysis	96
<i>Stage-2: Evaluating the Digital Storytelling Process</i>	98

Data Collection (Stage-2)	98
Data Analysis (Stage-2)	99
<i>First Level of Analysis</i>	99
<i>Second Level of Analysis</i>	99
<i>Third Level of Analysis</i>	100
<i>Stage-3: Screening of Digital Stories with Nurses and Healthcare Managers</i>	101
Setting and Sample (Stage-3).....	102
Recruitment and Sampling Approaches (Stage-3).....	102
Data Collection of Focus Groups (Stage-3).....	104
Data Analysis of Focus Groups (Stage-3)	106
<i>First Level of Analysis</i>	106
<i>Second Level of Analysis</i>	107
<i>Third Level of Analysis</i>	108
Ethical Consideration.....	109
<i>Digital Storytelling Participants</i>	109
<i>Focus Group Participants</i>	112
Rigor Criteria	114
Chapter 5: Findings.....	123
Description of Participants	123
Digital Storytelling Process.....	124
<i>Figure 1: Digital Storytelling Process</i>	124
<i>Constructing the Story</i>	125
Identifying/Describing Physical Health Issue.....	126
Managing the Logistics.....	132
Managing Risks	135
<i>Digital Storytelling as a Powerful Process for Storytellers</i>	140
Content of the Digital Stories.....	144
<i>Figure 2: Content of the Stories</i>	144
<i>Bodies as a Contested Site of Struggle</i>	145
Body as a Biological Entity in Relationship with Society	145
<i>(In)visible Patients</i>	150
Paternalism.....	150
Disseminating Stories.....	155

<i>Figure 3: Disseminating stories.....</i>	<i>155</i>
<i>Using Digital Stories.....</i>	<i>156</i>
Second Step of the Study: Screening the Digital Stories	161
<i>Description of Participants.....</i>	<i>161</i>
<i>Table 2) Demographic Characteristics of Nurse Participants.....</i>	<i>162</i>
<i>Reflecting on Digital Stories.....</i>	<i>163</i>
<i>Figure 4: Reflecting on Content of Stories</i>	<i>164</i>
Psychiatry as a System of Subordination and Lack of Representation.....	165
Psychiatry as an Ideological System in Need of Solution	170
Viewing Digital Stories	181
<i>Figure 5: Viewing Digital Stories.....</i>	<i>181</i>
<i>A Powerful Process for Patients.....</i>	<i>181</i>
<i>A Powerful Process for Viewers/Consumers</i>	<i>184</i>
<i>Viewers Envisioning Impacts of Stories.....</i>	<i>187</i>
<i>Figure 6: Viewers Envisioning Impact of Stories</i>	<i>187</i>
Using and Sharing the Digital Stories.....	187
Chapter 6: Discussion	197
Subaltern Identity of People with Psychotic Disorders.....	197
Subaltern Status of People with Psychotic Disorder	203
Subaltern Voice of People with Psychotic Disorders.....	207
Digital Stories: Towards Epistemic Justice.....	212
Digital Stories-Overcoming Subalternity by Establishing a Line of Communication.....	220
<i>Digital Stories-Disrupting Dominant Ideologies and Practices.....</i>	<i>222</i>
<i>Digital Storytelling- Disrupting Dominant Ways of Knowledge Creation and Education</i>	<i>227</i>
<i>Digital Stories-Disrupting the Development of Policies and Reforms</i>	<i>231</i>
Nurses' Ambivalence with Political Agency	236
Implication for Nursing	245
<i>Research.....</i>	<i>246</i>
<i>Practice</i>	<i>248</i>
<i>Education</i>	<i>252</i>
<i>Administration and Policy</i>	<i>255</i>
Limitations and Suggestions	258
Concluding Remarks	261

References	265
Appendix A: Relevance of Postcolonial Theory-Colonization in Psychiatry	321
Appendix B: Inclusion & Exclusion Criteria of Digital Storytelling Participants with Justification	322
Appendix C: Letter to Help with Recruitment Process	323
Appendix D: Information Letter & Consent	325
Appendix E: Recruitment Poster for the Digital Storytelling Participants	335
Appendix F: Interview Guide for Digital Storytelling with Participants.....	336
Appendix G: Interview Guide for Evaluating the Digital Storytelling Process with Participants	337
Appendix H: Reflective Questions	338
Appendix I: Justification of Inclusion/Exclusion Criteria for Focus Groups	339
Appendix J: Recruitment Poster for Focus Groups	340
Appendix K: Information Letter & Consent for Focus Groups	341
Appendix L: Focus Group Facilitation Questions	345

Chapter 1: Introduction

My Initial Research Plans

Recognizing high rates of obesity among people with psychotic disorders and the limited nursing direction for this problem during my nursing career, I was interested in researching this topic for my graduate studies. I further found a gap regarding how nurses manage obesity in people who have a psychotic disorder, which increased my dedication to research that focused on this problem. As a nurse, I felt accountable to the public with a social mission and responsibility to advance knowledge to improve practice. I was eager to contribute to closing the knowledge gap that existed for nurses in the management of obesity in people with psychotic disorders at a large mental health facility in Eastern Ontario.

The initial strategy for this research was to develop a multifaceted "knowledge translation" intervention for mobilizing weight management knowledge to nurses and inter-professional teams. From my experience working at this facility, weight gain among people with psychotic disorders was a concern to patients and was not well addressed. The plan was to use the *Knowledge to Action framework (KTA)* to facilitate the use of knowledge by practitioners (Graham et al., 2006). KTA framework consists of two interrelated complex components: knowledge creation and action cycle (Graham et al., 2006). The knowledge creation part or "knowledge funnel" represents how knowledge is refined and tailored to the needs of the knowledge users (Graham et al., 2006). The refinement process includes knowledge inquiry, synthesis, and presenting the knowledge in the forms of knowledge tools/products such as clinical pathways, decision aids, or practice guidelines (Graham et al., 2006). By using a knowledge tool or products, I aimed to influence stakeholders' practice and behaviour.

The action cycle of the KTA framework is a process by which knowledge is implemented, evaluated, and sustained in the practice setting (Graham et al., 2006). This process

starts by identifying the KTA gaps through rigorous methods and engagement of relevant stakeholders (Graham et al., 2006). Early stakeholder involvement and analysis of their knowledge on the topic and decision-making abilities were integral for successful uptake (Graham et al., 2006). Therefore, I arranged a meeting with the leaders at the facility to explore institutional priorities and establish a collaboration back in 2014.

We investigated the institution's current weight management practices, including available guidelines and resources, nurses' role in relation to weight management, barriers to providing weight management for nurses and other healthcare providers, and potential barriers that may impede or limit the uptake of the knowledge at the setting. Leaders at the designated site confirmed the gap for weight management of people with psychotic disorders. The setting was not following any guidelines, and although nurses assessed patients' weight and blood pressure, leaders were not certain how that information was being used. Leaders considered weight management of people with psychotic disorders important and believed nurses could facilitate the implementation of weight management strategies. Since leaders wanted to take action, they welcomed my research and offered their support.

After our meeting with the setting, I had to initiate the "knowledge creation" process. I spent the next few months searching, appraising, synthesizing, aggregating, and summarizing international guidelines (Canada did not have a national guideline at that time) and doing a meta-analysis for recommendations and level of evidence to help create a program for weight management at the setting. After a long and extensive search and investigation, there was sufficient information to conclude that exercise, diet, and education provide the best non-pharmacological intervention for weight loss for people with mental illness. However, these strategies for weight loss were directed at excess calories leading to weight gain without

considering the external factors such as side effects of the mental illness and antipsychotic medications and complex socioeconomic, cultural, and contextual factors on weight gain and obesity. In addition, it was not clear if interventions of diet, exercise, and education were based on the needs of people with psychotic disorders for weight management.

Despite substantial and sufficient research about the importance of physical health management of people with psychotic disorders to improve quality of life and reduce morbidity and mortality (Nash & McDermott, 2011; Phelan et al., 2001; Roberts et al., 2006; Smith et al., 2013; Stanley & Laugharne, 2014), limited qualitative research had investigated the perspectives and challenges of physical health management for people with psychotic disorders, including barriers and facilitators to strategies that are feasible and acceptable (Abed, 2010; Melamed et al., 2019; Vandyk & Baker, 2012). In addition, the few studies that had investigated patients' perspectives reported barriers and factors that were not reflected in the weight management interventions of education, diet, and exercise. For example, social isolation, lack of energy, poverty, side effects of the medications and symptoms of the mental illness were factors that affected the lifestyle choices of people with psychotic disorders (Abed, 2010; Vandyk & Baker, 2012).

To me, limited research exploring personal experiences of people with psychotic disorders in relation to weight gain was problematic. Although obesity is physiologically associated with caloric imbalances, the overall cause of obesity cannot be explained merely from a perspective that excludes the complex interrelationship of socio-political, economic, cultural, and contextual factors on weight management (Schroeder et al., 2015). Moreover, implementing weight loss research studies does not guarantee sustainability in practice. To sustain success, researchers need to address dominant factors that affect people's personal resources and self-care

practices at both individual and collective levels (Etherington et al., 2020; Hankivsky & Christoffersen, 2008; Van Herk et al., 2011). This can only be achieved when care recipients' voices, experiences, perspectives, needs, and realities are investigated and incorporated into the intervention's design, implementation, and delivery (Etherington et al., 2020; Hankivsky & Christoffersen, 2008; Van Herk et al., 2011). According to Holmes et al. (2008a), "care cannot exist without the patient's right to his or her own experience...such right[s] can exist only in a space where the person can speak and where power is exerted by or for them" (p. 46). However, in my planned research setting, the epistemological approach for knowledge translation made marginal space for patients' experiences and was limited to certain types of knowledge. As Holmes et al. (2008a) explain, knowledge produced through the dogmatic exclusion of alternative modes of knowing is epistemologically biased. Moreover, knowledge that is only based on the results of systematic reviews and meta-analyses, which are highly influenced by researcher's interpretations and limitations, cannot serve as the "best evidence" because they are only best evidence within the context of their knowledge limitations (Holmes et al., 2008b).

A silenced representation of marginalized people, including people with psychotic disorder risks ignoring, misinterpreting, or distorting their knowledge and realities (Holmes et al., 2008b; Loh et al., 2007), that can potentially lead to practices that are ineffective and oppressive. As well, such practices may result in the blaming of individuals for poor outcomes (Moffat, 2010). Excluding people's perspectives of factors that profoundly influence them at both individual and collective levels is a barrier to effective, empowering, and high-quality care (Owens et al., 2011; van Bruinessen et al., 2014). I also saw the inclusion of patients to seek their input on barriers and facilitators to implementing "best" knowledge that has been pre-selected by people in positions of authority and power as a subtle form of domination that is exclusionary

and oppressive. I therefore strove to understand what forces caused the silenced representation of people with psychotic disorders about their physical health. It was clear that I became situated within the critical social paradigm, questioning the effect of external forces on the marginalization and oppression of people with psychotic disorders and the exclusion of their knowledge from informing practices and policies. In the next section, I provide more details about the evolution of my worldview and the ensuing transformation of my research.

The Evolution of My Epistemic Stance

Prior to reading Kuhn's (1962) book, *The Structure of Scientific Revolution*, in the first year of the Ph.D. program (in 2015), I considered post-positivist approaches to inquiry as the most productive way to support practice needs and outcomes. I also considered the post-positivist view superior, contributing to effective nursing interventions through the most rigorous and valid methods. Kuhn's critique of the ontological and epistemological assumptions underlying the positivist paradigm challenged my perceptions about the received view's claims of credibility, objectivity, and validity. Kuhn (1962) challenged the received view by proclaiming that perceptions are heavily conditioned by our background beliefs, making “facts” value-laden, subjective, and modifiable. He referred to historical scientific revolutions such as transitions of Thalmic to Capricorn astronomy, Newton to Einstein physics, and Darwinian revolution in biology to demonstrate that data or “facts” are a reflection of the adapted paradigm, and paradigm shifts can result in displacement of an existing set of facts by a completely different set. While I still valued the contribution of post-positivism to knowledge generation, being exposed to Kuhn's discussion, I no longer considered the received view superior to other paradigms. In this transition, I asked myself what made me believe specific knowledge was more valid than others? Did any external force influence that belief, or did I mentally construct the

belief because it resonated with my personal experiences? Or should I perhaps go back to when I was first introduced to different forms of knowledge and ask the following questions: was presenting a pyramid with meta-analysis and systematic reviews at the top and expert's opinion and case-reports at the bottom a neutral way of delivering certain information? Did the pyramid indeed present a hierarchy of evidence or an arbitrary agreement between certain scientists? Did the knowledge at the top of the pyramid dominate other forms of knowledge or did they all have equal power? Could the hierarchy mean something other than validation and evidence, perhaps domination and control? Was the hierarchical pyramid open for discussion and input? Could I select all four options on a multiple-choice question that asked about which knowledge has the highest evidence and still get a correct mark? Was getting tested on the hierarchy of evidence in my curriculum a way of enforcing that information as a 'fact'? Why has the order of evidence not been questioned by students? Is it because they trusted the information or trusted the presenter? How influential is a nursing student's opinion compared to those delivering the information or those who invented that hierarchy? What makes someone more influential? Is it their position or the power that the person has over a particular part of another person's life at a given time (e.g., teaching, employing, treating, or nursing)? And do we perhaps have similar hierarchies for sex, race, religion, ethnicity, and professions that are not being questioned?

I started to realize that social and positional power act similar to a prism placed between the light source and the observer. What the observer cognitively processes and perceives is the light's refraction and not the light itself. Although an infinite number of equally valid descriptions can be ascribed to the perceived shades of light, the prism dictates what range of shades is allowed to be seen. Suppose a dark object replaced the prism; what is now available for perception is limited to dark colours. Belief systems that are presented and treated as facts

through political and social powers act similarly and produce their version of reality to maintain control while preventing individuals from "correctly perceiving their true situation and real interest" (Campbell & Bunting, 1991, p. 3).

Human beings are born into existing structures and are exposed to predetermined forces that continually shape and control their beliefs (Kirkham & Anderson, 2002). According to Foucault (1980), "We are subjected to the production of truth through power, and we cannot exercise power except through the production of truth" (p. 131). Truth is, therefore, the product of multiple forms of constraints that each society creates to govern its population (Townley, 1993). The hidden power of social and political domination on the knowledge development of individuals can be so subtle that they are sometimes only comprehended when individuals get liberated from those forces (Campbell & Bunting, 1991). Power can turn knowledge into a system of domination by defining reality and delineating an individual's position in relation to that reality to constrain the possibilities for thoughts and action (Higgs & Titchen, 1998). Certain knowledge has achieved a status of superiority, not because it reflects reality, but because of influential scientists who are awarded the power of rulemaking (Higgs & Titchen, 1998). Therefore, the validity and authority of specific knowledge is derived from power and politics and not from epistemology (Higgs & Titchen, 1998). Campbell and Bunting (1991) make this clear by stating, "personal meanings are shaped by societal structures and communication processes and are therefore all too often ideologic, historically bound, and distorted" (p. 5). Social constructs are patterns built into society by the ruling class through conventions or mandates (Campbell & Bunting, 1991). These structures consist of assumptions, beliefs, and values that have developed into inherent truth and fixed realities by forces such as media, religion, educational system, economy, and law (Campbell & Bunting, 1991). I have come to

realize that the way we perceive and comprehend the world is found in discourses (including written and verbal exchanges, conversations, and discussions) that constitute power relations and knowledge (Manias & Street, 2000). Because there is inherent power in the positions that are socially created, the notion that one status is more powerful and influential than the other can influence us to craft a particular view of reality (Manias & Street, 2000). Dominant discourses such as law or medicine have an established institutional base and can create and exert their version of truth by determining what counts as relevant and essential knowledge (Manias & Street, 2000). According to Lyotard (1984), "knowledge and power are two sides of the same question: who decides what knowledge is, and who knows what needs to be decided?" (p. 8-9)

Critical theory paradigms study power, seek to address injustice and aim for transformative outcomes (Antonio, 1981; Cook, 2005; Friesacher, 2017; Holmes et al., 2008a). The ontological stance of critical social theories is grounded in the premise that factors such as gender, ethnicity, socio-political, cultural, and economic forces affect people's realities (Guba & Lincoln 1994; Weaver & Olson, 2006). Epistemologically, knowledge is considered socially constructed and influenced by the positional power of advocates of that knowledge (Cohen et al., 2007). By situating myself within the critical social paradigm, I strive to understand and shed light on factors that subjugate voices of people with psychotic disorders from informing research, practices, and policies. I believe that the transformation of my research focus reflected significant personal growth, which was exciting but also challenging. With my research taking a different direction, I required a new theoretical framework and methodological approach. In the next section, I provide details about the transformation of my research, including the new inquiries and directions.

The Evolution of My Research-New Inquiry and Direction

I decided to use postcolonial theory as a lens for my research as a way of showing power asymmetry that often oppresses and dominates patients based on exclusion (Kirkham & Anderson, 2002). Looking at the social context of mental illness and the history of psychiatry revealed troubling practices of violence, oppression, and marginalization against people with psychotic disorders (Barney, 1994; Gøtzsche, 2015; Kleinman, 2008; Whitley, 2012) that appeared similar to acts of colonization that legitimize domination through stereotyping of people with psychotic disorders (i.e., in need of rescue, dangerous, barbaric, and primitive). Colonizers then conquer a dependent country and usually exploit its resources and commit violence against its population. In the context of psychiatry, stereotypes of patients as violent, incurable, dependent and unpredictable have legitimized psychiatry to 'colonize' or suppress the voice, power, and agency of people with a mental illness (Gøtzsche, 2015). To protect society and rescue the mentally ill, many scholars have described psychiatry as committed violent and oppressive practices such as physical and psychological punishment, lobotomy, eugenics and sterilization as a form of cure to terminate the reproduction of mentally ill people (Foucault, 1965; Kleinman, 2008; Nasrallah, 2011; Gøtzsche, 2015; Whitaker, 2010; Whitley, 2012). I found that much like colonial ideologies, which require the construction of an inferior "other" to justify domination, psychiatry excludes patients' voices and justifies the use of authority, expertise, and domination. Compulsory admission and treatment and physical restraint are highly controversial approaches that continue to be performed in mainstream psychiatry and constitute more apparent forms of power and violence against this population (Gøtzsche, 2015). However, more subtle domination by exclusion of patients in the contemporary construction of knowledge is also evident. By using an unusual framework such as postcolonial theory, I wish to delve into the marginalized experiences of people with psychotic disorders beyond the typical discussion of

overt forms of oppression and violence and move them from the margins to become the starting point in knowledge construction for my research.

I was aware that uncovering voices of people with psychotic disorders and bringing their ideas to light required an approach that could engage them in a direct and active role in knowledge production. The decision to use digital storytelling as an approach for my research was made after attending a workshop on digital storytelling at the University of Ottawa. The presenter, Mr. Lang, is a digital storytelling specialist, researcher, and film director/producer. Digital storytelling was introduced as a narrative and participatory approach to create an audio-visual vignette of approximately 2-5 minutes in length. In the workshop, Mr. Lang described digital storytelling as an innovative approach to research and showed several digital stories that covered a wide range of topics. I was amazed by how digital stories conveyed participants' messages in a clear, powerful, and concise manner. The stories made experiences and meanings tangible and helped me reflect on my beliefs, values, and practices. The process of digital storytelling also appeared powerful in assisting storytellers in voicing their concerns through a relatively safe medium. I then started looking at the digital storytelling literature and how it has been used in research.

Summarizing the literature on digital storytelling, I came across the first review conducted by De Vecchi et al. (2016) on “*how digital storytelling is used in mental health.*” The review found a dearth of research in mental health using digital storytelling. It recommended conducting more studies in service provision to build on solidarity and a social justice agenda. None of the studies included in the De Vecchi et al. (2016) review involved people with psychotic disorders. Therefore, for my research, I decided to explore the use of digital stories with people with psychotic disorders and to use the stories to initiate a dialogue with healthcare

providers and leaders as a critical approach to exposing and possibly deconstructing dominant ideologies (through awareness and reflection). To learn the digital storytelling techniques and processes, I attended a three-day workshop in Toronto, hosted by StoryCenter (2017a), which provides digital storytelling workshops to individuals and organizations.

Research Objective and Questions

The overarching purpose of this thesis was to explore the process of digital storytelling with people with psychotic disorders as a means of expressing their voice and understand how nurses and healthcare leaders engage with the digital stories.

1. How do people with psychotic disorders express their physical health needs, concerns, and priorities via digital storytelling?
2. What is the process of making digital stories with people with psychotic disorders about their physical health?
3. What are nurses' and healthcare leaders' reactions to the digital stories, including the format and the content of the stories? How do they foresee the use of digital stories in healthcare practices and policies?

Chapter 2: Review of the Relevant Literature

Definition, Diagnosis and Treatment of Psychotic Disorders

Psychosis, in which a person exhibits signs of hallucination and delusion, is considered the hallmark of psychotic disorders by psychiatry (American Psychiatric Association, 2013). Psychosis can present in differential diagnoses such as schizophrenia, schizoaffective disorder, schizophreniform disorder, delusional disorder, brief psychotic disorder, major depressive/bipolar disorder with psychotic features, and psychotic disorder caused by medical illness or alcohol and other substances (American Psychiatric Association, 2013). Therefore, the

duration of the illness, substance use, co-occurrence of depression and mania are considered for diagnosing a specific psychotic disorder. For example, in schizoaffective disorder, a person experiences a combination of psychosis and mood disorder for a substantial portion of the total duration of the illness. Schizophreniform disorder, on the other hand, has a similar presentation to schizophrenia. However, the duration of symptoms lasts less than six months (American Psychiatric Association, 2013). Given that schizophrenia is the most prevalent form of psychotic disorders, I decided to mostly focus on this specific psychotic disorder.

Schizophrenia affects approximately 1% of the population, impacting 300,000 Canadians and more than 21 million people worldwide (Schizophrenia Society of Canada, 2020). Mainstream psychiatry defines schizophrenia as a chronic mental disorder characterized by altered thoughts, perceptions, emotions, and actions over an extended period (World Health Organization [WHO], 2019). Throughout the 1990s and 2000s, using the 4th version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV and DSM-IV-TR), psychiatrists provided a diagnosis of schizophrenia to individuals who presented with two or more of the following symptoms for a minimum of 6 months and at least one month of active-phase symptoms including, "delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behaviour, negative symptoms"(American Psychiatric Association, 1994, p. 298). In 2013, DSM-5 presented a new modification mandating at least one of the symptoms to include delusions, hallucinations, or disorganized speech (American Psychiatric Association, 2013). After ruling out factors such as brain tumours or medical conditions, diagnosis is made by history taking, examining the mental status and clinical observation of constellation of signs and symptoms (American Psychiatric Association, 2013). Therefore, diagnosis is based on a

consensus model and not scientific fact (Gøtzsche, 2015; Szasz, 1997; Wand, 2015; Whitaker, 2016).

Schizophrenia is believed to be “the darkest chapter in psychiatry’s history book” (Gøtzsche, 2015, p. 114). Postulating various theories to explain the underlying cause of schizophrenia has led to dangerous and coercive psychiatric interventions to tackle the perceived underlying causes (Albee, 2002; Foucault, 2003; Gøtzsche, 2015). For example, believing that schizophrenia was caused by a disturbed “will” as opposed to “disturbed judgement” resulted in changes in treatment from walking, resting, and engaging with nature to interrogation, moral talks, servitude, isolation, and cold showers (Whitaker, 2001). These interventions were believed to help confront and renunciate the ill will of patients (Whitaker, 2001). Another theory that tried to explain the underlying cause of schizophrenia was that “distorted” thoughts and emotions were linked to internal infections (Whitaker, 2001). This belief led to interventions such as removing patients' body parts (teeth, large intestine) (Whitaker, 2001). In the first half of the 1900s, the belief that mental disorder is an inherited disease led to the intervention of eugenics to castrate the “insane” (Foucault, 2003). Other measures such as barbiturates to restore the nervous system, insulin coma, electroconvulsive therapy (ECT), and prefrontal lobotomy are interventions that were exercised based on various explanations of the underlying cause(s) (Gøtzsche, 2015; Whitaker, 2001). Fractured bones and teeth, broken muscles resulting from convulsion, permanent brain damage, internal hemorrhage, paralysis, and death are documented side effects of such interventions (Whitaker, 2001). The interventions also created fear and reactions in patients (screaming, tearing clothes, jumping outside the window, and begging staff not to torture them) to resist inhumane treatment (Whitaker, 2001). Now changes in brain biochemistry (increased dopamine and serotonin), structural and neurological alternation

(changes in neural connection and reduced gray matter volume), and genetics are being proposed as underlying causes for developing schizophrenia (Albee, 2002; Bass, 2008; Breggin, 2012; Gøtzsche, 2015; Owen et al., 2016; Whitaker, 2010). In 1955 president of the U.S. Society of Biological Psychiatry introduced the idea that antipsychotic medication works like insulin for diabetes, and the first generation of antipsychotic medications (FGAs) started to be used regularly (Moncrieff, 2013). Chlorpromazine (FGA) was considered a chemical lobotomy because it produced the same effect in patients. The medication hindered the brain's functionality by inhibiting dopaminergic pathways, leading to altered behaviour, thinking and emotions (it made patients feel like 'Zombies') (Whitaker, 2001). While studies claimed side effects to be rare, Parkinsonism became an established side effect in most patients (Whitaker, 2001). Involuntary and irreversible muscular symptom known as tardive dyskinesia (torture-like inner agitation that compels muscles into repetitious movements) was also seen in care recipients in the first year of treatment and this risk increased with more prolonged use (Jibson et al., 2014; Muench & Hamer, 2010; Whitaker, 2001). According to Breggin (2012), the pharmaceutical companies kept the general public ignorant about the harm of chlorpromazine for about twenty years (Breggin, 2012). The American Psychiatric Association's silence stopped only when lawsuits for negligence were filed (Whitaker, 2001). It is estimated that 100,000 people died from this medication in 20 years (Whitaker, 2001). Antipsychotic medications continue to be used based on the speculation that chemical and neurological imbalances are responsible for the mental health symptoms, despite lack of diagnostic tests or biomarkers (Hall, 2019). According to Gøtzsche (2015),

what is tragic about all this is that the psychiatrists have consistently hailed all their harmful treatments as being effective [...] The patients have rarely agreed with the staff's success criteria, but their views are often ignored even today,

though the treatments imposed on them are harmful and causes many deaths (p. 114).

Mainstream psychiatry claims that they use three main treatment pillars of medications, psychosocial interventions, and rehabilitation (Rössler et al., 2005); however, pharmacological treatment continues to dominate the treatment of people with psychotic disorders (Albee, 2002; Gøtzsche, 2015; Harrow & Jobe, 2018; Wand, 2019; Whitaker, 2016). According to Migone (2017), “psychiatrists, in general, prescribe only drugs and disregard the possibility of suggesting psychotherapy to patients” (p.136). Given the questionable effectiveness of psychotropic medications and their harmful effect, many suggest nonpharmacological strategies (exercise, psychotherapy, cognitive behavioural therapy, etc.) (Gøtzsche, 2015; Migone, 2017; Shedler, 2010; Whitaker, 2001). In his award-winning book, *Deadly Psychiatry and Organized Denial*, Gøtzsche (2015) claimed that antipsychotic medications have been responsible for the death of over half a million people each year in the United States and Europe for the past 70 years. Gøtzsche (2015) claimed that “Most patients don’t respond to the drugs they receive and, unfortunately, the psychiatrists’ frustration at the lack of progress often lead to the prescribing of more drugs or higher doses, further harming the patients” (p. 12). He explained how society could reduce its current consumption of psychotropic drugs by 98% while improving patients’ mental and physical health and survival (Gøtzsche, 2015).

Researchers believe that triggers such as socio-economic disadvantages, war, rape, stress, and bullying play a role in activating schizophrenia (World Health Organization, 2013). For example, hallucination in 77% of people with schizophrenia is shown to be related to traumatic experiences; therefore, emphasizing that pharmacological treatment can mend such experiences is believed to be unrealistic (Wand, 2019). Silencing hallucinations (voices) through medication is also thought to interfere with accepting, processing and understanding the meaning of voices

through psychotherapy (Mosquera & Ross, 2017). Bracken et al. (2012) argued (using data from research studies) that psychiatric practices that rely on medication and pathologizing mental illness are less effective than non-technological interventions such as careful listening to patients, establishing a trusting and therapeutic relationship, and understanding the meaning of symptoms in the context of patients' life. Nevertheless, investment in non-pharmacological treatment (building on the evidence and in practice) is limited. According to (Migone, 2017), "If psychiatry can attract investments because of the possible income derived by the commercialization of drugs, of course there is no interest in investing in psychotherapy research where there are no drugs to sell" (p. 137). Psychiatry is believed to be a "goldmine" for pharmaceutical companies and knowledge, practice, and policies in psychiatry are believed to be heavily influenced by the pharmaceutical industry (Albee, 2002; Bass, 2008; Gøtzsche, 2015; Migone, 2017; Whitaker, 2001, 2010). Migone (2017) emphasized that,

Big Pharma virtually supports – directly or indirectly – every journal and scientific meeting of the field. Without the income due to advertisements, most psychiatric journals would cease publications and many meetings would be cancelled [...] Also the scientific information that reaches every practitioner is heavily controlled by pharmaceutical companies [...] Pharmaceutical companies finance most – if not all – Randomized Controlled Trials (RCT) on the efficacy of medications [...] so that for many years the empirical evidence on the effects of many drugs has been heavily distorted [...] The impression is that often we are not dealing with an Evidence-Based Medicine, but with an Evidence-Biased Medicine. (p. 136)

Coercive interventions (involuntary admission and medication) and prolonged pharmacological treatment and polypharmacy remain controversial practices that expose care recipients to the risk of morbidity and mortality (Albee, 2002; Gøtzsche, 2015; Kirk et al., 2017). Struggles with current psychiatric approaches in diagnosing and treating people with psychotic disorders was summarized by Thomas Insel (2010), the director of the American National Institute of Mental health (from 2002-2015), as follows:

The diagnoses are vague and easy to manipulate, and many drugs are hilariously expensive, although they are not any better than off-patent drugs, but that's no hindrance for their widespread use. Leading psychiatrists are at high risk of corruption, both financially and of their academic integrity and objectivity, and in fact psychiatrists collect more money from drug makers than doctors in any other specialty; they are also "educated" within industry's hospitality more often than any other speciality. (p. 1192)

Poor Physical Health of People with Schizophrenia

While the cause and course of schizophrenia are unique for each person, the morbidity and mortality of people with schizophrenia remain higher than the general population (Owen et al., 2016). A systematic review and meta-analysis by Walker et al. (2015), including 203 studies representing 29 countries and six continents, indicated that pooled relative risk of all-cause mortality of people with severe mental illness, including schizophrenia, was 2.22-fold higher than the general population (Walker et al., 2015). Similarly, Gatov et al. (2017), who examined the mortality rates of people with schizophrenia in Ontario, Canada between 1993-2012 using a population-based, repeated cross-sectional study, found that mortality rates among people with schizophrenia were three times higher compared to the general population. While the relative risk of suicide in people with schizophrenia is significantly high (increased 12-fold; the lifetime risk of approximately 6.5%) (Nordentoft & Mortensen, 2011), preventable physical health diseases such as cardiovascular diseases (CVD), stroke, and cancer remain the leading cause of death for people with schizophrenia (Doherty & Gaughran, 2014; De Hert et al., 2011a; Laursen et al., 2012; Saxena & Maj, 2017).

In 2018, the World Health Organization (WHO) identified poor physical health of people with a mental illness as a serious international problem needing attention. People with schizophrenia die, on average, 15-20 years earlier than the general population (Ashworth et al., 2017; WHO, 2018). In particular, CVD accounts for 50% to 75% of the total mortality rates (Nordentoft et al., 2013). People with schizophrenia also have higher rates of diabetes and are at

increased risk for developing diabetes-related complications (Annamalai et al., 2017; Becker & Hux, 2011). The metabolic syndrome and obesity rates in people with schizophrenia are two to three times higher than the general population (Correll et al., 2010). A study conducted in the US found that approximately 80% of the sample (n= 10,084) with severe mental illnesses, including schizophrenia, were overweight or obese (Correll et al., 2010).

A meta-analysis using 13 cohort studies involving 3,549,950 participants with follow-up periods ranging from 1.6 to 36.0 years showed that people with schizophrenia had higher risks of CVD, congestive heart failure, coronary heart disease, and stroke (Fan et al., 2013). A recent study using a large scale meta-analysis to determine incidence and prevalence of CVD of 3,211,768 people with severe mental illnesses, including schizophrenia and 113,383,368 controls (Of the included 92 studies, 38 studies included people with schizophrenia, with 29 of the studies being longitudinal) also confirmed that people with schizophrenia were at significantly increased risk for coronary heart disease, cerebrovascular disease and congestive heart failure (Correll et al., 2017). The authors concluded that people with severe mental illnesses require urgent clinical attention as they are at significantly increased risk for CVD-related mortality (Correll et al., 2017).

The risk of developing stroke in people with schizophrenia is also higher (Correll et al., 2017). A meta-analysis of 6 cohort studies from Canada, the USA, China (2), Finland, and Sweden showed that people with schizophrenia had a significantly increased risk of developing stroke than those with no schizophrenia (Li et al., 2014). The study concluded a statistically significant positive association between schizophrenia and stroke incidence and mortality as well (Li et al., 2014). After adjusting for risk factors such as hypertension, diabetes, and hyperlipidemia, individuals with schizophrenia continued to be significantly at risk for stroke (Li

et al., 2014). Authors speculated the differences in risk to be related to disparity in healthcare (Li et al., 2014).

Poor physical health of people with schizophrenia is not limited to circulatory diseases. People with schizophrenia also have higher rates of infectious diseases such as tuberculosis, HIV and hepatitis (Leucht et al., 2007; Loftis et al., 2006; Rosenberg et al., 2001; Senn & Carey, 2008, WHO, 2018). In Sweden, a nationwide, population-based, cross-sectional study of 97,797 adults with diagnosis of severe mental illness including schizophrenia showed the odds of HIV (2·57), hepatitis B (2·29), and hepatitis C (6·18) two to six times higher than the general population (Bauer-Staeb et al., 2017). Respiratory diseases also remain disproportionately higher in people with schizophrenia compared to the general population (Leucht et al., 2007). A population-based study using a nationally representative sample of 8028 in Finland showed that people with schizophrenia have lower lung functions and are at increased risk for COPD, chronic bronchitis, and pneumonia (Partti et al., 2015). Parkinson disease (Smith et al., 2013), hypothyroidism (Carney et al., 2006), osteoporosis (Leucht et al., 2007), chronic pain (Smith et al., 2013), tooth decay and periodontal diseases (Löffler et al., 2003; McCreadie et al., 2004), sexual dysfunction (Olfson et al., 2005; Wirshing et al., 2002), constipation (De Hert et al., 2011b), bowel obstruction (Schulte & MacCabe, 2014), and nocturnal enuresis are other physical problems that are higher in people with schizophrenia (De Hert et al., 2011b). Multiple factors are involved in these poor health outcomes, which will be reviewed next.

Factors Contributing to Poor Physical Health of People with Schizophrenia

Antipsychotic Medications Leading to Physical Conditions

Reduced neurological side effects have encouraged the widespread use of second-generation antipsychotics (SGA) over the past 20 years (De Hert et al., 2009; Moore et al.,

2015). While SGA have lower extrapyramidal effects (bradykinesia, akathisia, tremor, rigidity, dystonia...etc.), their use is associated with brain atrophy with long-term use (Ho et al., 2011), lower rate of recovery with long-term use (Wunderink et al., 2013), and higher incidence of metabolic syndrome which includes a cluster of conditions such as abdominal obesity, hypertension, weight gain, dyslipidemia, and type 2 diabetes (Mitchell et al., 2011). In the United States, the prevalence rate of metabolic syndrome prevalence in people with severe mental illness was shown to be 52% (with a mean age of 44.7 years) (Correll et al., 2010) compared to the 20-25% in the general population (Ford et al., 2002). Metabolic syndrome contributes to higher mortality rates in people with schizophrenia by increasing the risk for cardiovascular disease, stroke, and cancer (Esposito et al., 2012). Gautam and Meena (2011) found that after using a single SGA for four months, 11.66% of patients develop metabolic syndrome. Mitchell et al. (2011) emphasized that one in three people using antipsychotic medication will eventually meet the criteria for metabolic syndrome (Mitchell et al., 2011).

SGAs, especially olanzapine and clozapine, alter endocrine and metabolic functioning, causing prolactin elevation, insulin resistance, appetite dysregulation, and sedation leading to weight gain and obesity (McIntyre et al., 2001; Reist et al., 2007; Wirshing et al., 2003). A meta-analysis by Allison and Casey (2001) showed that patients receiving standard doses of SGAs over 10 weeks had an increased weight of 4.45 kg with clozapine, 4.15kg with olanzapine, 2.92 kg with sertindole, 2.10 kg with risperidone, and 0.04 kg with ziprasidone (Allison & Casey, 2001). In a longitudinal study, using a national inpatient sample in the U.S from 1988 to 2002, Reist et al. (2007) found an increased net difference in weight gain from +4.7% in 1988 to +14.7% in 2002, suggesting that the introduction of SGAs have resulted in striking net increase in the prevalence of obesity in people with schizophrenia (Reist et al., 2007). Reist et al. (2007)

suggested that SGAs are associated with a 10% increase in prevalence rates of obesity in patients (Reist et al., 2007). Vandenberghe et al. (2015) found that more than 5% weight gain after one month of using antipsychotic medications was a predictor of long-term weight gain in people with schizophrenia (Vandenberghe et al., 2015).

Weight gain and obesity are problematic as they increase coronary, vascular and artery diseases by 50% (Rimm et al., 1995). Weight gain increases metabolic disturbances and formation of cardiometabolic risk factors of hyperlipidemia, hyperglycemia, and hypertension (Cooper et al., 2016; Czernichow et al., 2002). Obesity increases a person's risk of developing hypertension by 40% to 60% (Thompson et al., 1999). The risk of acquiring type 2 diabetes is also five times higher in obese individuals than those with a normal body mass index (England, 2014). Obesity is further associated with poor psychosocial functioning related to stigma, negative self-image and self-esteem, leading to emotional distress, depression, anxiety, and social isolation (Radke et al., 2010). In Canada, the direct healthcare cost of obesity is estimated at \$5 to \$7 billion annually, increasing to 9\$ billion by 2021 (Obesity Canada, 2020). Obesity in people with schizophrenia results in increased healthcare costs due to added use of medical services and additional healthcare expenses on medication costs (Chwastiak et al., 2009).

People with schizophrenia have higher rates of diabetes and are at increased risk for developing diabetes-related complications (Annamalai et al., 2017; Becker & Hux, 2011). A retrospective study of emergency department (ED) visits and hospital admissions in Canada, Ontario between 1995-2005 found a 74% greater risk of ED visits and hospital admissions for diabetes mellitus related complications (hypo or hypoglycemia and infections) in people with schizophrenia compared to the general population (Becker & Hux, 2011). A systematic review on the metabolic side effects of the SGA concluded that type 2 diabetes was the most frequent

outcome for SGAs, with Clozapine and Olanzapine having the strongest association with the development of type two diabetes in patients (Hirsch et al., 2017). Antipsychotic medications are also associated with other adverse side effects such as constipation (De Hert et al., 2011b), postural hypotension, dizziness, headache, muscle tension, dry mouth, sexual dysfunction (De Hert et al., 2009; Olfson et al., 2005; Wirshing et al., 2002), amenorrhea, gynecomastia, hyperprolactinemia, metabolic syndrome, photosensitivity, cataracts (Halter & Varcarolis, 2013), and cardiac arrhythmia (Ray et al., 2009).

While many studies show the effectiveness of antipsychotic medications at controlling mental symptoms, preventing suicide, and increasing quality of life (Taipale et al., 2020; Zhang, 2016), the available data need to be examined carefully. According to Gøtzsche (2015), “almost all trials of psychotropic drugs summarised in Cochrane reviews are flawed. You, therefore, need to be critical when you read reviews; in particular, the harms of the drugs are often downplayed or missing” (p. 269). Claims about the safety of medication also need to be critically evaluated in light of all the side effects. According to (Gøtzsche, 2015), “prescription drugs are the third major killer after heart disease and cancer, and that very many unnecessary deaths are caused by psychiatric drugs” (p. 269).

Some believe that antipsychotic medications are responsible for what people think are caused by schizophrenia, including sleepiness, vacant facial expression, awkward gait, lack of motivation and initiative (Moncrieff, 2013; Schneider et al., 2005; Whitaker, 2001, 2016). Whittaker (2016) published an extensive analysis of the research on antipsychotic medication from the 1950s to the present and concluded that while antipsychotic medications may provide short-term benefits, they worsen long-term outcomes by creating physiological changes to the brain, leaving patients more vulnerable to psychosis. Long-term use of antipsychotic medications

was shown to develop dependence, worsen psychotic symptoms, impair functionality and impede recovery (Whittaker, 2016). In addition, through his review, Whitaker (2016) reported that studies from developed countries (USA, Netherland, and Australia) found that minimal or no use of antipsychotic medications is associated with a better outcomes. Several other studies also show no positive results with long-term use of antipsychotic (Bland & Parker, 1978; Harrison et al., 2001; Harrow et al., 2017; Kotov et al., 2017; Moilanen et al., 2013; Morgan et al., 2014; Wils et al., 2017; Wunderink et al., 2013). For example, Harrow et al. (2017) used a longitudinal multi follow-up research in 139 people diagnosed with schizophrenia and schizoaffective disorders over 20 years and compared the influence of antipsychotic medications on the functioning of those who were prescribed antipsychotics compared to those who were not prescribed antipsychotics, using statistical controls for inter-subject differences. While medications helped decrease symptoms during the acute phase, those not prescribed medication had significantly better work functioning than those who were not prescribed medication at 4.5 years follow-up. A large percentage of those who continued to take the medication were also hospitalized multiple times. The authors concluded that there is no evidence to support the medication use beyond three years. There is also a significant concern about the withdrawal effects of psychotropic medications, which can last for many months after discontinuation (Cartwright et al., 2016; Hall, 2019; Ostrow et al., 2017; Read et al., 2018). Reduction of drugs should be done slowly because withdrawal symptoms can be severe, long-lasting and dangerous. Unfortunately, withdrawal effects are mainly attributed to the “disease” and are considered “relapse” of their condition (return of the disease) instead of signs of dependence associated with the medication (Gøtzsche, 2015; Wand, 2019; Whitaker, 2001, 2016). In addition, due to their side effects, antipsychotic medications are reported to result in suicide in patients (Mihanović et

al., 2010). According to Gøtzsche (2015), “Many psychiatric drugs not only increase total mortality but also increase the risk of suicide and homicide” (p.12).

Social Factors and Their Impact on Physical Health

A study comparing cause-specific mortality of 668,881 people with schizophrenia over a 10-year period (1996-2006) in Finland suggested that living conditions play a role in physical diseases and mortality of people with schizophrenia (Tiihonen et al., 2009). Poor dietary intake, physical inactivity, high smoking, alcohol and substance use are factors that contribute to the poor physical health of people with schizophrenia (Brown et al., 1999; Henderson et al., 2006). Research on dietary intake reports that people with schizophrenia have a high consumption of fast food, saturated fats, and unhealthy snacks and low consumption of fibre, protein, fish, fruits, vegetables, and essential vitamins and minerals (Beebe & Harris, 2013; Heald et al., 2017; Stokes & Peet, 2004; Strassnig et al., 2003). Research further reveals that individuals with schizophrenia have a sedentary lifestyle (Heald et al., 2017; Soundy et al., 2013), with less than 25% engaging in the recommended amount of physical activity of 150 minutes per week (Faulkner et al., 2006). In addition, people with schizophrenia suffer from disproportionately high tobacco use and its associated economic and health consequences (Heald et al., 2017; Steinberg et al., 2004). Fifty to 90% of people with schizophrenia are tobacco smokers compared to 25% to 35% of the general population (Steinberg et al., 2004). People with schizophrenia spend approximately one-third (27%) of their income on tobacco (Steinberg et al., 2004). Heavy tobacco use is associated with increased asthma, pneumonia, chronic obstructive pulmonary disease, and lung cancer (Go et al., 2014).

Alcohol and substance use are also 50% to 70% higher in people with schizophrenia (Schizophrenia Society of Canada, 2012). Alcohol and illegal substance use are associated with

psychosocial and physical morbidities such as exacerbation of mental symptoms, incarceration, homelessness, intentional and unintentional self-harm, and increased risk of contracting HIV and hepatitis C infections (Schizophrenia Society of Canada, 2012). The following section will present how social factors such as higher than average unemployment rates, poverty, lack of social support, isolation, discrimination, and stigma contribute to living conditions of people with schizophrenia that lead to physical health conditions.

Socio-economic Status. Income and social status, determined by control and ownership over physical, organizational, and financial resources (Oakes & Rossi, 2003), are among the strongest predictors of health and well-being. According to WHO (2010), "income has a 'dose-response' association with health" (p.30). Income and social status determine a person's living condition, social connections, access to resources, lifestyle behaviours, personal health practices, and coping skills (Allen et al., 2014; WHO, 2010). Higher socioeconomic status is associated with adopting lifestyle behaviours such as low alcohol and tobacco consumption, healthy dietary intake, increased physical activity, and lower morbidity and mortality (Allen et al., 2014; WHO, 2010). Education, employment, and occupation are important indicators of social and economic status (Allen et al., 2014; WHO, 2010).

Education is directly associated with socioeconomic status by affecting individuals' employment opportunities and income (WHO, 2010). The initial onset of psychosis, which generally occurs in early adulthood, and lack of attention and declarative memory during crisis, interferes with the cognitive functioning and educational attainment of people with schizophrenia (Canadian Mental Health Association, 2020b, c). With low academic achievement and less formal qualifications, people with schizophrenia are at risk for low-income jobs, precarious employment, dangerous or unhealthy working conditions, and unemployment (WHO, 2010).

Unemployment can lead to inadequate income, poverty, and unhealthy lifestyle and coping behaviours as well as stress, depression, anxiety, loss of status, identity and social support (WHO, 2010).

In Canada, 70% to 90% of individuals with severe mental illness, including schizophrenia, are unemployed and depend on social services to live (Canadian Mental Health Association, 2020b,c). Social assistance recipients live below the poverty line and typically live with inadequate and unsafe housing, poor nutrition, limited access to resources and programs, and poor physical health (Canadian Mental Health Association, 2007). A 10-year follow-up study investigating the relationship between socioeconomic status and mortality among people with schizophrenia found the death rates highest for those with low socioeconomic status (Tsai et al., 2014). Low income is a barrier in purchasing high quality and healthy food products; access to safe and stable housing, education and resources such as cooking classes and exercise facilities; and adherence to treatment plans and lifestyle changes increasing susceptibility to poor physical health (Lo et al., 2009; Zhang & Wang, 2004).

Networks and Belonging. Presence and quality of social support network is an important key determinant of health and well-being (Government of Canada, 2013). Individuals with a solid and meaningful social support network are more likely to be employed, have higher income, engage in group activities and competitive sports, and have healthy dietary habits (Umberson et al., 2010). Clinical symptoms of the disorder, stereotypes (dangerous, unpredictable, burden), and negative attitudes towards people with a mental illness usually creates distrust, ineffective communication, discrimination and loss of meaningful social support network, leaving most of them isolated and lonely (Angermeyer & Matschinger, 2003; Ganguly

et al., 2018; Manu et al., 2015; Rüsch et al., 2005). Close family is often the only source of support for most people with schizophrenia (Ganguly et al., 2018).

Lack of high-quality support network is associated with feelings of isolation, personal failure, low self-esteem, low quality of life, depression, anxiety, and poor coping strategies (Patel et al., 2018). A recent study conducted in a large Canadian city (n=30) found that people with mental illness, including schizophrenia adopted lifestyle practices that were deemed unhealthy (e.g., eating at fast-food restaurants, smoking tobacco, consuming alcohol, and smoking marijuana) to cope with social isolation and gain a sense of belonging to society (Patel et al., 2018). Oliveira and Furegato (2014) investigated the degree of nicotine dependence and meaning of smoking for people living with schizophrenia and other mental disorders (n=270) in Brazil. They found that people with mental illness used smoking as a mechanism to increase socialization as well as alleviate the symptoms of the mental illness and side effects of the medications, increase self-control, and decrease impulsivity. Antipsychotic medication can also lead to increased use of smoking and alcohol in consumers to help counteract decrease in dopamine caused by the medication (Gøtzsche, 2015).

Healthcare Disparity Leading to Physical Conditions

Health services are an important determinant in the provision of health promotion, disease and injury prevention, and treatment and rehabilitation (Government of Canada, 2013). Health Services are most effective when accessible and responsive to individuals' needs and requirements (Government of Canada, 2013). Disparities in healthcare activities such as screening, health promotion, and treatment contribute to increased morbidity and premature mortality in individuals with schizophrenia (Saxena & Maj, 2017). Access to comprehensive health services for most people with mental illness remains insufficient, especially in addressing

their physical health needs (WHO, 2018). While monitoring for the presence of cardiometabolic risk factors such as weight gain, dyslipidemia, hypertension, smoking are essential (Cooper et al., 2016), the literature indicates that people with mental illness receive insufficient treatment, screening, monitoring, counselling for modifiable risk factors, and support (De Hert et al., 2011a; Saxena & Maj, 2017). In addition, people with chronic illness are advised to take a more proactive role in self-management (Ehrlich et al., 2017). Inability to manage physical health can predispose people with schizophrenia to be viewed as disinterested in health and health outcomes and acting irresponsibly in the face of serious health risks (Kendall et al., 2011). Ehrlich et al. (2017) undertook a qualitative study in a metropolitan area in Queensland, Australia, to understand how people with severe mental illness approach their physical health and healthcare providers' role in supporting patients in managing their physical health (Ehrlich et al., 2017). They found that people with severe mental illness rely on healthcare providers to undertake comprehensive health monitoring activities. They recommended person-centred care and a recovery-oriented approach by understanding and making sense of individual narratives (Ehrlich et al., 2017).

The WHO's (2013) *Comprehensive Mental Health Action Plan 2013-2020* encouraged its member states to develop policies to improve the physical and mental health of people with severe mental illness. Despite substantial and sufficient research about the importance of physical health management of people with schizophrenia to improve quality of life and reduce morbidity and mortality (Nash & McDermott, 2011; Phelan et al., 2001; Roberts et al., 2006; Smith et al., 2013; Stanley & Laugharne, 2014), limited qualitative research has investigated the perspectives and challenges of physical health management for people with schizophrenia (Abed, 2010; Melamed et al., 2019; Happell et al., 2016; Vandyk & Baker, 2012). Chadwick et al.

(2012) undertook a literature review regarding the perceptions of people with severe mental illness on barriers to accessing physical healthcare and found that most research reported difficulties from the perspectives of various healthcare providers, with limited research from the standpoint of care recipients. Chadwick et al. (2012) concluded that little attention is given to the voices of people with mental illness in research since their systematic review only found six qualitative and three quantitative studies investigating the perspective of people with severe mental illness over 10 years. Although more qualitative research exploring the views of people with psychotic disorders has since emerged, the breadth of the literature continues to be limited (Melamed et al., 2019). Most qualitative researchers tend to explore the perspectives of healthcare providers in relation to physical health needs, interventions, and availability of services for people with psychotic disorders (Gronholm et al., 2017; Nash et al., 2021). Excluding people's perspectives of factors that can profoundly influence their circumstances is a barrier to effective, empowering, and high-quality care (Owens et al., 2011; van Bruinessen et al., 2014). Only through inclusive approaches can mutual dialogue occur to identify barriers and solutions to delivery of care and services (De Vecchi et al., 2017). Inclusive approaches to knowledge creation are also important to challenge dominant discourses and ideologies in mainstream services, policies and practices that subjugate the experiences of marginalized populations (Caxaj, 2015; De Vecchi et al., 2017).

Voice, Power and Agency of People with Psychotic Disorders in Psychiatry

The dearth of research exploring the perspectives of people with psychotic disorders in relation to their physical health created my interest to retrace the history of psychiatry and the movements that have challenged psychiatric practices and policies. Since the establishment of asylums in the 18th century, exclusionary and oppressive psychiatry practices have been

identified to varying extents. Resistance to oppression due to subordinating practices led to several parallel movements to reform or dismantle the system. The following section presents some of those movements as a way to challenge taken for granted past and current practices that purport promises of beneficial, inclusive, patient-centred, and holistic care.

The Antipsychiatry Movement

For the past 60 years, the field of psychiatry has been under increased scrutiny due to its contested foundation and practices, including subjective diagnostic processes, the unequal power relationship between psychiatrists and care recipients, coercive admission and invasive pharmacological and surgical treatment (Kleinman, 2008). Ex-patients who experienced harm through psychiatric practices have been the main drivers of this oppositional movement.

"Antipsychiatry" is a term coined in 1967 by David Cooper, a psychiatrist and theorist in the UK.

The term defines a movement that challenged the practices and foundations of mainstream psychiatry (Kleinman, 2008; Whitley, 2012). While the foundation for this advocacy work existed prior to the 1960s, he had a major influence on the movement on a national and international scale (Whitley, 2012). Ernest Becker, Erving Goffman, R.D. Laing, Aaron Esterson, Thomas Scheff, and Thomas Szasz are some activists who criticized the hegemony of the medical model and oppressive and violent practices of psychiatry, including involuntary hospitalization, ECT, and forced medication (Barney, 1994). Through the Philadelphia association in the UK, which David Cooper initially founded in 1965, R.D. Laing established more than 20 therapeutic communities where medication use was voluntary, and patients and healthcare providers assumed equal power and status (Calton et al., 2008). Similar places were established in the U.S. and were ex-patient-led services (Calton et al., 2008). The anti-psychiatry

movement was also inspired by individuals who claimed being harmed by psychiatry and receiving advantage by other methods (Barney, 1994).

Antipsychiatry questions the validity of psychiatric diagnoses by suggesting that “mental disorders” are subjected to the imposition of human values and interpretations (Grob, 2011; Szasz, 1961). Watts (2012) showed that when therapists were asked to use DSM criteria on healthy people, one-third of them received a psychiatric diagnosis (Watts, 2012). Antipsychiatry advocates provide examples such as the classification of homosexuality as a mental illness by the American Psychiatric Association in 1974 and diagnosing enslaved people who tried to escape with a mental disorder called "drapetomania" to highlight cultural biases about “normality” that are promoted by psychiatry following specific social norms (Nasrallah, 2011). Antipsychiatry warns about negative consequences such as violations of patient rights and oppressive behaviours that psychiatric diagnoses can cause by using ideas and labels as an absolute truth to a “diseased” mind (Nasrallah, 2011). Antipsychiatry advocates also criticize unjustified and excessive use of institutionalization and the routine and uncritical use of terms and models that can result in stigma, discrimination, and exploitation (Summerfield, 2001), especially since psychiatry has been accused of misusing psychiatric diagnoses and labelling to incarcerate people with no mental illness whatsoever (e.g., disobedient wives) (Gøtzsche, 2015). Therefore, the movement continues to challenge current classifications of mental illnesses, the diagnostic criteria used, and the influence of pharmaceutical companies on psychiatric practices, research, and treatments (Frances, 2013; Staub, 2011).

According to Szasz (1961), mental “diseases” are “counterfeit and metaphorical illnesses” (p. 34). Antipsychiatry advocates believe that DSM has taken a scientific and objective stance when diagnoses are unscientific, arbitrary, and based on consensus (Gøtzsche, 2015).

Antipsychiatry advocates argue that diagnoses in psychiatry are not based on measurable physiological factors but a collection of symptoms that are often subjectively interpreted (Frances, 2013). Gøtzsche (2015) challenges the DSM by emphasizing that “[r]eal sciences do not decide on the existence and nature of phenomena they are dealing with via a show of hands with a vested interest and pharmaceutical industry sponsorship” (p. 23). Antipsychiatry also challenges the DSM's reliability and validity at providing a diagnostic criterion. For example, after his various experiments to determine the validity of psychiatric diagnosis, David Rosenhan (1974) concluded that “we cannot distinguish the sane from the insane in psychiatric hospitals” (p. 257). David Rosenhan (1974), a psychologist and Stanford University professor, conducted several experiments, one of which included admitting seven healthy individuals (including himself) into several psychiatric hospitals. Their goal was to feign hallucinations to enter psychiatric institutions but get discharged again by their own devices after convincing the staff that they had no mental illness. As soon as they got admitted, they behaved completely normal and asked the staff to discharge them; however, they were hospitalized for an average of 19 days, were prescribed medications and released with a diagnosis of “schizophrenia” in remission. In another study, the staff were warned that pseudo-patients would attempt to be admitted to the psychiatric institution in the next three months. Although none of those sent to the facility were “pseudo-patients,” 41 of 193 care recipients were believed to be pseudo-patients by at least one member of the staff. These experiments highlighted an important bias in diagnosis making.

According to Rosenhan (1974),

If the sanity of such pseudopatients were always detected, there would be prima facie evidence that a sane individual can be distinguished from the insane context in which he is found. Normality (and presumably abnormality) is distinct enough that it can be recognized wherever it occurs, for it is carried within the person. If, on the other hand, the sanity of the pseudopatients were never discovered, serious

difficulties would arise for those who support traditional modes of psychiatric diagnosis. (p. 238)

Rosenhan (1974) warned about the risk of dehumanization and labelling in psychiatric institutions because once a diagnosis was made, it was difficult to reverse. Rosenhan (1974) explained that the label was powerful to a point that many pseudo patients' normal behaviours were overlooked to help fit them into a diagnosed category. Therefore, he warned that diagnosis would make the person accept and behave according to the diagnosis. Antipsychiatry advocates emphasize that many people experience fantasies, thoughts and beliefs if isolated in a psychiatric interview would support a mental illness diagnosis (Whitaker, 2001). For example, Watts (2012) showed that when therapists were asked to use DSM criteria on healthy people, one-third of them received a psychiatric diagnosis (Watts, 2012). Therefore, antipsychiatry adherents believe that research in psychiatry is not reliable because diagnoses are arbitrary and unscientific, and medication withdrawal is often interpreted as "disease" symptoms.

Antipsychiatry advocates refuse to consider psychiatry a form of medicine and condemns medical interventions (Nasrallah, 2011; Staub, 2011). They believe the closure of Victorian asylums is due to economic imperatives and realization of the adverse effects of institutionalization instead of the introduction of new medication (Kirk et al., 2017; Moncrieff, 2013; Whitaker, 2001). Supporters of the antipsychiatry movement reject the medical model of mental illness and the use of antipsychotic medication. They argue that for medical treatment to be rational and specific, the etiology and pathogenesis underlying the symptoms should be clear (Fromm & Anderson, 2017). Therefore, antipsychiatry advocates challenge the term "unintentionally" induced side effects of antipsychotic medications by suggesting that the side effects are well established and are not unintentional (Kirk et al., 2017; Moncrieff, 2013; Whitaker, 2001). They also challenge the use of biomedical approaches such as ECT and

antipsychotic medications that rest on contested evidence (Staub, 2011). Antipsychiatry advocates believe that the harms of antipsychotic medications are vastly underreported, and almost all randomized controlled trials are performed by the pharmaceutical industry (Gøtzsche, 2015). In addition, psychiatrists are believed to overlook or minimize the side effects of the medication and automatically attribute any improvement to the medication and lack of progress to the unresponsive “disease” (Gøtzsche, 2015). Antipsychiatry advocates trust anecdotes to evidence because data published by pharmaceutical companies are believed to be manipulated data. According to Gøtzsche (2015), “the industry, which downplays the harmful effects of their drugs by pointing out that they weren’t statistically significant, often after they have manipulated the data to ensure that no significant differences would see the light of day” (p. 223). Therefore, they specifically question the increased influence of pharmaceutical companies in psychiatric practice and research. According to Frances (2013),

We are now in the midst of several market-driven diagnostic fads [ADHD in children] ...The DSMs have introduced many new diagnoses that were no more than severe variants of normal behavior. Drug companies then flexed their powerful marketing muscle to sell psychiatric diagnoses by convincing potential patients and prescribers that expectable life problems were really mental disorders caused by a chemical imbalance and easily curable with an expensive pill. (p. 111)

Antipsychiatry advocates question psychiatry’s strenuous efforts of proving the physiological origins of mental illnesses through neurochemistry and genetics (Staub, 2011). They believe that attitude towards mental illness is rooted in social values (unadjusted culture) and that mental illness represents hierarchical structures of societies and not defined qualities that differentiate a healthy and sick mind (Spitzer et al., 2005). According to Fromm and Anderson (2017),

many psychiatrists and psychologists refuse to entertain the idea that society as a whole may be lacking in sanity. They hold that the problem of mental health in a

society is only that of the number of 'unadjusted' individuals, and not of a possible unadjustment of the culture itself. (P.6)

Antipsychiatry advocates challenge the notion of harm by people with psychotic disorders by referring to all humans as a species who display complete insanity by having tendencies to destroy each other and their environment through war and exploitation (Foucault, 1965). They argue that psychiatry as a form of social control through confinement, punishment and torture has changed in appearance only and is now a system of psychological oppression and internalized control and restraint (Foucault, 1965). Antipsychiatry recommends that disorders related to brain problems be assigned to neurologists and that psychiatry as a non-medical field becomes a new discipline based on behavioural and psychosocial approaches instead of medical and pharmacological approaches (Nasrallah, 2011). By challenging the classifications of mental illnesses, the institutionalized alienation and oppressive approaches to treatment, antipsychiatry advocates for total liberation and the plain abolition of psychiatry as a whole (Nasrallah, 2011).

A The Critical Psychiatry Movement

Critical psychiatry grew out of what mainstream psychiatry considers "antipsychiatry". The Critical Psychiatry Network was first established in 1999 in the UK with a small group of psychiatrists in response to increased coercion in their field to encourage a self-critical attitude to psychiatric practice. The network was primarily created for psychiatrists, medical students and residents interested in psychiatry. Compared to most psychiatrists who believe that mental illness is a brain disease, critical psychiatrists do not hold that belief and therefore have different treatment approaches. Instead of favouring a single word diagnosis, they are interested in understanding the person and why they present with the problem they have in their life situation (Middleton & Moncrieff, 2019; Szasz, 1962). Critical psychiatrists argue that mental health disorders cannot be categorized as "diseases" or "illnesses" because these terms are relevant to

physical medicine and not the human mind (Middleton & Moncrieff, 2019; Szasz, 1979). Since illnesses are understood in relation to structural or functional deviation from a defined norm, critical psychiatry considers defining a condition as a mental illness in relation to a psychosocial norm problematic (Szasz, 1979). They also consider normative boundaries arbitrary and diagnostic lines and medical treatments poorly justified (Szasz, 1979). According to Wand (2015), “Diagnostic systems based on consensus models are inventions (not discoveries) and therefore represent merely one version of the truth” (1083). While they acknowledged the difficulties that some people encounter and present with, they prefer to conceptualize them as "problems in living" rather than mental illnesses or diseases (Szasz, 1962). Although they acknowledge a legitimate role for psychiatrists in helping people with "problems in living", they emphasize that relationships should be based on consensus and not coercion (Szasz, 1962). They also criticize mainstream psychiatry for claiming to have the most expertise to help people with their living problems (Szasz, 1962).

Critical psychiatrists are not psychotherapists who see people on a voluntary basis. However, they try to minimize coercion and are against community treatment orders (Middleton & Moncrieff, 2019). While they may use medication in their practice, they are skeptical about the evidence regarding their efficacy. They consider the side effects and risks of discontinuation and withdrawal associated with psychotropic medication and therefore use medication minimally and with caution (Middleton & Moncrieff, 2019). They refer people to psychotherapy and emphasize the need to improve care recipients' social situation and make them independent. Critical psychiatry is considered a minority position within mainstream psychiatry (Middleton & Moncrieff, 2019). While psychiatrists are different in their approaches to “patient-centred” care, some psychiatrists do endorse some views of critical psychiatrists by giving up the brain disease

model in their practice (Middleton & Moncrieff, 2019). Critical psychiatry criticizes biomedical epistemology in education, practice, and policy and claims that while mainstream psychiatry claims to use a biopsychosocial approach to care, its practice is largely dominated by biomedical approaches (Middleton & Moncrieff, 2019).

The Recovery Movement

The recovery movement aims to challenge the conventional paternalistic approach to care and neutralize the power dynamic between healthcare providers and patients by promoting and respecting patients' experiences (Mental Health Commission, 2015). Instead of focusing on the biological aspects of mental health disorders and associated symptoms, diagnosis, compliance and risk reduction, the recovery movement as a vision focuses on power-sharing and control, optimism and hope, building resilience and supporting people with mental illness to establish a meaningful life regardless of any deficits or persistent symptoms (Jacob, 2015). The recovery movement is perceived as a paradigm shift for healthcare providers, especially psychiatrists (Jacob, 2015). Although the recovery approach does not aim to exclude medical treatments, it strives to change the traditional culture of care (Jacob, 2015). The approach encourages focusing on the person; recognizing and supporting their abilities, goals and interests; and establishing a collaborative decision-making relationship based on the notion that care recipients are experts in their care (Jacob, 2015). The movement also encourages working with individuals on a recovery plan to identify their goals, strengths, and limitations and building networks for training, volunteering, and education (Jacob, 2015). The recovery approach also realizes the importance of social inclusion and active engagement within one's community, recognizing that social, economic, political, and cultural contexts impact physical and mental well-being. Therefore, it

encourages acknowledging and overcoming barriers to recovery at an individual, community, and systemic level (Jacob, 2015).

Over the past few decades, the government of Canada has advanced mental health recovery by focusing on advocacy and political changes through self-help and advocacy groups, peer support network activities (O'Hagan et al., 2009) and community and economic development initiatives (Church, 1997; Hartl, 1992). Kirby and Keon's 2006 report, *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*, was the first Canadian report to identify recovery as a central principle for mainstream mental health reform (Kirby & Keon, 2006). The Kirby Report used medical as well as psychosocial approaches to describe recovery by stating, "for many individuals [recovery] is a way of living a satisfying, hopeful, and productive life even with limitations caused by the illness; for others, recovery means the reduction or complete remission of symptoms related to mental illness" (Kirby & Keon, 2006, p. 42). The Kirby report identified choice, community and integration of services as three principles of recovery. It recommended that government funding be allocated to services and initiatives that are operated by people with mental illness (Kirby & Keon, 2006). As a result, the Mental Health Commission of Canada was established to reform the country's mental health policies and services (Kirby & Keon, 2006). The first draft of the national mental health framework, *Toward Recovery and Well-Being: A Framework for a Mental Health Strategy for Canada*, was presented in 2009 to endorse and adopt recovery as the overarching principle for mental health reform in Canada (Kirby & Keon, 2006). Recovery was defined as a "*journey of healing*" for those affected by the illness and "*well-being*" for every individual (Mental Health Commission of Canada, 2009).

In 2012, *Changing Direction, Changing Lives: A new mental health strategy for Canada* was introduced (Mental Health Commission of Canada, 2012). Strategies aimed at improving mental health and well-being for people with mental illness by actively involving them and their families in decision-making and focusing on reducing social inequities through enhanced access to meaningful resources, support and opportunities (Mental Health Commission of Canada, 2012). The release of the Mental Health Commission of Canada's strategy in 2009, *Toward Recovery and Well-being - A Framework for a Mental Health Strategy*, met varying degrees of approval and uptake at the provincial level. According to Piat and Sabetti (2012), in Ontario, "Recovery [was] taken up under the heading of 'person directed services', meaning that service users should have an opportunity to make informed decisions about their personal care and support within the formal system" (p. 9). In addition, the plan asserted that recovery should be based on "the right mix of integrated, evidence-informed services and supports" (Minds, 2011, p. 5). It is unclear whether these policy shifts have had any meaningful success at changing/transforming the treatment and status of mental health patients.

Explicit and implicit forms of domination and power continue to be evident through compulsory admission and treatment and exclusionary discourses in research and practice (Chien et al., 2013; Perron et al., 2010; Roberts, 2005). Professional attitude, stigmatizing behaviours in healthcare and society, and persistence of the medical paradigm in mental health services continue to be barriers to embracing recovery as a more comprehensive process (Piat & Sabetti, 2012; Stomski & Morrison, 2017). Other challenges for planners in various provinces in Canada include making social structures more inclusive and actively involving people with mental illness and their families in designing and determining the service (Piat & Sabetti, 2012). In addition, some consider the paradigmatic shift of recovery in mental health and evidence-based practice to

have conflicting orientations since evidence-based approaches privilege scientific and quantifiable findings that have long excluded the voices of psychiatric patients and that support the effectiveness or efficacy of particular (predominantly biomedical) interventions (Anthony et al., 2003; Davidson et al., 2009; Piat & Sabetti, 2012; Tanenbaum, 2006). In contrast, systems built on a recovery-oriented philosophy and mission are oriented towards emphasizing the client's expertise and self-determination, and subjective outcomes of empowerment, quality of life, and choice (Anthony et al., 2003; Davidson et al., 2009; Piat & Sabetti, 2012; Tanenbaum, 2006). Therefore, building a recovery-oriented system around evidence-based services might be defeating recovery goals unless privilege is given to subjective experiences of care recipients in both research and practice (Anthony et al., 2003; Davidson et al., 2009; Piat & Sabetti, 2012; Tanenbaum, 2006). A recent meta-synthesis review on participation and shared-decision making in mental healthcare found that efforts at the policy level to include people with mental illness in their care, an essential component of a recovery-oriented approach, have still not been translated into practice (Stomski & Morrison, 2017). According to Wand (2015),

Mental health service provision is presently dominated by the assessment and management of risk, biomedical model of illness and disorder, and emphasis on pharmacological and physical treatment and the routine use of restrictive measures [...] An assessment with a recovery orientation would instead pour attention on strengths, attributes, resources, coping skills, past successes, positive intentions, hopes and the broader context of the individual's life and social circumstances. Rather than re-casting problems of living as symptoms of pathology, a recovery perspective reassures people engaged with mental health services by having their circumstances normalised, not pathologized. (p.1084)

Tokenism, power imbalances, and healthcare providers' enduring paternalistic attitude and stigmatizing beliefs about the reduced capacity of people with mental illness in decision making continue to create barriers to genuine collaboration and recovery-oriented approach in clinical practice (Stomski & Morrison, 2017).

Creating knowledge to invoke meaningful change at practice or policy levels requires understanding the experiences, values, and needs of those served, and vulnerable and marginalized people's voices are typically not heard (Caxaj, 2015; Gubrium, 2009). Only by listening to the voices of marginalized people, such as those with psychotic disorders, can we support their capacity to engage in their care and receive the care they need (Chadwick et al., 2012). Disrupting the psychiatric system is believed to be difficult because,

As a social and political entity, psychiatry (...) has developed an astonishing ability to both absorb and control counter-discourses about mental health (e.g. women, gay, and patient rights movements) that dispute its activities and legitimacy. It absorbs those very initiatives (e.g. women's groups, self-help initiatives, psychiatric survivors networks, holistic approaches) that aim to depart from its oppressive and normative function, thus producing a seemingly new, adaptable, versatile, modernized, and responsive model of intervention. (Jacob et al., 2014, p. 8)

However, identifying, critiquing and disrupting dominant, oppressive, and controversial philosophies, practices, and policies that keep many people with psychotic disorders in a state of powerlessness and oppression is considered necessary. As Cutcliffe and Riahi (2014) explain:

to continue to engage in care (...) without [examining and] critiquing our practice (and the philosophical positions, theory, and evidence that underpins practice), would constitute the irresponsible position. Without such examination and deconstruction of practice during our past, perhaps Psychiatric/Mental Health practitioners would still be forcing clients into ice baths, providing so-called aversion "therapy" to "treat" homosexuals, or engaging in eugenics-driven forced sterilization of clients as occurred during World War II. (p. 236)

Including voices and experiences of people with mental illnesses in research can help preserve the rights of those who have suffered repression and marginalization by the dominant political, economic, cultural, and scientific discourses (Kirkham & Anderson, 2002). This change for inclusion, respect, empowerment, and justice requires critical examination of the subtle forms of power exerted by old and new policies and practices (Kirkham & Anderson, 2002; Perron et al., 2010). In addition, dominant discourses that have the power and potential to subjugate care

recipients' experiences and voices should also be examined, critiqued, and deconstructed (Holmes et al., 2008a). Since discourses are attached to all areas of knowledge, we also need to question how we are sustaining or interrogating inequities by the knowledge we produce (Holmes et al., 2008a; Kirkham & Anderson, 2002). Overcoming and preventing oppressive practices, people's experiences, subjectivity, and sense of agency, which are so important when working with people who are vulnerable to stigmatization, oppression, and marginalization, should become the starting point in knowledge construction (Holmes et al., 2008b; Perron et al., 2010). This requires using an approach that could meet the epistemological imperative of promoting the voice and the subjugated knowledge of excluded persons while questioning the hegemonic discourses that exclude other forms of knowing (Holmes et al., 2008a). To help accomplish this task, I used digital storytelling. The following section will provide details about the advantages of using digital storytelling.

Art-Based Research-Audiovisual Methods

Digital storytelling is a form of art-based method. McNiff (2008) defines art-based research as "the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies" (p. 29). Art can be included in forms of written (narrative, poetry, creative prose), performance (theatre, dance), and audiovisuals with or without technology (music, photographs, drawings, paintings, film, video, and collage) (Banks & Zeitlyn, 2015; Leavy, 2015). It can be used at all stages of the research process, including identifying and constructing a research question, data collection, analysis, interpretation, or dissemination (Emmison & Smith, 2000; Hartel & Thomson, 2011; Leavy, 2015). Art can be used to elicit meaning about a given research topic or as a way to

convey the results of a research project (Harper, 2002; Wang & Burris, 1997). It can also be produced by the researcher (e.g., documentary films) or by participants (e.g., photovoice) or in collaboration with the participants as in digital storytelling or participatory video (Harper, 2002; Wang & Burris, 1997).

McNiff (2008) suggests that art-based research has emerged in psychiatry and psychology from the practice of creative art therapies, which "promoted themselves as ways of expressing what cannot be conveyed in conventional language" (p. 11). Nevertheless, social sciences such as anthropology and human geography also have a long history of using art in form of visuals to provide information about their subject (Gillian et al., 2016). According to Gillian (2016), "anthropology and human geography have used visual images as a research tool for as long as they have been established as academic disciplines" (p. 15). Anthropologists and sociologists collected videos and photographs to document and analyze visual phenomena that were important, interesting, or incomprehensible (Gillian, 2016). They also used images to communicate intangible aspects of cultures (Banks & Zeitlyn, 2015). While photographs and films were the most used visual methods in anthropological and sociological inquiry, with the development of new technology, anthropologists along with social scientists and scholars in queer studies started to engage with video as a new visual method for their inquiry and knowledge production (Banks & Zeitlyn, 2015). Compared to film, which was extensively used in research in the 1970s, video provided durability and utility at a lower cost (Banks & Zeitlyn, 2015; Pink, 2011). The rise of postmodernism, which recognizes the importance of images and text in understanding social constructs, also created favourable conditions for arts in research (Pink, 2013; Rose, 2016). Nevertheless, it was not until the 1990s that art-based research gained prominence (Pink, 2011; Rose, 2016). Further development in technology, especially digital

video, invited new possibilities in research and representation (Banks & Zeitlyn, 2015; Pink, 2011). Over the past decade, the use of art-based methodologies has flourished in qualitative research as a means of constructing and communicating holistic and integrated perspectives (Boydell et al., 2015).

Traditionally, videos, films, or visuals were produced mainly by researchers and used as a recording or illustration tool for naturally occurring situations in the field (Hartel & Thomson, 2011; Savin-Baden & Wimpenny, 2014). However, "a paradigm shift occurred when social scientists began to ask research subjects to produce the visual data" (Lorenz & Kolb, 2009, p. 263). Researchers started to use art-based methodologies to engage community members as co-investigators rather than research subjects. With this approach, participants were able to actively use the power of visual imagery and other forms of art to raise public awareness, challenge hegemonic and stigmatizing social positions or views about a particular population and engage with the policymakers for systematic change (Molloy, 2007; Wang & Burris, 1994). Digital storytelling and photovoice, which is a combination of participant produced photos as their "voice" in combination with or without words to extrapolate meanings or relevance of the images, are examples of art-based methodologies in which participants and facilitators collaborate and use visual materials to produce powerful stories (Hardy & Sumner, 2014; Wang & Burris, 1994).

Digital Storytelling

The term 'digital storytelling' was coined in the 1990s to describe the workshop process designed by Atchley, Lambert and Mullen to teach ordinary people how to use narrative and participatory media to create short videos about their lives (Hardy & Sumner, 2014; Hartley & McWilliam, 2009). Prior to that, digital storytelling was mainly the production of experts such as

filmmakers and digital artists (Hartley & McWilliam, 2009). Increased accessibility to digital media by the domestic market created a paradigm shift and increased the use of digital storytelling by lay people (Hartley & McWilliam, 2009). Digital storytelling in its generic sense can refer to a story told using digital media, including podcasts, recorded interviews, or a vox pop. However, a specific conception and what I focus on in this research is Lambert and colleagues' co-creative practice and its flexible variations.

Lambert and colleagues established The Center for Digital Storytelling in the United States, named StoryCenter in 2015. The philosophical and epistemological core of StoryCenter is the power of engaging with stories for reflective practices, education, community mobilization, and advocacy for social justice and change at individual, community and policy levels (StoryCenter, 2017a, 2017b). Since its inception in 1993, StoryCenter has provided public workshops and partnered with organizations to help individuals and communities develop and share their stories (StoryCenter, 2017b). Hardy and Sumner adopted digital storytelling for healthcare in the UK in 2003 to help humanising a healthcare system. The use of digital storytelling methodology through their Patient Voices Program offered a novel and innovative way of conveying care recipients' experiences to those who need to understand them to design and deliver care and services that are patient-centred, effective, compassionate, and safe (Victoria, 2016).

Hardy and Sumner are currently considered the leading practitioners in digital storytelling in healthcare internationally (Patient Voices Program, 2017). They have facilitated over 100 projects to help healthcare providers, caregivers and care recipients develop over 1000 digital stories about their experiences and have conducted research into the use and impact of stories as a reflective tool for education and healthcare quality improvement (Patient Voices

Program, 2017). By conveying the voices of care recipients and people who use healthcare services, digital storytelling created a forum for reflection, discussion, debate and understanding to help increase empathy and compassion and improve services. Digital storytelling is currently being used in various ways and contexts, including community development, education, training, professional development, and participatory research (de Jager et al., 2017).

Digital Storytelling Workshop. The traditional digital storytelling workshop, as described by Lambert and colleagues, is 3-5 days in length, during which participants engage in immersive activities to develop a story using digital media (Hardy & Sumner, 2014; Lambert, 2009). This process can be more flexible to meet the needs of participants. In the workshop, participants are introduced to digital storytelling concepts; assemble for an oral story circle where they share and receive feedback about their stories; construct a 250-300 word narrative with coaching from workshop facilitators; edit, refine and distill the story to reveal its essence and discover its meaning; record their story and incorporate visual materials related to the narratives; and produce a 2-5 minute video using digital editing software (Hardy & Sumner, 2014; Lambert, 2009).

Digital Storytelling in Research, Practice, and Policy. As an emergent form, practice, and movement, digital storytelling is currently used worldwide (Hartley & McWilliam, 2009). The Patient Voice program in the UK (2003), Kids for Kids in Israel (2003), Australian Centre for the Moving Image (2002), Men as Partners Engender Health in South Africa (2005), Million Youth Life-Stories in Brazil (2006), and Capture Wales BBC in Europe (2001) are examples of digital storytelling programs around the world (Hartley & McWilliam, 2009). Digital storytelling in healthcare has been used across various fields and for multiple purposes. Several reviews have been conducted to explore the use of digital storytelling in research, including 1) a meta-

narrative analyzing the evidence on how stories including digital storytelling can enhance humanistic cultural change in healthcare organizations (Rose et al., 2016), 2) a literature review examining the process and impact of digital storytelling in middle school students (Kindergarten to Grade 12) (Behmer, 2005), 3) a literature review exploring and focusing on the therapeutic impact of digital storytelling on children with cancer (Wilson et al., 2015), 4) a systematic review on the use and benefits of digital storytelling in research in all context (de Jager et al., 2017), 5) a systematic review exploring the use of digital storytelling in healthcare professional education (Moreau et al., 2018), and 6) a scoping review exploring the use of digital storytelling with people with mental illness (De Vecchi et al., 2016).

Digital storytelling in research has been used for therapeutic and educative purposes and knowledge translation, preserving cultural heritage, participatory approaches, and social advocacy (de Jager et al., 2017). As ready-made knowledge translation products, digital stories created in research have been disseminated to family, friends, practitioners, researchers and policymakers through project websites (Rice et al., 2015; Wexler et al., 2014), social media (YouTube, Facebook) (Burgess et al., 2010; Cunsolo Willox et al., 2013; Morgan & Castleden, 2014; Treffry-Goatley et al., 2016), community screening (Wexler et al., 2013), academic articles (Burgess et al., 2010; Gubrium et al., 2014; Morgan & Castleden, 2014; Wake, 2012; Wexler et al., 2013), local health clinics (Treffry-Goatley et al., 2016), control settings as an intervention (Willis et al., 2014), and conferences (Ferrari et al., 2015; Kent, 2016; LaMarre & Rice, 2016).

Digital Storytelling in Mental Health. Interest in using digital storytelling in mental health stemmed from the desire and the need to provide people living with a mental disorder a forum to articulate their perceptions and emotions in a creative and accessible manner while

helping listeners to engage with the stories (De Vecchi et al., 2016). For example, to help undergraduates develop compassionate care for people with dementia, a digital storytelling workshop that included seven individuals with early-stage dementia and a healthcare provider was conducted in the UK by Stenhouse et al. (2013). The stories developed in this workshop served as an e-learning package for educating nursing students. Despite encountering various challenges related to telling a story (reading and speaking) and anxiety about using technology, participants experienced positive outcomes from the process, including increased connection, improved self-expression and gaining a sense of purpose and identity. Facilitators played an important role and were critical elements in creating a safe space, helping participants overcome challenges by being sensitive to their needs (Stenhouse et al., 2013). The workshop demonstrated that people with early-stage dementia could engage with digital storytelling and develop their stories. In another project conducted by Spector et al. (2011) in the UK, ten digital stories were created with five care recipients with mental illness for the training of staff and helping increase understanding of inpatient care. Digital storytellers reported the process to be therapeutic; however, support was required as the process could trigger past trauma. Stories enabled reflection on practice and discussion of complex issues, and the authors recommended using digital stories during therapy with other patients.

The first review I uncovered to identify how digital storytelling has been used in mental health was conducted by De Vecchi et al. (2016). This scoping review defined mental health as people experiencing psychosis, complex responses to trauma, dual diagnosis, psychosocial disability, dementia, and anxiety. Nine databases were searched for peer-reviewed literature published in English between 2000 -2015. According to De Vecchi and colleagues, this timeframe was selected due to a dearth of literature on digital storytelling in mental health before

this date. Digital storytelling was searched in the title, keywords, abstract or full text and 15 articles were included in this scoping review. Most studies were reported to be from Western countries, including Australia (2), Canada (3), New Zealand (1), UK (4), USA (4), and Zimbabwe (1). Except for one article (published in 2008), all were issued on or after 2010 (De Vecchi et al., 2016). The included studies involved people living with mental illness from various settings such as early psychosis intervention services, dementia units, acute inpatient units, and community settings. The use of digital storytelling in the context of mental health varied across the 15 included studies. Some studies had people living with a mental health disorder; others focused on the mental health/wellbeing of specific groups, including Indigenous people from Alaskan and New Zealand, marginalized children with psychosocial problems in the USA, HIV-positive adolescents in Africa, and refugee women in Australia. None of the 15 included studies included people living with psychotic disorders. De Vecchi et al. (2016) reported that digital storytelling in mental health had been used to enhance learning skills (gaining skills in digital literacy, technology, etc.), learning about personal or other people's lived experience, and educational intervention. The review concluded that digital storytelling could increase mutual understanding of and empathy towards lived experiences in mental health. However, there is a dearth of research in this area and recommended to conduct more research to advance "a recovery orientation in service provision that is built on solidarity and a social justice agenda" (De Vecchi et al., 2016, p.183).

De Vecchi et al. (2017) claimed that no studies exist that describe the process of participation in digital storytelling from the perspectives of consumers, clinicians, and workshop support personnel in mental health. Therefore, they used a case study involving mental healthcare providers and patients as an innovative approach in the creative process of digital

storytelling to share their experiences (De Vecchi et al., 2017). They aimed to explore if the digital storytelling process can be a useful participatory research method in mental health services for facilitating lived experience using the perspectives of consumers, carers, clinicians, and workshop support personnel. They also provided commentary on the potential of digital storytelling as a research method for enabling shared dialogue between stakeholders in mental health on lived experience. This approach helped create a space where power differentials between healthcare providers and patients were minimized, and shared discussion was developed (De Vecchi et al., 2017). However, it is unclear if the care recipients included people with psychotic disorders.

Traditional approaches used to address the needs of people with psychotic disorders are oppressive and exclusionary, constricting their power, agency, experiences, and voices (Aho, 2008; Crowe, 2006; Walsh et al., 2008). Digital storytelling is believed to provide a forum for people with mental disorders to represent themselves as creative and capable experts (Ferrari et al., 2015; LaMarre & Rice, 2016; Rice et al., 2015). The experiences of people with psychotic disorders became the starting point to construct knowledge in this research. I aimed to explore the process of digital storytelling for people with psychotic disorders to express their voice and understand how nurses and healthcare leaders engage and respond to digital stories. The next chapter will detail the theoretical framework that guided this inquiry.

Chapter 3: Theoretical Framework

Postcolonialism

Postcolonialism has expanded beyond its initial definition of governing influence of a nation over a dependent country or territory and its aftermath (Cashmore, 1996) to consider a wider range of systems and policies that cause inequality and oppression while maintaining hegemony and influence (Ashcroft et al., 1998). Postcolonial approaches strive to understand

"colonial discourses as an imaginative and material practice within which a particular idea, people, institution, and action produce inequalities" (De Leeuw et al., 2009, p. 5). For this research, Spivak's theory of subalternity was used as a framework to explore the process of digital storytelling with people with psychotic disorders as a means of expressing their voice and understanding how nurses and healthcare leaders engage with the format and content of the digital stories. First, I present the contribution of the co-founders of postcolonial theory and the differences in their perspective on how power, domination, and subjugation over a designated inferior 'other' are created, maintained, and disrupted. Next, I present the use of postcolonial theory in nursing and outside its original scope. I then examine Spivak's theory of subalternity in more details to describe the core concepts and assumptions of the theory as well as its limitations and strengths. I also discuss the relevance of Spivak's theory to this research and in informing decisions about data collection, methodology, analysis, and interpretation of data.

The Contribution of the Co-founders of the Postcolonial Theory

Postcolonialism has expanded beyond its initial definition of governing influence of a nation over a dependent country or territory and its aftermath (Cashmore, 1996) to consider a broader range of systems and policies that cause inequality and oppression while maintaining hegemony and influence (Ashcroft et al., 1998). Postcolonial approaches strive to understand "colonial discourses as an imaginative and material practice within which a particular idea, people, institution, and action produce inequalities" (De Leeuw et al., 2009, p. 5). For this research, Spivak's theory of subalternity was used as a framework to explore the process of digital storytelling with people with psychotic disorders to express their voice and understand how nurses and healthcare leaders engage with the format and content of the digital stories. First, I present the co-founders' contribution to postcolonial theory and the differences in their

perspective on how power, domination, and subjugation over a designated inferior 'other' are created, maintained, and disrupted. Next, I present the use of postcolonial theory in nursing and outside its original scope. I then examine Spivak's theory of subalternity in more detail to describe the core concepts and assumptions of the theory and its limitations and strengths. I also discuss the relevance of Spivak's theory to this research and in informing decisions about data collection, methodology, analysis, and interpretation of data.

The Contribution of the Co-founders of the Postcolonial Theory

Writing about colonialism, colonial power, and its relations dates back to the sixteenth century (Ashcroft et al., 1998; Kirkham & Anderson, 2002). Anti-colonial movements in countries such as Egypt, Algeria, India, Ghana, and the Caribbean formed the foundation of postcolonialism. Leaders such as Gandhi, Fanon, and Nkrumah assisted in defining major ideologies of colonialism to help understand the oppressive relationships between the Western and non-Western societies that were created as a result of imperialism (Ashcroft et al., 1998). Colonization by European empires created control and exploitation of the colonized people and their lands, leading to active and passive resistance to end colonization (Young, 2009). While some nations could achieve national sovereignty and independence (Griffiths & Ashcroft, 1995; Stausberg & Engler, 2016), colonized countries continued to be controlled by local powers who served the interest of former colonizers (Young, 2009). In addition, as colonized countries moved from colonial to postcolonial status, they usually suffered from national insecurity, lack of socio-political identity, and economic struggle, forcing them to accept support offers in exchange for economic and diplomatic partnership from former colonizers (Young, 2009). The continued relationship maintained the experience of subordination, oppression, and economic inequality post-colonization. Terms such as imperialism by Said (1993) and neo-colonialism by

Ashcroft et al. (2013), and Loomba (1998) were used to describe the practice of dominance without formal colonies or direct political leadership. Unlike colonialism which led to building colonies in the colonized land, under neocolonialism, domination and control were inflicted through the political and economic ideologies (Said, 1978; Stausberg & Engler, 2016).

The foundation of postcolonialism is based on studying the issues that stem from the socio-economic, political, and psychological effects of colonial relationships (Kirkham & Anderson, 2002). By focusing on human experiences and consequences of domination and exploitation of populations who have been colonized, postcolonialism provided "a radical philosophy that interrogated both the past history and ongoing legacies of European colonialism in order to undo them" (Schwarz, 2000, p. 4). Postcolonialism also developed into generating theoretical frameworks and models to challenge the dominant and hegemonic ways of Western perceptions, ideologies and definitions of the colonized societies (Mandair, 2016). Such analysis and processes, also known as postcolonial theory, became a worldview to study the impact of oppression on specific groups (minorities and those subjected to subaltern classes) and provide critical approaches based on concepts of otherness and resistance (Riach, 2017; Young, 2009). Race, ethnicity, nation, subjectivity, identity, power, and subalternity are themes that are central to the postcolonial theory (Barker, 2000; Kirkham & Anderson, 2002). While many activists and philosophers contributed to the postcolonial literature, Edward Said (1973), Homi Bhabha (1994), and Gayatri Spivak (1988) are acknowledged as the co-founders and "holy trinity" of postcolonial theory (Bickford, 2014; Kirkham & Anderson, 2002; Young, 1999). The co-founders' postcolonial theory will be described in more detail in the next section.

Orientalism by Edward Said

As the United States' foremost spokesman for Palestinians, Edward Said is one of the most influential founders of the academic field of postcolonial studies (Riach, 2017; Young, 2016). His groundbreaking book *Orientalism* in 1978 established the first phase of postcolonial theory (Said, 1978). The book provided a critical analysis of how Western and European countries legitimized their political and economic domination through colonial thinking and stereotypes of Eastern countries, particularly the Arab world (Abu El-Haj, 2005; Buchowski, 2006). Said's core arguments focused on the interplay between what he called the 'Occident' (Europe, the West, 'us') and the 'Orient' (the East, 'them') (Riach, 2017; Said, 1978). He presented the concept of 'Orientalism' to demonstrate that European colonialism was a worldview that informed a subtle and persistent Eurocentric prejudice and misinterpretation of the Orient as 'exotic,' 'dirty,' 'passive,' 'barbarian' and sometimes 'dangerous' compared to the 'just,' 'rational,' 'civilized,' and 'superior' Occident (Said, 1978). His idea of "representation for consumption by the West" explored the role of Orientalism "as an instrument of colonial power" (Selby, 1998, p. 31). According to Said, presenting inaccurate, misleading and stereotypical cultural representations of the East allowed colonization to be defended by the colonizer as a benevolent enterprise of spreading civilization (Inden, 1986; Said, 1978; Selby, 1998). Said examined a variety of texts and imagery produced by the West about the cultures of the colonized and concluded that Occidentals created distorted images and facts based on their preconceived notions, rather than observable facts to maintain superiority and power (Ashcroft & Ahluwalia, 2008; El-Haj, 2005; Said, 1978). He conceived the Western academic work of the Orient to be a form of political intellectualism used for cultural discrimination and imperialist domination (Rizvi & Lingard, 2006). According to Said (1978), knowledge created outside of and about the Orient was central to imperialism since it perpetuated distorted stereotypical ideologies about the

East, which promoted differences, created inferior 'others', and justified Western interventions for 'rescue'.

Despite various critiques regarding the binary division of East and West and lack of consideration for the complexities of colonial relationships, Said's text has been recognized as an important work of the twentieth century on postcolonialism (Riach, 2017; Williams & Chrisman, 1994). *Orientalism* (1978) is credited for helping to explore the association between Enlightenment and colonization, by examining colonial discourses and their effects on the perceptions of reality (Ashcroft & Ahluwalia, 2008; Williams & Chrisman, 1994). His work continues to challenge the misrepresentation of cultural, political, and economic conditions of formerly colonized groups or territories (Ashcroft & Ahluwalia, 2008; El-Haj, 2005, Young, 1999). Said suggested using "contrapuntal analysis" as a method to recover the voices of the subjugated 'other'. Using this approach, scholars read and analyze the history "in relation to its spatial and political relations to empire, as well as in counterpoint to the works that colonized people themselves produced in response to colonial domination" (Rizvi & Lingard, 2006, p. 301). Overall, *Orientalism* created a new framework for academics to relate to their subject, question stereotypical views towards other cultures, and deconstruct ideologies and inaccurate representations of the colonized (Ashcroft & Ahluwalia, 2008; El-Haj, 2005, Young, 1999).

Homi Bhabha's Discussion of Cultural Hybridity

Homi Bhabha (1994) is an Indian academic and a major theorist who contributed significantly to postcolonial theory (Williams & Chrisman, 1994). In his collection of innovative essays, *The Location of Culture* (1994), Bhabha challenged colonizers' ideologies of pure and civilized "identity" by claiming that colonizers have traces of colonized others in them. Bhabha introduced the theoretical concepts of hybridity and mimicry to present the instability and mixed

nature of colonizers and colonized identities (sense of self) (Bhabha, 1994; Owczarzak, 2009). Unlike Said, who presented colonial discourses as a symmetrical relationship of binaries (either/or) such as orient/occident, superior/savage or colonizer/colonized, Bhabha claimed that identities are fluid as they are composites of different cultures and beliefs with which they interact (Bhabha, 1994; Owczarzak, 2009). According to Bhabha (1994), sharing languages, ideas, and material goods forces both the colonizer and the colonized to adapt and change in relation to one another. These interactions and negotiations create a form of blending and transculturation, resulting in hybridity or a mixture of identities. Hybridity stresses the interdependence of different races and cultures and their intersections. Hybridity is neither 'the one' nor 'the self' but what is new; 'the third space' (Bhabha, 1994; Riach, 2017).

In postcolonial theory, mimicry is an imitation of cultural customs and a strategy used by a person or group to adapt and incorporate ideas from other cultures (Bhabha, 1994). Mimicry is also used to express subservience to the more powerful (Bhabha, 1994). According to Bhabha (1994), resistance turns mimicry into mockery when the colonizer's power is resisted. Bhabha (1994) used the term 'uncanny' to demonstrate how Western colonial powers produced cultural and physical violence while still presenting themselves as civilized and ordered. Unlike Said, Bhabha (1994) did not challenge the accuracy of stereotypes but argued that representation of the colonized by European colonies not only justified conquest but rendered the colonized suitable for subjugation (Riach, 2017). Bhabha's critique of Said's presentation of colonial discourses as a one-way monologue suggests that the symmetrical relationship between the colonizers and colonized can only be escaped by inverting the relationship (Williams & Chrisman, 1994). However, Bhabha believed that the most meaningful resistance to colonialism emerges from a committed exploration of the ideological contradictions of colonialism (Williams & Chrisman,

1994). Bhabha moved beyond a simple analysis of European attitudes towards the Orientals to demonstrate that the 'ambivalence' or internal inconsistencies, contradictions, fear, and ambiguity inherent in humans resulting from hybridity are the place where Western colonies projected their stereotypes of the Orient (Riach, 2017; Owczarzak, 2009; Williams & Chrisman, 1994).

Bhabha's work helped construct an innovative theoretical framework to challenge the authority and superiority of colonial interpretation and representation of colonized countries (Owczarzak, 2009; Riach, 2017).

Subalternity by Gayatri Spivak

Gayatri Spivak is an Indian scholar, literary theorist, and feminist critic who had a significant influence on the development of the postcolonial theory (Riach, 2017). Spivak's essay, *Can the Subaltern Speak?* (1988) is a central pillar of postcolonial theory in which she examined several themes, including the damaging effect of Western thinking in non-Western contexts; ethical problems of representation; and the doubly oppressed position of subaltern women subjected to colonialism and patriarchal systems (Morris, 2010; Morton, 2003; Riach, 2017; Spivak, 1988). Spivak (1988) used the term subalterns to refer to people who are assured of inferior rank and those outside the hierarchy of social, political, and hegemonic power (Riach, 2017). The term subaltern was initially adopted by Antonio Gramsci (1937), an Italian Marxist intellectual, to refer to workers who were subjected to oppression by the hegemonic powers of the ruling class in the Soviet Union. However, the term gained increased prominence after being used by Spivak in 1988 (Riach, 2017).

In her essay, Spivak (1988) claimed that subalterns have no voice and are silenced through discourses of power in society. Spivak criticized the elite and Western scholars who investigated marginalized populations by excluding their voices and speaking for them.

According to Spivak (1988), representation by influential people has prevented the subalterns from representing themselves and having their voices heard. Spivak also argued that applying Western thinking in non-Western contexts has caused damage as inquiries into Eastern nations occurred with ideological biases that could only produce biased knowledge. Spivak asserted that only by allowing subalterns to speak for themselves can one accurately represent them.

According to Spivak, overcoming subalternity starts with self-representation and communication with those in power.

Controversies Surrounding Postcolonial Theory

While the term 'postcolonial' might appear to mean what comes after colonization, the concept has been redefined “to mean resistance to the colonial at any time—literally in the case of decolonized societies, and ideologically for still colonized societies” (Young, 2009, p. 13). Therefore, some have criticized the prefix 'post' for implying a chronological order of events and suggesting the end of colonialism and the end of colonial exploitation (Mandair, 2016). In addition, some have suggested that postcolonial theory is detrimental to nations and people who want to move beyond the colonial experience and continue to have a good relationship with former colonizers. The argument is that presenting categories (colonizer vs colonized) and sharing the experiences of the colonized risks creating further oppression and marginalization of the group by reinforcing the oppressed identity and 'victim' discourses on them (Young, 2009). Others debate that understanding the profound disruptive effects of colonization that continue to shape the social, psychological, economic, cultural, and health context of the colonized is beneficial (Mandair, 2016). Critical examination of problems within historical contexts is believed to create awareness about the continued effects of past colonization on current situations, thereby helping to promote equity and decreasing the perpetuation of stereotypes and

stigma (Mandair, 2016). Other discussions focus on the practicality and effectiveness of postcolonial theory as an emancipatory tool (Young, 2009). While many believe that using a postcolonial lens has helped address how inequalities are propagated through knowledge creation, modes of representation, and power inequalities (Said, 1973; Young, 2009), others debate the extent to which postcolonial theory has been successful at creating change, considering the current conditions of dominant Western knowledge and global capitalism (Rizvi & Lingard, 2006; Tikly, 1999; Young, 2009).

Many schools of thought, such as postmodern and poststructuralist traditions, neo-Marxism and feminism have contributed to the postcolonial literature leading to controversies on how postcolonial theory is constructed, and whether it should be approached as one theory with various concepts and contributions from various theorists or as multiple postcolonial theories (Bickford, 2014; Kirkham & Anderson, 2002). For example, some scholars consider the texts written by the co-founders of postcolonial theory (Said, Bhabha, Spivak) and other theorists who contributed to the postcolonial literature to propound multiple theories such as a theory of subalternity, a theory of hybridity, a theory of the third space and so on (Barker et al., 1996; Ramone, 2011; Prasad & Sarkar, 2010). Others consider the postcolonial theory one theory with multiple key concepts such as culture, power, hegemony, and identity (Bickford, 2014; Kirkham & Anderson, 2002). The uncertainty regarding the construct of postcolonial theory was reflected by Bickford (2014), who stated that “one must piece together this theory using the writings of many scholars from a variety of disciplines to arrive at a satisfactory explanation of what it is that postcolonial theory or postcolonialism is” (p. 219). Other scholars have also emphasized the uncertainty around the construct and structure of postcolonial theory (Carl, 2006; Strongman, 2014).

Postcolonial theory has also been challenged to meet the scientific definition of a theory since it does not present "a coherently elaborated set of principles that can predict the outcome of a given set of phenomena" (Young, 2009, p. 24). There is also no explicit information about how the concepts within this theory are organized or which concepts are critical to this theory (Bickford, 2014; Kirkham & Anderson, 2002). While postcolonial theorists analyze similar themes related to colonization, their definitions of concepts and approaches towards decolonization and resistance are different (Kirkham & Anderson, 2002). For example, Bhabha (1994) critiqued Said's concept of 'Orientalism' as a symmetrical relationship that can only be escaped by inverting the relationship (Riach, 2017). He believed that meaningful resistance emerges when ideological contradictions within colonialism are exposed (Bhabha, 1994; Williams & Chrisman, 1994). Therefore, postcolonial theory has been described to resemble feminism and socialism in providing "a related set of perspectives, a cluster of concepts, which overlap or are even juxtaposed against each other, on occasion contradictorily or poetically" (Young, 2009, p. 24). Bickford (2014) also challenged postcolonial theory's ability to meet the nursing definition of a theory due to lack of clarity and consistency in the definition of concepts. According to Bickford (2014), postcolonial theory best meets the definition of a conceptual/theoretical framework.

Controversies about the construct of postcolonial theory might be related to a divergence of opinions as to what constitutes a theory. Definitions and constructs of theories are different depending on scholars' worldviews and paradigms (Wacker, 1998), and postcolonial theory has an interdisciplinary character, with contribution from various disciplines such as anthropology, sociology, political science, psychoanalysis, and literary and cultural studies (Kirkham & Anderson, 2002). Researchers who use postcolonial theory as a framework to analyze a

phenomenon usually select concepts or contribution of a specific postcolonial scholar to guide their research because the shared contribution of postcolonial theory scholars are not unified (Bickford, 2014; Kirkham & Anderson, 2002). Although they analyze similar themes, the various contexts and conflicting opinions and approaches to decolonization challenge their work's unity to construct one theory.

Use of Postcolonial Theory

In nursing, the use of postcolonial theory outside its original definition continues to be limited (Chulach & Gagnon, 2016). For example, some nursing scholars have examined how postcolonial theory can further nursing's understanding of cultural frameworks (Blackford 2003) or cultural safety (Anderson et al., 2003), while others have examined how a biomedical healthcare model is a form of colonial patronage that perpetuates powerful discourses in nursing to maintain the status quo (Holmes et al., 2008a). Postcolonial theory has also been used to demonstrate how powerful hegemonic forces of biomedicine construct the roles and identities of nurse practitioners to subordinate their role in the healthcare system (Chulach & Gagnon, 2016).

Postcolonial theory can provide a framework to analyze and interpret marginalized experiences of people within mediating forces that shape those experiences. Postcolonial approaches enable us to interrogate inequities and meet the epistemological imperative of giving voice to subjugated knowledge while questioning hegemonic discourses that exclude other forms of knowing (Holmes et al., 2008a). Postcolonial theory can highlight how power in knowledge production enables the inclusion or exclusion of certain discourses (Czyzewski, 2011; Holmes et al., 2008a). For example, postcolonial critiques can help analyze and challenge the limits of dominant approaches in the generation of 'best evidence' that can make marginal space for peoples' experiences. It can further address the implementation of knowledge produced through

exclusionary research approaches as a subtle form of domination that can be oppressive and disempowering. Sharma (2018) used postcolonial theory to challenge patient engagement in medical education development and production. Sharma (2018) initially provided a summary of the literature about patient involvement in medical education and then used postcolonial theory as a framework to analyze the findings. Using postcolonial theory concepts, Sharma (2018) demonstrated and critiqued "colonial" patterns and approaches such as tokenism that marginalize patients' voices in medical education.

One of the social mandates of nursing is to foster social justice, uncover inequalities, and give voice to subjugated knowledge by examining systems and structures that exert discriminatory and colonizing power (Anderson, 2002; Kirkham & Anderson, 2002). This includes a critical examination of dominant ontological and epistemological discourses used by healthcare providers and nursing scholars to produce new knowledge and bring about change (Holmes et al., 2008b; Kirkham & Anderson, 2002). If nursing integrates colonial principles into its agenda without questioning them, it becomes part of the colonizing process (Holmes et al., 2008b). Therefore, nurses need to identify and challenge conditions, policies, and practices that might serve particular institutional interests but affect nursing's knowledge and practices (Mill et al., 2016). Dominant colonial discourses can be exerted by force or a more subtle and inclusive power, so it is imperative to deconstruct their excluding forces and ideologies (Browne, 2001; Holmes et al., 2008b). Nurses can use postcolonialism to challenge power relations and examine how nurses contribute to or participate in exclusionary practices at the clinical, research, and policy level (Mohammed, 2006). According to Mohammed (2006), using postcolonialism as a theoretical framework “can help nursing researchers and practitioners avoid the reproduction of

injustices and stereotypes, illuminate the complexities of life at the intersections, and contribute to the construction of a more just world” (p. 108).

Much like colonial ideologies, which required the construction of the inferior "other" to justify colonization, healthcare systems and healthcare providers can use similar approaches to justify authority, expertise, and domination (Sharma, 2018). Therefore, postcolonial theory can help resist pervasive power asymmetry in healthcare and critique practices and policies that oppress and dominate patients based on colonizing powers of exclusion and representation (Kirkham & Anderson, 2002). When using postcolonial theory as a framework, marginalized experiences and subjectivities are never rejected. Instead, they are moved from the margins to the mainstream to become the starting point in knowledge construction (Young, 2009).

Spivak's Theory of Subalternity

Spivak's work was strongly influenced by Said and several anti and poststructuralist philosophers and theorists such as Frantz Fanon, Aimé Césaire and Gandhi, who criticized colonial narratives of civilization and underscored the damages caused by forcing Western values onto non-Western populations (Morton, 2007). Spivak's theory of Subalternity brings deconstructionist, Marxist, and feminist approaches in a framework to formulate an argument about the oppression caused by differences in power and knowledge (Riach, 2017).

Deconstructionists interrogate the assumptions about the nature of reality by questioning the role of language and power structures in constructing truth. They encourage examining how reality is produced and questioning the stability and possibility of 'objective truth' (Turner, 2013).

Feminism focuses on the marginalization of women and strives to define and establish gender equality, while Marxism provides insights into how the economy and struggles between social classes drive history (Bowden & Mummery, 2014).

Spivak's early education by subaltern women shaped her ideas about the effect of societal hierarchies on decisions of the least powerful group (Morton, 2003). Spivak used the term subalternity to refer to conditions of subordination as a result of colonization or other forms of domination, including social, political, racial, linguistic, and cultural dominance (Beverley, 1999). In her essay, *Can the Subaltern Speak?* Spivak referred to subalterns as the most excluded members of society, the 'illiterate peasantry', and the poorest who are not heard and have no voice or power. According to Spivak, subalterns are at the margins of society and have little to no access to power due to their lower social status (Morris, 2010; Morton, 2003). Spivak considered the subalterns to have limited ability to contribute to accepted traditions and views and the reinterpretation of the motivation of people involved in hegemonic discourses (Spivak, 1988). The state of subalterns' existence, according to Spivak, is so oppressed and neglected that they have limited access to revisionist histories and capacity to challenge the established views held by those in power. Spivak considered that many who can speak out and make such contributions could not claim subaltern status because subalterns are in a position of utmost powerlessness. However, Spivak later considered "subaltern" to have a shifting meaning according to the context. By acknowledging the instability of the term "subaltern", Spivak allowed greater flexibility in using her framework for a broader range of marginalized people (Riach, 2017).

In her essay, Spivak argued that subalterns are silenced through representation by those in power and systems (historical, economic, legal, and ideological) that obstruct the possibility of speaking and being heard (Crehan, 2002; Spivak, 1996; Young, 2001). According to Spivak, subalterns have no voice or power in society and no means to get them because they are systematically denied the opportunity to represent themselves in political systems or public

debates. She questions how the current system and politics, with its various forms of oppression and marginalization that work together to determine subalterns' position in a society's hierarchy, can allow subalterns to speak and be heard. She attempted to explain this by analyzing the experience of a subaltern woman (Bhuvaneswari Bhaduri) who decided to commit suicide in the 1920s in Calcutta rather than executing a political assassination on behalf of the anti-colonial forces. Spivak (1988) considers the act of suicide a way of communicating and being heard since she was unable to speak through official channels. In 2002, in the wake of the terror attacks on the World Trade Center, Spivak's thinking returned to Bhaduri's suicide to examine the message that the terrorists attempted to communicate through a suicide attack.

The central concept of this theory indicates that subaltern voices are systematically silenced by people in power or the elite (Spivak, 1988). Spivak cautions that representation can be harmful as it can conceal the reality of what the subalterns want. Spivak's essay expressed harsh criticism of Western scholars who investigate marginalized populations by excluding their voices and speaking for them (Morris, 2010). Spivak (1988) argued that representation by powerful people in society had prevented subalterns from self-representation since representation takes place within the discourses of hegemonic power that serve the dominant classes.

Spivak claims that, to an extent, every representation of subalterns by non-subalterns can be a misrepresentation (Morris, 2010; Morton, 2003; Spivak, 1996). She indicated that any form of representation risks inaccuracy and misinterpretation, reducing individuals to crude stereotypes and preventing exposing their reality (Morris, 2010; Morton, 2003; Spivak, 1988). Representing subaltern also risks distortion of their position, further denying them a fair hearing (Spivak, 1988). Spivak argued that Western thinking in non-Western contexts could cause damage as inquiries into Eastern nations occur with ideological biases that can only produce

biased knowledge. Therefore, she argued that Western scholars could never truly understand the subaltern's context to faithfully represent them (Morris, 2010; Morton, 2003; Spivak, 1988).

Spivak (1988) distinguished between two different types of representation, *darstellen* and *vertreten*. *Darstellen* refers to functional transformation or aesthetic representation of a person's desires or wishes through, for example, painting a picture or a portrait. In contrast, *vertreten* refers to political representation and speaking and acting for someone. She criticized the latter types of representation, considering it biased toward the dominant values.

According to Spivak (1988), Western scholars and colonizers have a false belief that their values are universal; therefore, they maintain the subaltern as passive objects with a dependent agency in need of representation, instead of people who can recognize, express, and act on their decisions (Morris, 2010; Morton, 2003). She goes as far as analyzing the banning of Sati in 1829 by the British colonial government in India. Sati was a sacrificial practice in which the widow ascended to the pyre and took her own life by burning herself upon it shortly after her husband's death. Although Spivak (1988) supports ending Sati, she analyzes the process of abolishing the practice by colonial rule to present civilization to savage Indians, speaking about how women should be treated and acting on behalf of women. She argued that instead of involving and considering women as subjects who can act on their own terms, they maintained women as passive objects and denied them independent agency and the possibility of speaking for themselves. Therefore, Western scholars, politicians, and leaders were accused of ironically rehearsing the task of imperialism through 'epistemic violence' or violence imposed through discourses (Spivak, 1988). Epistemic violence is inflicted when systems of assumption and language are used to support a particular ideology or justify domination (Riach, 2017). While epistemic violence is not physical but inflicted through discourses that exclude subalterns'

contribution, it can lead to other forms of violence and oppression against the subalterns. For instance, portrayal of a group by the media or politicians as a threat can justify using force against them (Spivak, 1988).

Spivak (1988) challenged scholars who disapproved of the hegemonic structures that reinforced their place in society yet generated knowledge about the oppressed. Spivak's essay asks readers to question their thinking and be aware that perceptions are informed and affected by cultural background (Riach, 2017). In addition, Spivak examines how the privileged can ethically represent and speak for subalterns if they cannot speak and be heard (Riach, 2017). Meanwhile, she acknowledged the irony that her act of writing the essay on behalf of subalterns as an intellectual, far from an excluded member of society, and speaking out about the injustice done to subaltern might have her fall foul of her own criticism (Riach, 2017). However, in a subsequent interview, Spivak indicated that we have the responsibility to "work for the bloody subaltern...against subalternity" (De Kock, 1992, p. 46). According to Spivak, it is not enough to let the subalterns speak from their position of subalternity and that we should examine and deconstruct structural power that excludes members of society and creates subalterns (Chakravorty, 1999). According to Spivak, deconstruction starts with subaltern's self-representation and decolonization of oppressive systems (Crehan, 2002; Spivak, 1988; Young, 2001). While Spivak (1988) suggested that subalterns are not a homogenous group as they have differences between and inside them and a wide range of identities, she argued that acting as a homogenous group and sharing common identity can help subalterns achieve greater self-representation and political advantages (Riach, 2017).

Controversies Surrounding Spivak's Theory of Subalternity

Spivak has been criticized for presenting her ideas in an imprecise and obscure manner leading to difficulty understanding her writing (Eagleton, 1999). Multiple and complicated ideas and unexpected turns of argument have also been viewed as frustrating by some critics (Riach, 2017). Terry Eagleton, a literary critic, scolded Spivak for using language that “most intellectuals, too, find unintelligible” (Eagleton, 1999, p. 3). Debates over the inaccessibility of the text (difficulty in understanding) for someone who wants to provide subalterns with critical tools to overcome oppression and subalternity have been considered an unpleasant controversy in postcolonial studies (Riach, 2017).

Critics such as historian Gyan Prakash (1992) considered Spivak's deconstructionist approach for historians to be valid and relevant because historians cannot retrieve voices that do not exist. However, many members of the subaltern studies group and Marxist and feminist thinkers found Spivak faulty in ignoring the voices of subalterns that can be heard (Riach, 2017). For example, postcolonial scholar Ania Loomba (1993) strongly criticized Spivak's demonstration of the absence of subaltern voices and difficulty in recovering them. Loomba (1993) suggested that Spivak's conclusion that subaltern cannot speak was “disquieting for those who are engaged in precisely the task of recovering such voices” (p. 218). Loomba (1993) suggested that subalterns' lack of voice is wrong since scholarship in this area is taking place. Several critics also showed a harsh reaction to Spivak's deconstructionist approach, suggesting subalterns do not and cannot play a political role (Riach, 2017). For example, in her 1987 essay, *Problems in Current Theories of Political Discourse*, Benita Parry, a literary theorist, argued that in deciding that subalterns cannot speak, Spivak provided a "deliberate deafness to the native

voices where it is to be heard" (p. 39). According to Parry (1987), Spivak's approach prevents all forms of resistance and is similar to discourses of colonialism.

In response to these criticisms and what she considered a misunderstanding of her theory, Spivak indicated that those who criticized her confused subalterns speaking with being heard (Riach, 2017). She acknowledged that her work is considered somewhat misleading because while her essay explored the ability of subalterns to speak, she was more interested in their ability to be heard (Riach, 2017). According to Spivak, subalterns cannot speak because those in power usually speak for them. In addition, speaking from a subaltern's position in society means that they will not be heard (Spivak, 1988). In an interview with De Kock (1992), Spivak clarified that she perceives speaking to be an interaction between the listener and speaker by stating, "when you say cannot speak, it means that if speaking involves speaking and listening, this possibility of response, responsibility does not exist in the subaltern sphere" (p. 46). In addition, for Spivak, hearing requires transmitting a message in a way that can effect change, which subalterns cannot achieve.

Ten years after the publication of her essay, Spivak made significant changes to her original position. By publishing a revised version of the essay in 1999, she clarified that "the subaltern cannot speak" was "an inadvisable remark" (Spivak, 1999, p. 308). In the revised version, Spivak (1999) stated that "when a line of communication is established between a member of subaltern groups and the circuits of citizenship or institutionality, the subaltern has been inserted into the long road to hegemony" (p. 310). In other words, overcoming subalternity starts when subalterns communicate with those in the position of power and are heard. This change is considered crucial as it suggests a way of overcoming subalternity (Riach, 2017).

Relevance of Spivak's Theory of Subalternity to This Research

Although the use of postcolonial theory is limited to experiences of people within 'first world' colonial powers (Kirkham & Anderson, 2002), the theory can address issues related to "discursive operations of all types of empires" (Holmes et al., 2008a, p. 44). This, however, may present an array of challenges as the constructs are complex and theoretical purism can be valued by many. Nevertheless, the various approaches to postcolonial theory provide opportunities to apply the theoretical constructs to situations that are typically unrelated to colonization but use a similar form of power and domination (Sharma, 2018). Postcolonial theory can provide valuable insights and contributions to research and practice by providing a critical lens of power, domination and subjugation over inferior 'others' (Mohammed, 2006). As a critical social theory that incorporates the effects of micro political and macro structures of power on individuals' experiences and realities, expanding the use of postcolonial theory can help critique systems, practices and policies that cause inequality and oppression while maintaining the dominant hegemony and socio-political ideologies and institutional or individual practices (Bickford, 2014; Mohammed, 2006). For example, in 'first world' healthcare, postcolonial theory can challenge health inequalities linked to conditions and discourses that continue to oppress certain groups of people (Holmes et al., 2008b; Weaver & Olson, 2006). Postcolonial theory can also help us "understand how continuities from the past shape the present context of health and health care", and critically examine conditions and practices that hold certain people in power while oppressing and excluding others (Browne et al., 2005, p. 19).

A theory of Subalternity is concerned with power relations, hegemony, silencing of the marginalized, representation, and decolonization (Beverley, 1999). Although Spivak's work mainly focused on the Indian subaltern, its implication and application are not limited to that context (Morton, 2003; Morris, 2010). Her main idea that subalterns' voices are silenced in

political and legal systems, and systems of representation can be used to analyze other places and times (Morton, 2003; Morris, 2010). Using Spivak's theory as a framework enables us "to meet the epistemological imperative of giving voice to subjugated knowledge and the social mandates of uncovering existing inequities when addressing the social aspects of health and illness" (Kirkham & Anderson, 2002, p. 1). Spivak's work can help researchers and practitioners gain a greater understanding of how various systems act together to exclude voices of marginalized populations, promote subalterns' speech and develop new ways of hearing and learning to "learn from the subaltern" (Spivak & Harasym, 2014, p.160). Spivak considers herself a "classic deconstructivist" who seeks to solve problems situationally since no solution can apply to all times, places, and situations (Riach, 2017). Therefore, Spivak lacks commitment to a single and stable methodology. However, she suggests using radical approaches that help deconstruct power structures that deny subalterns from speaking and being heard (Riach, 2017). While the theory of subalternity suggests deconstructing power systems (political, economic, social etc.) that work together to silence subaltern's voices, it does not necessarily provide a clear direction, plan for action, or blueprint for change, which is considered to be both its greatest limitation and greatest strength (Riach, 2017).

People with a Mental Illness as Subalterns

Beliefs, practices, and power relations used to discredit, and 'other' individuals or groups of people have always been the focus of postcolonial theory, including Spivak's theory (McConaghy, 2000). Othering usually constitutes a negative and exclusionary attitude, power exploitation, and domination of a vulnerable group (Goffman 1963; Link & Phelan, 2001). In the process of 'othering', the dominant group assigns an inferior position to some people based on perceived undesirable or threatening characteristics such as sexual orientation, religion, skin

colour, or physical and mental (dis)abilities (Goffman, 1963; Link & Phelan, 2001). The dominant group then constructs assumptions, beliefs, and values that develop into inherent 'truths' and fixed realities by forces such as religion, economy, law, education, and even healthcare systems (Campbell & Bunting, 1991; Goffman, 1963; Link & Phelan, 2001). The skewed "knowledge" can justify discriminatory and criminal acts and force the group into compliance and acceptance of their lower status and inferiority as the ultimate truth (Aukst-Margetic et al., 2014; Link & Phelan, 2001). Individuals could be unaware of their participation in promoting the repressive condition, especially in an environment where interrogating values and assumptions, challenging social structures, exposing injustice, and engaging in social action are prohibited or severely punished.

The process of 'othering' and the power of external forces on knowledge development can be traced to historical events. Stigmatization of African populations by the Americans and Jewish by the Nazis and dehumanizing them resulted in acts of oppression, slavery, and genocide (Link & Phelan, 2001). The fallacious knowledge that operated at one group's interest was the product of socio-political and economic power, which led to prejudice (negative attitude) and justification of discriminatory behaviours by the influential group (Link & Phelan, 2001). The socially constructed myth also served to delude the stigmatized group into compliance and acceptance of their lower status and inferiority as 'truth'; beliefs primarily initiated and shaped by the dominant group (Link & Phelan, 2001). Othering can lead to prejudice, social rejection, stigmatization, discrimination, oppression and marginalization, resulting in decreased economic, social, and political opportunities and increased physical and psychological illnesses (Campbell & Bunting, 1991; Goffman, 1963; Link & Phelan, 2001). In the healthcare system, 'othering' impedes the establishment of therapeutic relationships with patients, resulting in ignorance,

inferior care, provision of negative prognoses, disrespect, and denial of adequate healthcare and social services (Canales, 2000; Evans, 2000; Morrison, 1985).

People with a mental illness have a long history of oppression and marginalization caused by the pervasive process of 'othering' in society and healthcare systems (Corrigan et al., 2001; Corrigan & Watson, 2007). They have been subjected to all forms of exclusion, discrimination, stigmatization, violence, and criminal acts and have been divested of what constitutes a citizen's experience of power, freedom, expression, inclusion, community participation, and political and economic involvement (Corrigan et al., 2001; Holmes & Federman, 2003; Perron et al., 2010). According to Rössler (2016), "there is no country, society or culture where people with mental illness have the same societal value as people without a mental illness" (p. 1251). People with psychotic disorders are more likely to experience employment and housing discrimination and homelessness compared to people without a mental illness (Hoftman, 2017). Disparities in access to healthcare, community support and resources and morbidity and mortality are also greatest among people with psychotic disorders (Henderson et al., 2014; Hjorthøj et al., 2017). Institutional stigma, which includes government and organizational policies, is shown to provide limited opportunities for people with psychotic disorders (Hoftman, 2017). According to Hoftman (2017), "mental illnesses including schizophrenia receive the least amount of funding per disability-adjusted life years despite having one of the largest disease burdens worldwide" (p. 6).

Attitudes and beliefs about mental illness are shaped by knowledge, cultural stereotypes, media stories, and interacting, working or living with someone with a mental illness (Rössler, 2016). Labelling of people with psychotic disorders as a result of socially significant differences (hallucination, delusions) and linking the labels to negative stereotypes (violent, unpredictable)

have resulted in social exclusion, status loss and discrimination (Hoftman, 2017). The public fears, rejects, and avoids people with mental illness, particularly persons with psychotic disorders, and considers them dangerous and unpredictable (Canadian Mental Health Association, 2020a). Research shows that people will keep a greater social distance from a person with schizophrenia than from depression (Schomerus et al., 2012). In addition, while mental healthcare providers report positive views about people with mental illness when the willingness for social contact is assessed, there is no difference between them and the general population in wanting to stay away from people with psychotic disorders (Henderson et al., 2014; Knaak et al., 2017). People affected by psychotic disorders also often strongly disagree that people are generally caring and sympathetic to them and often report feeling devalued and dehumanized (Hamilton et al., 2016). As a result of stigma, people with psychotic disorders experience hopelessness and lower self-esteem, self-efficacy, self-respect, and quality of life (Livingston & Boyd, 2010; Oexle et al., 2018).

Fear and rejection of people with psychotic disorders are believed to have increased due to deinstitutionalization and perception of risks with community treatment (Rössler, 2016). Providing biological explanations for psychotic disorders is considered to have also resulted in detrimental effects in accepting people with psychotic disorders (Schomerus et al., 2012). The general public is more likely to be sympathetic towards those whose mental illness is believed to be caused by life crises and stress (conditions everyone can relate to) (Schomerus et al., 2012). However, moving towards a biological explanation has increased the gap in understanding, connecting, and empathizing with their problems, leading to the desire to place social distance with people with psychotic disorders (Schomerus et al., 2012).

Mass media (news, films, entertainment programs, etc.) is one of the most critical contributors to the inaccurate, negative, and violent representation of people with mental illness, especially people with psychotic disorders. Media coverage of violence and crimes committed by individuals with psychotic disorders, which are rare, receives more attention than similar crimes committed by those who do not have a mental illness (Canadian Mental Health Association, 2020a). According to Rössler (2016), media coverage continues to emphasize a biased image of people with psychotic disorders as threatening and dangerous. Scarf et al. (2020) examined the association of viewing the films *Terminator: Dark fate* with prejudice toward individuals with mental illness. The lead character is depicted as a person with schizophrenia who becomes unstable and carries out a campaign of violence. The film earned over 1 billion dollars at the box office and was viewed by more than 100 million people worldwide. The study revealed that viewing the film “was associated with a higher level of prejudice toward those with mental illness” (Scarf et al., 2020, p. 2).

While we compare people with psychotic disorders to 'subalterns', we acknowledge that making such a comparison through postcolonial theory for a group or population that has not been geographically colonized in the traditional sense may be deemed problematic and controversial. Scholars who value theoretical purism assert maintaining a strict application of postcolonial theory to groups or populations who have been colonized by imperial and military forces (Kirkham & Anderson, 2002). In this research, I argue that power structures and practices of domination have radically transformed the personhood of people with psychotic disorders, subjugated their minds and bodies and redefined their identities, status, and social relations while forcing them into new relationships with healthcare providers (Foucault, 1965). In an attempt to assimilate them into mainstream society, people with psychotic disorders have been forced to

accept certain understandings about themselves as problematic, insufficient, deprived, and vulnerable; protective and caring terms that can also be oppressive, damaging and violent (Foucault, 1965). People with psychotic disorders also have been forced to form new understandings about their personal, biological, spiritual, sexual, and physical experiences and conform to standard expectations of good, normal, civil, noble, and functional persons. Similar to the process of colonization, they have been assigned an inferior position based on their mental condition, and psychiatry has legitimized its domination by the need to rescue the 'incurable', 'dependent', 'unpredictable' and 'violent' (Foucault, 1965). The program was accomplished through biological/pharmacological and psychotherapeutic interventions meant to help persons with psychotic disorders attain the standard and integrate those norms to re-socialize and be considered a truly functioning and contributing member of society (Foucault, 1965). Similar to colonization, domination through the psychiatric apparatus has led to explicit and implicit practices and policies that are considered oppressive, such as forced treatment and compulsory admission. The power differential further risks marginalization and colonization of the voice, power and agency (the ability to act independently) of persons with psychotic disorders through exclusionary discourses in research and practice. All these reasons lead to arguing that in such context, it is appropriate to consider this population 'subalterns' as per Spivak's revised conceptualization (See appendix A for a diagram demonstrating colonization in the context of psychiatry).

Opportunities for Resistance Through Radical Approach to Knowledge Creation

Spivak's theory of subalternity (1988) is concerned with power imbalances and provides a critical lens to address health problems related to colonial practices and discourses that silence those who are designated 'less-than' others (Crehan, 2002; Young, 2001). Spivak's theory of

subalternity provides a framework to examine, critique, and deconstruct dominant discourses that have the power and potential to colonize voices (Gilmour & Brannelly, 2010; Holmes et al., 2008; Kirkham & Anderson, 2002). While patient involvement in decisions and learning from their experiences has been posited as a way of humanizing clinical practice, the involvement of people with psychotic disorders in research, practice, and policy remains insufficient. Despite substantial and sufficient research about the importance of physical health management of people with psychotic disorders to improve quality of life and reduce morbidity and mortality (World Health Organization, 2018), limited qualitative research has investigated their perspectives and challenges for physical health management (Melamed et al., 2019). On the other hand, methodologies that are used to produce recommendations for clinical practice to address the physical health of people with mental illness usually involve quantifying measures that leave marginal space for patients' knowledge and experiences. Since discourses are attached to all areas of knowledge, researchers need to question if they are sustaining or interrogating inequities through the knowledge they produce (Holmes et al., 2008; Kirkham & Anderson, 2002). Spivak's theory enables us to examine inequities and meet the epistemological imperative of giving voice to subjugated knowledge while questioning the hegemonic discourses that exclude other forms of knowing (Young, 1999; Holmes et al., 2008). Spivak's theory provides perspectives to challenge contemporary constructions of knowledge for addressing the physical health of people with psychotic disorders, which continue to rely on patterns of inclusion and exclusion within healthcare settings that are reminiscent of colonialist practices (Crowe, 2000). When using Spivak's theory of subalternity as a framework, I, as a researcher, commit to allowing self-representation and generation of transformative knowledge that exposes forces that mediate

health and illness (Gilmour & Brannelly, 2010). This commitment requires selecting approaches that can best accomplish this purpose (Bickford, 2014; Kirkham & Anderson, 2002).

Showcasing the voices of people with psychotic disorders and bringing their ideas to light for a broader audience requires emancipatory research methodologies and processes (Bickford, 2014; Kirkham & Browne, 2006). Digital storytelling was selected as a methodology since it has "an epistemological commitment to the ways participants themselves interpret, give meaning to and make sense of their experiences" (Harrison, 2002, p. 865). Developed through a collaborative approach that facilitates critical reflection and safety, digital storytelling encourages participants to express their voices and share their realities and experiences. Visual, audio, and other forms of expression facilitate more accurate articulations of experiences and bring viewers closer to understanding and incorporating their knowledge (Hardy & Sumner, 2014). Digital storytelling emphasizes that conventional words used in interviews and focus groups are not sufficient to express the magnitude and complexities of many realities and experiences (Barone & Eisner, 2012; Frosh, 2004; Leitch, 2006). As recognized in the well-known cliché, a picture is worth a thousand words, the visual aspects of digital storytelling can amplify messages and experiences that cannot be adequately expressed by words (Gachago et al., 2013; Hardy & Sumner, 2014). Hearing storytellers' voices and emotions, seeing pictures, and listening to the words helps connect to people and places and enhance understanding about values and perspectives (Cunsolo Willox et al., 2013). With a strong aesthetic dimension, digital storytelling offers new ways for those in power to see and understand factors that impact people's health (Baden & Wimpenny, 2014). Participants' experiences and meanings become tangible through audiovisual representations that can influence the audience (Hardy & Sumner, 2014). Audiovisuals produced in digital storytelling can enhance understanding as researchers,

policymakers and health care providers engage with emotive, reactive and subconscious parts of stakeholders' experiences (Gachago et al., 2013; Hardy & Sumner, 2014).

Digital storytelling can help give voice to participants by providing them with the opportunity to collect, discuss, and present images and narratives that are relevant to their experiences (Hardy & Sumner, 2014). Using digital storytelling as a methodology in addressing the physical health issues of people with psychotic disorders, the construction of knowledge shifts from the voice of the powerful to the marginalized. In digital storytelling, participants have control over the research process and outcome, which can disrupt and redefine the traditional researcher/researched relationship of power and authority (Lenette et al., 2013; Lorenz & Kolb, 2009). Participants are fully engaged in every stage of the process, resulting in a finished short clip (Hardy & Sumner, 2018). Constructing their narratives and selecting audiovisuals that represent their experiences enable participants to have a direct and active role in the process of knowledge production and representation (Hardy & Sumner, 2014). The collaborative approach can assist previously excluded groups in producing their reality instead of reproducing dominant mainstream ideas and representations (Cox et al., 2014).

The digital storytelling process was informed by Spivak's theory of subalternity as storytellers were at the center of the process, and control of representation remained with those who have less power and voice in both the healthcare apparatus and the research process. In this research, I explored if the process of making digital stories about their physical health provided a means of finding their voicing and representing themselves outside the psychiatric power structures. In addition, Spivak's theory of subalternity provided a framework to uncover hidden power imbalances and unjust conditions that lead to health problems (Morton, 2003). The process explored how external forces have shaped participants' experiences to avoid reinforcing

negative stereotypes and mainstream opinions about social and health problems of a community or population (Hill, 2010). As the primary researcher and digital storytelling facilitator, my role was to explore their experiences within broader economic and sociopolitical circumstances to contextualize health issues not as individual problems but within the complex interplay between systems and structures (Hill, 2010). This research explored how participants express their needs and concerns via digital storytelling. Therefore, discussions about the making of the digital stories examined the physical health concerns within a broader context of participants' lives. Inquiries explored contributing factors and consequences of physical health concerns as perceived by the participants; barriers and facilitators to physical health management; dominant approaches to treatments and their effect on their physical health; and patient involvement in decisions. The stories were created to reveal why people with psychotic disorders are more susceptible to poor physical health, what it is about their social and economic situations and the care they receive that predisposes them to physical conditions, and what determines, to a larger extent, their social and economic positioning.

Deconstructing ideologies, practices, policies, and traditions in psychiatry is not a straightforward task. It requires a critical examination and understanding of a phenomenon within its historical context and origin since some of the practices, concepts, and theories may have become indispensable to our understanding and the foundation of most practices. In addition, disruption of theories and practices requires developing new approaches and practices that encourage inclusive dialogue to generate significant effect (Ekuma, 2019; Schwanen, 2018). Spivak argued that it is not sufficient to allow subalterns to speak from their position of subalternity, and there is a need to change factors that obstruct the possibility of being heard, such as historical, economic, legal, and ideological forces (Morris, 2010; Morton, 2003; Spivak,

1988). According to Spivak, one way of overcoming subalternity is establishing a line of communication with those in power (Morris, 2010; Morton, 2003; Spivak, 1988). By exposing nurses and leaders to the voice of people with psychotic disorders in the form of digital storytelling, I strived to help establish a line of communication with those in power. Using experiential knowledge of people with psychotic disorders in the form of digital stories to initiate a dialogue with leaders and healthcare providers was a radical approach consistent with Spivak's theory. It also helped expose and deconstruct dominant ideologies (through awareness and reflection) that exclude alternative forms of knowledge in psychiatry by capturing their reaction to the stories' format and content.

By establishing a connection with nurses and healthcare leaders, I aimed to understand how those in power respond to and reflect on concerns and experiences of people with psychotic disorders presented through digital stories. I sought to gain information in relation to factors that obstruct the possibility of hearing the voices of people with psychotic disorders and ways that can help promote hearing, learning from, and authentically involving patients in every stage of decision making in research, practice, and policy. In other words, I aimed to understand how the voices and struggles of the marginalized can be heard and acted upon by those in power. I also sought to understand the extent to which digital stories help provide a line of communication (enhancing empathetic understanding, encouraging powerful emotions and compassion, and creating the intention to use digital stories for change and innovation) with those in power.

I acknowledge that I have used the designation 'people with psychotic disorders' throughout the study to make the group identifiable to recruit and build the digital stories with them. While it is easy in the research context to use and consider such designations neutral, categorizing a group of people based on certain attributes and characteristics risks reinforcing a

specific identity and discourses on them. Therefore, I could be criticized for reinforcing the mental health aspect as their primary identity, something they may want to dissociate themselves from the most. In addition, the power dynamic that can marginalize the voice of certain people has been the main focus of this research project. By choosing a postcolonial lens, I emphasized my disapproval of the hegemonic structures that reinforce their place in society and generate knowledge about the oppressed. However, the privilege of being able to categorize a group by doing the research and determining what aspects are more meaningful at the expense of other things that they consider are important but are being dismissed is contradictory. I want to demonstrate my awareness of this problem which starts as soon as a group is identified based on some characteristics. We needed to identify them for the purpose of explaining and situating the research; however, they will be referred to as participants in the following chapters to de-emphasize the mental health aspect.

Chapter 4: Methodological Considerations

In this chapter, I describe the methods and procedures that were used to obtain data and answer the research questions. First, I provide a brief introduction to the unique characteristics of digital storytelling as a participatory approach in research. Next, I describe the sample of participants and the steps that were undertaken for recruitment, data collection and analysis of each of the three stages of the study: 1) developing digital stories with people with psychotic disorders; 2) evaluating the digital storytelling process; and 3) screening of digital stories with nurses and healthcare managers. In this chapter, I also elaborate on the ethical implications and rigor of the study.

Digital Storytelling: A Participatory Approach

Engaging participants from a marginalized group in the research process is a fundamental component of participatory and empowering research, which requires innovative strategies that can best support safe contributions and equal power-sharing (Graham et al., 2014). Marginalized groups, such as people with psychotic disorders, require researchers and organizational and policy decision-makers to understand their lived experiences and realities, including those that may be different from what is normal from the dominant hegemony and society (Hardy & Sumner, 2017). Co-developing knowledge with people with psychotic disorders requires an inclusive, participatory, and empowering approach (Hardy & Sumner, 2017). This is critically important when working with groups where research activities have historically functioned to produce knowledge that is meaningful to decision-makers but not necessarily to research participants (de Jager et al., 2017). Therefore, providing opportunities for people with psychotic disorders to have a direct and active role in knowledge production requires approaches that can

provide them with the support and time they need to formulate their thoughts and tailor their messages in a powerful and compelling way, which is heard, understood and integrated.

Digital storytelling has an epistemological commitment to developing authentic stories through the ways participants interpret, give meaning, and make sense of their experiences (Hardy & Sumner, 2017). When using digital storytelling as a methodology, the epistemological approaches are inclusive of the experiences and perspectives of participants (Victoria, 2016). Using a multisensory approach, digital storytelling engages participants to create first-person visual narratives using an audiovisual medium such as music, sounds, images, and pictures (Hardy & Sumner, 2018). It provides opportunities for storytellers to say what is important to them, which is critical when working with people who have a history of marginalization. The process of collecting and sharing stories through digital storytelling can help create capacity among participants to co-create and disseminate knowledge to decision-makers (Hardy & Sumner, 2018).

Methods

The overarching purpose of this thesis was to explore the process of digital storytelling with people with psychotic disorders as a means of expressing their voices and to understand how nurses and healthcare leaders engage with the stories. This study consisted of three stages. Stage 1 involved developing digital stories with people with psychotic disorders; Stage 2 was an evaluation of the digital storytelling process, and Stage 3 involved screening digital stories with nurses and healthcare managers to understand their reactions and perceptions about the content and format of the stories. In the next section, I describe the methods and approaches I used in each phase of this research to answer the following research questions:

- 1) What is the process of making digital stories with people with psychotic disorders about their physical health?
- 2) How do people with psychotic disorders express their physical health needs, concerns, and priorities via digital storytelling?
- 3) What are nurses' and healthcare leaders' reactions to the digital stories including, the format and the content of the stories? How do they foresee the use of digital stories in healthcare practices and policies?

Stage-1: Developing Digital Stories with People with Psychotic Disorders

Research Question#1: What is the process of making digital stories with people with psychotic disorders about their physical health?

Setting (Stage-1). The setting from which the participants were recruited included organizations and groups that provide support services and programs to people with a mental illness and their families, including Schizophrenia Society of Ontario (SSO), Ottawa Citizen Advocacy, Friendship Support Group, On Track Program, Family Peer Support, Canadian Mental Health Association, Family to Family Education Program, and Psychiatric Survivors of Ontario. By raising awareness, advocating on important problems, and providing supportive programs (educative, counselling, system navigation, networking), these organizations and groups help foster greater community participation, increase volunteering opportunities, reduce social isolation, build skills and confidence, and improve quality of life of people with a mental illness.

Sampling Approach (Stage-1). I used convenience sampling by relying on participants who were available and accessible for research (Lopez & Whitehead, 2013). I approached SSO because this organization has access to participants who lived in the community. SSO is the largest not-for-profit organization in Ontario, offering services and programs to individuals,

families, and communities affected by psychotic disorders across the province (Schizophrenia Society of Ontario, 2020). I chose SSO to help distribute the information because it has mailing lists and could connect me to other organizations and groups that provide services to people with psychotic disorders in the Ottawa region. In addition, by "reaching over 30,000 people each year, SSO is the largest organization representing people affected by psychotic disorders in Ontario" (Schizophrenia Society of Ontario, 2020). SSO acted as an intermediary by disseminating the recruitment flyers to their members and other organization and groups.

I used a snowball technique, known as network sampling (a convenience sampling method), to recruit participants (Green & Thorogood, 2018). This type of sampling is suggested for recruiting marginalized individuals who are not easily accessible to researchers (Green & Thorogood, 2018). I used word of mouth through my committees and supervisors' networks. I also asked potential participants to share the study's recruitment poster and consent form and my contact information with individuals interested in participating.

Eligibility Criteria (Stage-1). The goal was to recruit 6-8 individuals with psychotic disorders from the community who met the inclusion criteria. Given the intensive digital storytelling process, this number of participants could provide some diversity of experiences (e.g., age, sex, gender, physical health diseases/concern). Inclusion criteria consisted of the following: 1) primary diagnosis of schizophrenia/ schizoaffective disorder, 2) 18 years or older, 3) English speaking, and 4) living in the community and able to participate and provide consent. Eligibility was based on participants' self-declaration of their diagnosis with schizophrenia/schizoaffective disorder (see Appendix B for Justification of Inclusion/Exclusion Criteria).

Recruitment Process (Stage-1).

Gaining Access to SSO. We initially contacted SSO to grant their support in serving as a relay to help with recruitment. In order to help make the decision of supporting our recruitment effort, I sent them an information letter that outlined the purpose and importance of the research project, the number of participants we aimed to recruit, inclusion and exclusion criteria, and the process of digital storytelling (see Appendix C for the Letter). After reviewing our request, SSO agreed to help us with recruitment. Once ethics approval was granted, I met with the executive director of the organization to provide the consent/information form and recruitment poster for distribution to their members, potential participants, and organizations that provide services to people with mental illness (see Appendix D for the Consent Form & Appendix E for the Recruitment Poster). Members of these organizations (People diagnosed with psychotic disorders are also members of the organization) were free to directly contact me to seek more information about the project or enroll in the study. At no point did SSO share the members' contact information with me. However, I was copied on the emails sent to leaders of the organizations for follow-up. I was not copied on emails sent to members of the organizations or any potential participants.

Strategies to Approach and Recruit Participants. Some organizations contacted me for additional information, and four organizations asked me to present my research at their organization. The Ottawa Citizen Advocacy asked to present the project to their case managers, who then disseminated the information to the Assertive Community Treatment (ACT) team, as well as potential participants. The other three organizations, Friendship Support Group Program, On Track, and Family Peer Support, asked to present the project in their meetings. People with mental illness and healthcare professionals from different disciplines (registered nurses, occupational therapists, psychiatrists, social workers) attended the meeting and disseminated the

information to their support groups and potential participants. Organizations such as the Canadian Mental Health Association, the Family-to-Family Education program, and Psychiatric Survivors of Ontario also assisted with recruitment by disseminating the information to their members and potential participants. Those interested contacted me and were subsequently scheduled for a pre-interview.

Participants were recruited over six months. I only had one person recruited for this study in the first three months. As a result of slow enrollment, I adapted a more proactive recruitment strategy that included sending follow-up emails to the organizations initially contacted by SSO and meeting and presenting the project to organizations' leaders. This improved the recruitment results, and I was able to enroll additional five participants over three months for a total of 6 participants.

Data Collection (Stage-1)

I held the sessions at a convenient location of participants' choice to help create a comfortable and relaxed environment. The location needed to provide a quiet and private room to ensure confidentiality. I informed participants of options for location, including the Center for Research on Health & Nursing (451 Smyth Road, Ottawa, Ontario, Canada, K1H 8M5, Room 1118) or a conference room at the University of Ottawa, which also provided a comfortable, quiet, and private environment. I scheduled and held the sessions at a mutually agreed-upon time, including times outside regular working hours (e.g., Saturday) for 90 minutes. During each session, I checked in with the participants at 30 minutes, then 45 minutes, to offer them opportunities to stop the session and continue some other time to ensure they did not become disengaged or exhausted from the process. If after 45 minutes they wished to continue, then I continued for another 20-30 minutes as per participant's preferences (up to a total of 90 minutes).

This process was flexible, and participants could cancel and reschedule their sessions as needed. All participants received a phone call reminder one day before their sessions. I organized transport to and from the sessions and reimbursed participants for transportation expenses and parking if they decided to drive to the meetings. Since digital storytelling process could be challenging, I modified the format to one-on-one and weekly sessions to help accommodate participants' schedules and needs (cognitive, functioning, literacy). By providing concentrated, one-on-one assistance, I also strived to create a safe space, establish a trusting relationship, promote confidence, and decrease participants' anxiety.

At this stage, participants developed their digital stories with me. Making a digital story involved constructing a narrative and building the story using audiovisuals. Data sources for this stage included the narratives, reflective journals, and process log. Reflective journals are personal records that include reflection of one's own learning experiences that could generate insight, critical thinking, and understanding (Ortlipp, 2008). Methods of creating reflective journals included capturing all formal and informal events, including areas that pose difficulty (e.g., constructing a written narrative in one to two sessions) and those that are less problematic (e.g., selecting and constructing the audiovisuals). In this process, I reflected on issues of learning digital storytelling and facilitating digital storytelling sessions with the participants. Journaling was done before, during and/or after each storytelling session. The process included: 1) recording and describing situations (e.g., the course and context, people involved in the situation and actions and conversations that occurred); 2) reflecting on reactions, attitudes, beliefs, values, and feelings; and 3) gaining insight (e.g., what sense could be made of the situation, what could be demonstrated and improved because of the situation, and what was learned) (see Appendix H for Reflective Questions). A process log for developing the digital

stories included attendance records, research meeting notes/transcripts, correspondence from a recruiter, information about strategies used to recruit and maintain participation, the proportion of participants recruited, barriers to participation, number and length of sessions, and qualitative reflection and observation of the way participants engaged with me and making the digital stories (Saunders et al., 2005).

Developing the Stories. Participants engaged in a two-step process to develop their digital stories. They worked with me to create a script by identifying themes and crafting scenes central to their digital story. Here, participants were encouraged to discuss their physical health needs and concerns, as well as the obstacles and supports that helped them manage their physical health. Participants then received assistance composing and constructing their stories using video production software. Crafted scenes were used to guide the process. The outcome of this process was a 2-5 minute long, audiovisual vignette in digital format (see Appendix F for Digital Storytelling Guide).

Developing a Narrative. In digital storytelling, the narrative is usually limited to 250-370 words to identify what is most important in a story (Lambert, 2010). Participants write their narratives and then receive assistance from the facilitator (Lambert, 2010). Going through the process of digital storytelling, I was aware that developing, distilling, and refining a narrative required practice and experience and could be challenging and anxiety-provoking. I knew that leaving the participants to construct their narratives with limited direction (not knowing where to start, how much to write, and how to put it all together) could be an overwhelming task as it was a challenging process for me. Therefore, I adapted this process in the following ways. First, participants had the opportunity to construct their narrative verbally instead of writing. This modification aimed to help the sessions be shorter and less anxiety-provoking for participants. In

addition, I used an interview guide to provide a more focused, organized, and structured approach. The interview guide was designed to create a space of exploration and help participants articulate what was important to them about their physical health concerns and needs. Answers to the interview questions, in bullet points, provided a draft of the narrative. We then condensed and refined the answers for a final draft.

The interview questions helped explore participants' mental illness and its consequences, as well as physical health concerns of the participants within the broader context of their lives. I used the following questions to help the participants construct their narratives: When were you diagnosed with schizophrenia/schizoaffective disorder? What happened? Tell me about your physical health? Do you have any concerns about your physical health? How and when did it begin? How did it affect your life? Are you able to effectively manage your physical health problems? What is the hardest thing about managing your physical health? What keeps you from managing your physical health problem? Do you think you have the available resources to manage your physical health/deal with this specific problem? Please explain? If not, why do you think so? Do you think healthcare providers (doctors, nurses) help you manage your physical health effectively? If yes, how? If not, why do you think so? Do you think the available services, programs, and treatments meet your physical health needs? If yes, how, if not, why do you think so? What do you need to manage your physical health better? How do you want healthcare providers and leaders to address your concerns about your physical health? Do you have any suggestions?

Building the Digital Story. Participants and I used the narratives from Phase 1 to build the digital stories, which required recording the narratives and adding audiovisuals. Participants received one-on-one assistance to compose, edit, review, and construct a personally meaningful

digital story. I provided the computer (personal laptop) and the video-editing software (*Wevideo*) on which the digital stories were developed.

Recording the Voice-over and Adding Sound. Storyteller's voice helps contextualize the story by conveying the emotional tone, the character of the storyteller and their connection to the story (Lambert, 2010). I coached the participants to record an audio for their digital story. When necessary, the audio was re-recorded until tone, cadence, clarity, and pacing came together in ways that participants were satisfied with. We used background sounds (birds, water, traffic, etc.) to help create a sense of place and capture and convey emotions and feelings. Therefore, I encouraged participants to identify their feelings and select background music and/or sounds that described their feelings. I asked participants the following questions to facilitate this process: What sounds/music comes to mind when talking about your experiences? Have you heard this music/sounds before, and if so, where? What do the music/sounds remind you of? What do you like most about this music?

Participants could provide their own music or select sounds and music from the video editing program sources. I worked with participants to ensure the music and voice-over did not have conflicting meanings to them, and the music was not competing with the voice-over. Some participants used the music to highlight a turning point in their story, and some used the music throughout the story and scenes within. We ensured the layers of audiovisual and narratives complimented each other worked together and placed emphasis on the moment of change in the story since "the moment of change and the scenes built around it lead the audience to a river of understanding" (Lambert, 2010, p.14).

Photoshop Tutorial: Adding Emotions and Making the Story Visible. Gaining awareness of the emotional connection to the story can help an audience engage with a digital

story on a deeper level (Lambert, 2010). I encouraged participants to select images or photographs that implicitly or explicitly related to the emotional components of their stories that resonated with the situations they described. They either used images from their existing repository of photos or videos or from copyright-free sources such as *Creative Commons-search* (creativecommons.org/) and *Unsplashd Free Photos* (<http://unsplash.com>), to help contextualize their story and express emotional content. I used guiding questions to facilitate selecting and conveying messages through the use of visual materials (see Appendix F for Guiding Questions). Examples of the questions that I used include: 1) As you share your experiences, what emotions did you experience? If you were to draw or paint those motions, what would they look like? What images come to mind when talking about your physical health needs? Do you have these images somewhere (e.g., in a photo, painting, etc.)? Could you find/create these images?

I introduced participants to the image-editing software and the possibilities offered by the program to create a particular effect. In this collaborative process, I navigated the software with participants by placing the images/photographs/videos they had chosen against the relevant part of their voice-over. Participants determined how the visuals and audios complemented each other throughout the duration and pace of the story to ensure the control always remained with the participants.

Storyboarding. At this stage of the process, we had all the required components for assembling the digital stories; however, further composing, editing, and restructuring were required to complete each digital story. Participants and I ensured the images displayed in sequence and transitions were in accordance with the voice-over and the background sound. We added different effects and animation to the images and transition between images using

software features. Because we had limited time during our sessions, participants provided the pictures, effects, and animations they wanted, and I imported these into the stories using the software. In the following session, I invited the participants to provide their feedback on the editing and make changes accordingly.

Sharing the Story. Creating a personal story can be an exhilarating experience (Lambert, 2010). Participants of this study received a final version of their story on a USB flash drive, which they could share as they liked. Since one of the purposes of this study was to understand how nurses and healthcare leaders engage with the stories, the stories were presented to point-of-care nurses and nurses who held managerial positions during focus group sessions to understand their reactions to the digital stories (3rd research question).

Data Analysis of the Narratives (Stage-1)

Only the narratives of the digital stories were used for analysis in Stage-1. Field notes, reflective journals, and process logs for developing the digital stories were used in the analysis for stage 2 of the study to answer the following question: What is the process of making digital stories with people with psychotic disorders about their physical health? The reason for only selecting the narratives for analysis was that in digital storytelling, audiovisuals (music, background sounds, and images/pictures) are mostly used to help contextualize and convey the emotional aspects of the story. The narratives of the digital stories were transcribed verbatim and imported into qualitative data analysis software, NVivo 12, for analysis (QRS International, 2018). We conducted thematic analysis on the narratives, focusing "on identifying and describing both implicit and explicit ideas within the data, that is, themes" (Guest et al., 2012, p. 9).

First Level of Analysis. First, I engaged in a line-by-line deconstruction of participants' narratives, as recommended by Guest et al. (2012). This included inductively summarizing the narratives into codes (open coding) by examining the transcripts line by line and sorting, organizing, focusing, labelling and re-labelling relevant words, phrases, sentences, and sections into a codebook (Guest et al., 2012). Codes were then sorted into categories and re-evaluated several times for similarities and differences to identify discrepancies and ensure accuracy (Guest et al., 2012). I moved between the codes and the transcripts to ensure integrity and that parts are not taken out of context. At this stage, a researcher not familiar with the study was included as a second coder to read the transcripts and check the codes and categories. In meetings with the second coder, we re-explored the initial codes and categories to reach a consensus on the codes and categories. All conflicts were resolved through consensus. The second coder was not familiar with the postcolonial theory; however, we did not use the theory for analysis at this stage. The categories at this stage were broad and contained a few subcategories and many codes. For example, *Physical Health Concern* as a category included the following subcategories: physical conditions, consequences, attributing factors, self-management, and perceived barriers. Other categories included *Mental Health* and subcategories of symptoms, struggle, and consequences and *Addressing Physical Health Concerns* with the following subcategories: behaviours, priorities, goals, and needs/ recommendations.

Second Level of Analysis. A summary of the categories and subcategories, along with the transcripts were presented to my supervisors for further analysis. At this level of analysis, we re-explored the categories and patterns of interaction within and between the categories. We analyzed how participants spoke of their physical health experiences and how healthcare providers reacted to them about their physical health experiences. This evaluation resulted in

distinguishing between two types of concerns: 1) participants' concerns about their physical conditions and the strategies they used to resolve them, and 2) participants' concerns in relation to healthcare providers' attitudes and strategies they used to cope with it. For example, 'loss of employment/income', 'not fitting into clothes', and 'cancelling meetings and get-togethers' were concerns that were related to physical condition. We distinguished them from concerns related to healthcare providers' behaviours, 'bringing my father to appointments to advocate on my behalf', and 'I never felt heard or respected'. Therefore, we re-categorized the data into stories' first and second layer. The "First Layer" included: participants' physical health concerns, consequences, attributing factors and barriers to self-management. The "Second Layer" included: healthcare providers' reactions to participants' concerns and how participants negotiated their needs (see table 1).

Table 1-Results of the Second Level Analysis

Emerging Categories	
<u>Stories (First Layer)</u> 1. Physical conditions (e.g., Weight gain) 2. Role of meds in problem (etiology) 3. Consequences of health problem ➤ Employment/housing, family support ➤ Emotional toll ➤ Additional health problems 4. Barriers to resolving health problems ➤ Self-care fails	<u>Stories (Second Layer)</u> 1. HCPs' responsive/not responsive to pts' physical concerns ➤ Priority, goal 2. Pt's position & credibility-negotiating their needs

Third Level of Analysis. Analysis at this stage was informed by Spivak's theory of subalternity, in which data were analyzed in relation to the concepts such as power systems and power dynamics within the theory contributed to the experiences of participants. This included incorporating what participants said with health care structures, processes and policies to

uncover and expose the underlying systems that oppress people with psychotic disorders from meeting their health needs. According to Spivak (1988), subalterns are the people at the margins of society with little to no access to power due to their lower social status. Spivak (1988) asserts that subalterns are silenced through discourses of power systems/dynamics in their society. Therefore, participants' data were also analyzed in relation to perceptions, beliefs, attitudes, behaviours, practices, services, policies (i.e., power structures) that contributed to their experiences so I could uncover the underlying systems they saw as influencing their health. For example, participants' perceptions of being 'non-credible' and 'being ignored' or 'having to bring someone to advocate on their behalf' were analyzed in relation to the physician-patient power dynamic and their position within larger power structures of psychiatry. Analyses led to identifying themes (e.g., Body as a contested site, Invisible patients) and subthemes (e.g., Paternalism) that are informed by Spivak's theory of subalternity. Themes and subthemes were evaluated numerous times to ensure distinction and confirmed with my thesis supervisors.

To present supporting data for the themes and subthemes, I found myself re-reading the transcripts and summary tables, re-exploring the final themes, and comparing them to the preliminary categories and subcategories in the first, second, and third level of analysis. At this stage, each theme and subtheme was also re-evaluated several times to ensure supportive rationale was provided through data. Feedback from committee members and supervisors assisted in ensuring themes and subthemes were supported by enough data. While no significant changes were made, one subtheme was changed from 'Body as a mediator in social relationship' to 'Body as a mediator in society' because the supporting data represented problems with social relationships, as well as social problems. In addition, two subthemes were combined because the supporting data for one of the subthemes was not extensive. At each level of analysis, I moved

between the categories, codes, themes and the original transcript and summary tables to ensure that parts were not taken out of their original context. Analysis was a collaborative and iterative process that was conducted in numerous meetings. Analysis of the data in the results chapter is presented in a form of narratives with verbatim quotes.

Stage-2: Evaluating the Digital Storytelling Process

Research Question#2: How do people with psychotic disorders express their physical health needs, concerns, and priorities via digital storytelling?

After completing digital stories, participants were invited to participate in an individual semi-structured interview to evaluate the digital storytelling process. The goal was to investigate participants' digital story-making experiences (see Appendix G for the Interview Questions).

Data Collection (Stage-2). Sources of data included semi-structured interviews to understand participants' experiences with the process of digital storytelling. I asked the participants to reflect on the benefits and challenges of the digital storytelling process. I also asked the participants to reflect on the potential impact and uses of digital stories and provide recommendations and feedback about the process to help inform future investigators who want to use digital storytelling as a research approach. I asked the following questions to explore the process of digital storytelling: How was your experience with digital storytelling? Would you repeat this experience? Why or why not? Do you have any recommendations for researchers who want to make digital stories? How do you feel going through the process of making a digital story? Were you able to tell everything you wanted? Would you not share what you said in the videos with some people? Whom? Why? Who do you think should listen to your story? Why? How do you feel about sharing your story with the nurses and healthcare leaders? If there was one thing that you could change to improve the digital story-making process, what would that

be? Do you have any additional thoughts or comments you would like to make in relation to the process of digital story making? (see Appendix G for the Interview Guide).

Data Analysis (Stage-2). I used the data collected through semi-structured interviews for analysis. Data collected through reflective journaling and process log during stage 1 was used to explain the findings. The interviews were transcribed verbatim and imported into qualitative data analysis software, NVivo 12 (QRS International, 2018). I conducted thematic analysis on the narratives, focusing "on identifying and describing both implicit and explicit ideas within the data, that is, themes" (Guest et al., 2012, p. 9).

First Level of Analysis. At this stage, my goal was to find common patterns across the data set (Guest et al., 2012). First, I read the transcripts several times and then coded participants' responses to all the questions: How was your experience with digital storytelling? How do you feel about going through the process of making a digital story? Do you have any recommendations for researchers who want to create digital stories? Common, recurrent, and relevant responses were then organized into inductive codes. I moved between codes and the original transcript to ensure integrity and that parts are not taken out of context. A researcher not familiar with the research read all the transcripts and checked the selection of the coding and the categorization process. Examples of some of the categories and subcategories included: feelings associated with the process; process/procedures (what was easy, what was challenging, recommendations); factors facilitating the process (facilitation/format/patient's condition); benefits of digital stories (who should see them/why; what they could achieve); and potential use of digital stories. Conflicts were resolved through discussion.

Second Level of Analysis. A summary of the categories and subcategories, along with the transcripts, were presented to supervisors for further analysis. My supervisors and I re-explored

the categories and subcategories and re-examined related words, phrases, and sentences associated with some of the categories. Interactive analyses of the categories led to refinement and re-categorization of data. At this level of analysis, we explored how participants spoke of their experiences about the process of digital storytelling and their perceptions about the final product (digital story). For example, feelings of "accomplishment" or "rewarding" were the result of going through the process, and feelings of "empathy", "compassion" and "knowledge" were what they wanted to be achieved by the digital stories. Therefore, we re-organized the data into "Process of Making Digital Story" and "Purpose/Use of Stories". We further explored these categories for similarities, differences, and discrepancies (see Table 2).

Table 2-Results of the Second Level Analysis

Emerging Categories	
Process of Making DS	Purpose/Use of Stories
1. Choosing topics, music, pictures, putting it together 2. Managing the process (being creative trusting with L.W/self, anxiety...etc.) 3. Managing risks (who should not see it) 4. Evaluating the process (compelling, sense of accomplishment, empowering...etc.)	<u>Dissemination & Change</u> 1. What's next steps 2. Who should view the stories and why 3. Hopes & Doubts • Seeing the person in the patient • Provide empowering approaches • Empathy and compassion • Long road to change

Third Level of Analysis. At this stage, I used Spivak's theory of Subalternity for analysis to determine the extent to which digital storytelling as a research approach: 1) provided a forum for people with psychotic disorders to express their voice outside the power structure and feel heard, 2) enabled representation of a story that is authentic to them, 3) provided a safe and empowering space to express their voice, and 4) represented their concerns in a compelling way

to be heard. Analysis of categories led to identification of themes (e.g., A powerful process for storytellers), and each theme was evaluated numerous times to ensure distinction. For example, words described by participants that signified the powerful process of digital storytelling process in representing their concern included "awakening", "enlightening", "rewarding", and "fulfilling".

To present supporting data for the themes and subthemes, I found myself re-reading the transcripts and summary tables, re-analyzing the final themes, and comparing them to the preliminary categories and subcategories in the first, second, and third level of analysis. At this stage, each theme and subtheme was also re-evaluated several times to ensure data provided supportive rationale. Feedback from the committee members and supervisors assisted in ensuring themes and subthemes were supported by enough data. Minor changes such as renaming a theme (dissemination of stories instead of the impact of stories) were made. This change came after suggestions from the research team that data and verbatim quotations represented "dissemination" more than "impact". Evaluating each theme in relation to the presented data also led to combining two subthemes because the data associated with one of the subthemes (Sharing digital stories) was not in-depth or extensive. At each level of analysis, I moved between categories, codes, themes and the original transcript and summary tables to ensure that parts were not taken out of their original context. Analysis was a collaborative and iterative process conducted in collaboration with supervisors in numerous meetings. Analysis of the data in the results chapter is presented in a form of narratives with verbatim quotes.

Stage-3: Screening of Digital Stories with Nurses and Healthcare Managers

Research Question#3: What are nurses' and healthcare leaders' reactions to the digital stories including the format and the content of the stories? How do they foresee the use of digital stories in healthcare practices and policies?

Setting and Sample (Stage-3). The setting from which I recruited the participants included the University of Ottawa, graduate courses and supervisors' and committee's networks. An initial sample of 6-12 participants was proposed. Inclusion criteria consisted of the following: 1) Nurses (RN, RPN, NP) with a minimum of six months of current experience in mental health, including with people with psychotic disorders, 2) healthcare managers (currently practicing, mental health experience not required), and 3) English speaking (see Appendix I for Justification of Inclusion/Exclusion Criteria). I targeted nurses for this study because they are the largest healthcare professional group and have a central role in healthcare delivery (Canadian Institute for Health Information, 2017). Due to their proximity to patients, nurses can advocate and collaborate with other healthcare providers to ensure patients' voices (needs, concerns, experiences) are heard at every level of care for inclusive, empowering, and patient-centered care. Therefore, I determined it was essential to understand nurses' perspectives and reactions to the content and format of the digital stories. I selected managers to participate in this study because they can contribute to facilitating change in the health care system as they are strategically positioned to negotiate funding, allocate and disperse resources, enforce policies and procedures, foster organizational learning climates, develop infrastructure and strategies to support innovation, encourage and engage staff, role model and create a culture that values research use and is receptive to change (Thompson et al., 2012). Therefore, I include healthcare managers to gain insight into system-level factors.

Recruitment and Sampling Approaches (Stage-3). I conducted two focus groups; one with nurses (RNs) who had minimal mental health experience and one with mental health nurses

(RNs) and managers. Ideal focus group sizes range from 4 to 12 participants, depending on the nature of the study, the complexity of the topic, diversity of participants, expectation, and skills of the facilitator (Carey, 1994). For the first focus group, I used convenience sampling by relying on participants who were available and accessible (Lopez & Whitehead, 2013). Study information for the focus group was distributed at the University of Ottawa at graduate courses to ensure feasibility (see Appendix J for Recruitment Poster and Appendix K for Consent/Information). Courses at the master's and Ph.D. levels were targeted since these courses are mandatory in the English and French MScN and Ph.D. programs. These programs enroll practicing nurses and nurses who hold management and leadership positions in healthcare settings, all of whom included the target population for recruitment. Advertisement was also used to disseminate the study information for the focus group. I posted an advertisement on information boards at the University of Ottawa. Word of mouth was used through my committees' and the supervisors' networks. We were not able to recruit nurses or managers who had more than six months of working experience with people with psychotic disorders from the MScN or Ph.D. programs, partly because most of the nurses enrolled in the program at that time did not identify themselves as mental health nurses (did not have a minimum of six months of working experience with people with a mental health illness, including psychotic disorders). However, we included nurses (RNs) who had some working experience with people with psychotic disorders (less than six months). Since nurses provide care to people with psychotic disorders in different settings and across the lifespan, we included them in our study.

For the second focus group, I used purposive sampling to select those who had at least six months of working experience with individuals with psychotic disorders to ensure the generation of data from those who are more familiar with this population's needs and concerns (Guest et al.,

2012). According to Lopez and Whitehead (2013), "Purposive sampling is designed to provide information-rich cases for in-depth study. This is because participants are those who have the required status or experience, or are known to possess special knowledge to provide the information researchers seek" (p. 7). A total of 10 point-of-care nurses and nursing managers working in tertiary and community health care settings in Ontario were invited to participate in the study. Potential participants received an explanation of the project's goals, assessment strategy, timeline, and data collection method. Those expressing interest in participation were subsequently scheduled for the focus group meeting. Since all recruited managers were mental health managers, we included them with mental health nurses in one focus group to help initiate a discussion between those who create and/or reinforce policies, protocols, and guidelines for people with mental illness and nurses who implement them.

Data Collection of Focus Groups (Stage-3). Both focus groups were scheduled for 90 minutes. Participants were informed of options for location, including the Creative Practice Center (451 Smyth Road, Ottawa, Ontario, Canada, K1H 8M5, Room 1125) or a classroom at the University of Ottawa. Sessions were scheduled and held mutually agreed upon, which included times outside of regular working hours (e.g., Saturday). Participants were encouraged to attend the meeting in person; however, I accommodated those who could only join the meeting online. Participants who chose to join the focus group via Skype were able to see and interact with all the attendees and view the digital stories simultaneously as everyone. Formal consent was obtained at the outset of the meeting for those attending in person and by email for those attending online.

Focus groups encourage a wide range of responses and are effective for investigating experiences, impressions, perceptions, feelings, beliefs, points of view, and understandings

(Leung & Savithiri, 2009). Interactions within a focus group have the potential to help participants build on each other's ideas, and the synergies that are created can elicit a richness in dialogue (Leung & Savithiri, 2009). Developing a non-threatening and permissive environment where participants feel comfortable expressing their views without fear is crucial for a successful group discussion (Hennink, 2007). Therefore, the focus group was conducted at the University of Ottawa to help establish a safe and open environment for participants to discuss information that might be difficult to share at their workplace (e.g., conflicting with professional or organization's mission). I did not include the digital storytellers in the focus groups. The rationale for this decision was to create a safe space for nurses and healthcare managers to voice their reactions and thoughts and discuss how digital storytelling can be used as a form of evidence to inform practices and policies in the current configuration of the psychiatric system.

After introducing myself, I presented the project, the purpose of the meeting as well as ground rules at the beginning of the focus group session. I also reminded the participants not to breach patients' confidentiality by declaring or revealing that they are or were care providers for someone to help eliminate the risk of social repercussion. All digital stories (n=6) were screened at the beginning of the session, and participants spent the rest of the meeting reflecting on the videos. I encouraged expression of divergent and negative opinions as an aspect of the focus group. I was prepared to bring out ground rules to help the participants focus on the research issues if any apparent tensions, emotions or conflicts escalated.

I facilitated both focus groups using several open-ended guiding questions that explored participants' reactions, emotions, thoughts, beliefs, and perceptions toward the digital stories. I used an interview guide to facilitate the discussion and asked the following questions: What do you think about the stories? What did you like/dislike about the digital story? What was strong?

Why? What stayed with you? Why? What do you think about the content of the stories? What do you think the digital stories say about the physical health needs of people with psychotic disorders? Are you surprised by these stories, or you are aware of these problems? How well do you think the physical health of people with psychotic disorders is being managed, within nursing specifically and more generally within other disciplines and at an inter-disciplinary level? Is the physical health of people with psychotic disorders an organizational priority? If yes, what structures and processes are in place? If not, why do you think this? What do you think about the format of the stories? How do you think these digital stories can be used? Do you think the healthcare system (psychiatry) is ready to use digital stories as a form of evidence? If yes, how? If not, why? Do you think digital stories can be used to inform/change practices and policies? In what way? How? (see Appendix L for Guiding Questions and Ground Rule).

Data Analysis of Focus Groups (Stage-3). All interviews were audio-recorded, transcribed verbatim, and imported into NVivo 12 qualitative data analysis software (QRS International, 2018). We conducted thematic analysis on the narratives, focusing "on identifying and describing both implicit and explicit ideas within the data, that is, themes" (Guest et al., 2012, p. 9).

First Level of Analysis. First, I read the transcripts several times and then coded participants' responses to each question; What do you think about the stories? What was strong? What stayed with you? Why? I engaged in a line-by-line deconstruction of the participants' reflection of the stories, as recommended by Guest et al. (2012). Common, recurrent, and relevant responses were then organized into inductive codes. Categories were developed and re-evaluated several times to identify similarities, differences, and discrepancies. At this stage, I coded the data from each focus group separately to identify differences and similarities between

the two focus groups. A researcher not familiar with the research read all the transcripts and checked the selection of the coding and the categorization process. Conflicts were resolved through discussion. The following are examples of categories from the first level of analysis: 1) Barriers to addressing physical concerns, 2) Benefits of digital storytelling for people with a mental illness, 3) Advantages of viewing digital stories, 4) Potential use of digital stories and potential benefits, and 5) Suggestions on the format of stories.

Second Level of Analysis. I shared the categories and subcategories with supervisors for further analysis. Interactive analyses of the categories led to further refinement and re-categorization. For example, we distinguished between participants' reflection on "content", "format", and "purpose/use" of the digital stories. We then analyzed each category in more depth by exploring how participants situated the content of digital stories or the use of digital stories in a border context of their practice. We explored how participants spoke of similar situations ("treatment as a threat of admission" or "exclusion of patients from decisions"), and if they took responsibility for such practices directly or indirectly. We also explored how participants reflected on positive outcomes (patients receiving holistic and comprehensive care) compared to adverse outcomes (patients' concerns ignored). For example, participants spoke about the values of the healthcare provider for positive outcomes but blamed prevalent discourses in education and care (e.g., quantifying measures) for adverse outcomes. In analyzing the format and use of the digital stories, we also explored how participants spoke about the use of digital stories (experiential knowledge) in the context of their practice and the barriers to its integration for changing practices or policies. At the end of the second level of analysis and after re-examining the categories of both focus groups numerous times, we decided to combine the data and merge the categories and subcategories due to similarities.

Third Level of Analysis. At this stage, Spivak's theory was used to explore how participants spoke of pre-determined power structures in forms of practices, policies, ideologies, traditions and attitudes that influence the experiences of people with a mental illness. According to Spivak (1988), various systems act together to exclude the voices of the subalterns. Spivak's theory was used to determine the extent to which power structures in forms of perceptions, beliefs, attitudes, behaviours, practices, services, policies support or obstruct the use of stories as experiential evidence to improve services, enhance understanding, raise awareness, and drive change. Words described by participants that signified these power structures included: "biomedical model of care", "objective measures and use of numbers take things out of context", and "stigma".

The analysis also explored how participants created meanings of their experiences and practices. This is crucial because institutions, as power structures, mediate ways of being and acting (Alvesson & Deetz, 2000). Trigger words described by participants that signified an overarching power structure in mediating participants' way of managing, operating and providing care included; "organization doesn't put a priority", "cutbacks to budget ", "I just do it because it's there and it has to be done". Participants talked about fundamental changes to the educational system, philosophy of care, and organizational culture for inclusive and patient-centered care. Using Spivak's theory, we conceptualized these ideas to reflect the effect of a broader power structure in colonizing practices of healthcare providers and subordination and oppression of patients. Therefore, preliminary themes such as "quantitative approaches to care", "no collaboration", and "lack of holistic care" were reorganized to include "psychiatry" as the ultimate power structure that colonizes practices and subordinates people with a mental illness.

At the writing stage, I re-read the transcripts and summary tables, re-explored the final themes and compared them to the preliminary categories and subcategories that we formed in the first, second and third levels of analysis. At this stage, each theme and subtheme were also re-evaluated several times to ensure supportive rationale was provided by enough data and minor changes were applied. For example, I renamed one of the themes (dissemination of stories instead of envisioned impact of stories) after receiving feedback from the research team that data and verbatim quotations represented "dissemination" more than "impact". Evaluating each theme in relation to the presented data also led to combining two subthemes because data for one of the subthemes (Sharing digital stories) was not extensive. At each level of analysis, I moved between the categories, codes, themes and the original transcript and summary tables to ensure that parts were not taken out of original context. Analysis was a reiterative and collaborative process conducted in numerous meetings. Analysis of the data in the results chapter is presented in a form of narratives with verbatim quotes.

Ethical Consideration. Ethical research requires considering risks against benefits and respecting participants' rights and dignity (Vanclay et al., 2013). The followed section provides more details about how I used the guiding principles of ethical research, including informed consent, voluntary participation and right to withdrawal, privacy and anonymity and protection of personal information (Vanclay et al., 2013). This study received ethics approval from the Research Ethics Board of the University of Ottawa (File Number: H01-18-03).

Digital Storytelling Participants. I met with each participant pre-enrollment in an introductory briefing session to ensure they understood the study and were able to provide free and informed consent. I started the "pre-interview" session by informing them about my previous role and experiences as a mental health nurse (witnessing care recipients struggle with weight

management and limited nursing direction for weight management of people with psychotic disorders), as well as the evolution of my research as a result of limited studies looking at the perspectives of people with a psychotic disorder about their physical health. I also explained the purpose of the study, described the process of digital storytelling from conception to post-production, reviewed examples of digital storytelling and obtained free and informed consent from participants. Only participants who could comprehend the nature of the study and their participation and who could provide free and informed consent were recruited. Being a mental health nurse, I had the training and skills to engage and assess their mental status by observing, listening, and communicating with them. During this phase, I was attentive to signs or behaviours that suggested that participants' understanding or ability to consent may have been affected. For example, individuals who displayed signs of heightened anxiety, distress, irritability, suspicion, inattentiveness, disorientation to self, time, and place, incoherent speech, and tangential, incoherent, and disorganized thought processes were considered ineligible to provide free and informed consent.

I also explained the risks and benefits of participating in the study and provided information about confidentiality, anonymity, and data conservation. For example, I explained the benefits of participating in the study as follows: Participation in this study might give you a sense of creative accomplishment and empowerment. You will have the opportunity to produce a digital story that you can share with others. Your participation in this study will also give you an opportunity to express your physical health needs and concerns and, if you consent, share these with healthcare providers in an innovative way. Many people with psychotic disorders report feeling unheard or misunderstood. Your participation in this study will help determine if digital storytelling can provide a means of expressing and sharing your voice with healthcare providers.

Being identified in digital storytelling may give you a sense of empowerment for owning your story. I also explained the risk associated with the study. For example, I told the participants that their enrollment in this study would entail sharing personal information that could reveal their identity. In addition, they may feel anxious to create something that I find "satisfactory".

Given the nature of digital storytelling, information in digital stories may not be completely confidential if the stories are shared beyond the developers. I made it clear that participation in this study entailed sharing personal information (use their voices and possibly images of themselves), which could reveal their identity. Participants determined the extent to be identified through personal photos and evaluated the risk of using personal photos or other materials that could identify them. In recognizing participatory research principles of ownership (Victoria, 2016), participants had the option to be identified and use their real names/ photographs/ voice in connection with the stories. In ensuring privacy, participants were provided with options for anonymity. For example, they could use a pseudonym for their story and change their voice using the software. Instead of using personal photos, participants could use images or videos from the software or copyright-free sources. However, participants also had the option to remain anonymous. Participants who decided to be anonymous were given a pseudonym, and their identifying information was modified. In addition, I informed the participants that being identified in the digital video would disclose their identity and their illness to the members of the focus groups (nurses/healthcare managers). Participants could determine the extent to which their digital story was shared with: 1) the primary researcher and supervisors, or 2) the primary researcher, supervisors and nurses and healthcare managers who participated in the focus groups. They could revise their consent for sharing their digital story with the focus group once their story was complete.

I was sensitive to the risk of mental health deterioration or triggering the sentiment of persecution in participants. I provided all participants with the contact information of Mental Health Crisis Service if they experienced distress after the sessions. Should participants have experienced distress during the session, I was prepared to stop the interview and stay with them to decrease their anxiety and contact a significant other (family member, spouse, friend) on their behalf to talk to or to pick them up. I was also ready to direct them to their primary care provider and the Mental Health Crisis Service for assistance. If participants were to experience mental health problems or other symptoms during the study, they would be withdrawn from the study and referred to their primary healthcare provider.

Consent for digital storytelling participants was ongoing, and throughout the study, I regularly checked in with the participants to determine if they still wished to continue participating in the project. I regularly reminded the participants that participation was voluntary, and they could withdraw at any time without any negative consequences and without needing to justify their decision. In addition, I recognized that participants' time was valuable and offered them \$30 compensation in appreciation of their time at the beginning of the first session. Refreshment was provided at each session.

Focus Group Participants. At the time of recruitment for the focus group, I emailed the potential participants the consent form, which was reviewed at the start of the session. The consent form provided detailed information about the study, risks, benefits, confidentiality, anonymity, conservation of data, and voluntary participation. I started the session by informing the participants about my previous role and experiences as a mental health nurse witnessing patients' struggle with various physical ailments, as well as the evolution of my research as a result of limited studies looking at the perspectives of people with psychotic disorders in relation

to their physical health. I also explained the purpose of the study and explained the benefits and risks of participation.

The purpose of the focus group (stage 3) was to explore the reactions, emotions, thoughts, beliefs, and perceptions toward digital stories. I informed the participants that they might feel discomfort watching the digital stories or partaking in the discussions since participation in this study entailed sharing personal opinions in a group session. I also informed them that they might feel uneasy reflecting on conflicting opinions and/or revealing practices or policies that might be conflicting with professionals' or organizations' missions. However, I told them they were not obligated to answer questions or share experiences that made them uncomfortable. I also asked them not to reveal organizations' names or practitioners' identities in the focus group. I explained to the participants that taking part in the focus group will allow them to share their experiences, perceptions, feelings, beliefs, and understandings about the physical health of people with psychotic disorders. Since digital storytelling helps uncover voices of marginalized people and bring their ideas to light, watching and reflecting on the stories could potentially increase awareness, enhance empathetic understanding, promote compassion, transform attitude and behaviour, and/or create an intention to use digital stories for change and innovation. Therefore, I told the participants that their participation in this study would further help understand how nurses and healthcare managers engage with the digital stories.

Given the nature of the focus group, researchers cannot guarantee that participants uphold confidentiality. Therefore, I included this information in the consent form. I asked the participants not to disclose the information discussed within the context of the focus group. By agreeing to participate, they agreed to keep all comments made during the focus group confidential and not discuss the content of the discussions outside the meeting. However, I

informed the focus group participants that other members would know their identity, and as a researcher, I could not guarantee that participants would respect the group's confidentiality. I informed the participants that participation in this study was voluntary. They could withdraw from the study at any time and/or refuse to answer any questions without suffering negative consequences. I provided all participants with the contact information of Mental Health Crisis Service. I asked them to seek counselling help from their employee assistance program if they experienced distress after the sessions. In case anyone experienced anxiety during the session, I was prepared to stop the interview and assist them by staying with them to decrease their anxiety and contact a significant other (family member, spouse, friend, etc.) on their behalf to talk to or to pick them up. I was also ready to direct them to their employee assistance program and the Mental Health Crisis Service for assistance.

Rigor Criteria. The moral principles that researchers must follow are beyond receiving ethical clearance. Interaction between researchers and participants can create ethical dilemmas, and being personally involved in all stages of the research, can influence the process of data collection, analysis and presentation of findings (Clancy, 2013; Doody & Noonan, 2013). According to Eakin and Gladstone (2020), "there is no neutral platform from which to conduct research, no position that lies outside of the inquiry or its context" (p. 5). Therefore, being aware and acknowledging personal values, goals, and benefits are essential to ensure acting responsibly and with integrity (Watson & Girard, 2004). Being a mental health nurse has undeniably contributed to my interest in exploring the physical health needs/concerns of people with psychotic disorders. While my initial interest was to design a program for weight management at a mental health facility in Ontario, my doctoral research took a major detour after finding limited literature exploring the physical health needs of people with psychotic disorders. I was honest

and transparent with all participants about my previous role as a mental health nurse and the evolution of my doctoral research, including my epistemological stance within the critical social paradigm. I was also transparent by declaring my position at the outset of each interview and the outset of the research process in the epistemic stance in the introduction of this text. I have acknowledged my role and experiences as a mental health nurse and shared my epistemological stance pre-study. Reflective journaling throughout the study and discussions and debates with the research team, especially academic supervisors, helped me recognize the ongoing engagement with my experiences as a mental health nurse, which has been a growing and learning opportunity.

Lincoln and Guba's (1985) four criteria of confirmability, credibility, dependability, and transferability were considered to help enhance the trustworthiness of the findings (Lincoln & Guba, 1985). Since researchers are the primary data collection instruments in qualitative studies, they become part of the study and can influence the process of data collection, analysis and presentation of findings (Clancy, 2013; Doody & Noonan, 2013). Confirmability refers to the ability to demonstrate that the presented data is reflective of participants' points of view and experiences (Cope, 2014; Lincoln & Guba, 1985). To help deepen self-reflexivity, increase confirmability and ethical outcomes in facilitating digital storytelling, the *Patient Voice Program*, which is an organization that has been conducting workshops to help produce and distribute insight from within institutions through digital storytelling since 2003, recommends following the principles that are grounded in mindfulness, "an awareness that emerges through paying attention on purpose, in the present moment, and practicing non-judgment of the experience throughout each moment" (Kabat-Zinn, 2003, p. 145). I used mindfulness for facilitating digital storytelling sessions to help capture and present participants' voices and

experiences accurately. Mindfulness is rooted in Buddhism and can be used as both a state and a trait (Prohl, 2018). When used as a state, being mindful is time-limited; however, regular mindfulness practice can make it a stable characteristic (Prohl, 2018). The practice of mindfulness has gained prominence in medicine as a way of helping decrease depression and anxiety in patients (Prohl, 2018). However, its application has expanded to organizations to support their employee become emotionally intelligent, centered, and resilient (Prohl, 2018). Mindfulness is also believed to be especially useful in conversations and meditative activity to create a comfortable climate for participants to respond honestly and comprehensively (Lemon, 2017).

In research, mindfulness is believed to help strengthen listening, engaging, and immersing in conversation, because the researcher is not engaged in an inner dialogue (Lemon, 2017). In general, most people engage with and react to thoughts and memories that randomly arise in their minds (Shapiro et al., 2005). Similarly, most people project beliefs and values through habitual and impulsive responses in communications and interactions with others (Shapiro et al., 2005). Being in a state of mindfulness prevents impulsive acting and projection of personal thoughts and emotions (Chiesa & Serretti, 2009). Being highly aware of the present moment, accepting the moment, and having a neutral observation of thoughts and feelings creates the possibility of co-existing with thoughts and emotions but keeping them distant from the task at hand (Shapiro et al., 2005). As an intervention during data collection, mindfulness can interrupt an automatic state of thinking and responding (undisciplined mind/mindlessness), thereby allowing researchers to be a reliable data collection instrument (Nagata, 2003). According to Lemon (2017), “Cultivating awareness through mindfulness removes the duality

associated with research (researcher vs. participant) and creates an intentional relationship where the participant and researcher are participating in the co-construction of the data” (3309).

Researchers who want to use mindfulness to increase the trustworthiness of their research are advised to engage in mindfulness practices and training (Lemon, 2017). By practicing mindfulness, you intentionally bring your attention to the present moment and observe your thoughts and emotions without engaging with them. Mindfulness training provides the ability to refocus your attention on the present moment, let go of one object of concentration, and focus on another. Attention is brought back to the present moment by focusing on breathing or body scanning, where one progressively focuses attention to senses in different parts of the body but without engaging with them. In a state of mindfulness, you train yourself to be non-judgmental, patient, and perceive things with an open mind. In addition, by practicing mindfulness, you embrace the present moment without rushing into the next moment or striving for better moments. Therefore, you accept the present experiences, emotions, and senses without denying or resisting them. You also train your mind to focus on the journey, not just the destination. I completed a 3-month mindfulness training prior to graduate school and have been a member of the *Treasure of Presence Foundation* since 2014. The foundation practices mindfulness through classic Persian poets and philosophers such as Molana (Rumi), Hafez, Attar, Ferdousi and many more. The foundation is not aligned with any cultural beliefs and traditions. The founder of the organization, Parviz Shahbazi, is widely recognized as one of the most original and inspiring teachers among Persians. Being a member of the foundation, I have been receiving lectures biweekly to practice mindfulness.

To facilitate the digital storytelling sessions, I used mindfulness techniques of being present at the moment, observing thoughts and feelings without engaging or judging them. I

learned from what was emerging now rather than reflecting on past knowledge and experiences. I also shifted my attention to the here and now throughout the session and constantly refocused my attention on the task at hand. I completed memos before and after the interview to evaluate my mindfulness. The memos allowed deeper reflexivity and mindful maturity (Fielden, 2012). For example, I was aware that as a researcher, I did not want to lose any participants and wanted the process to be exciting and empowering. I also wanted to accomplish as much as possible during each session. Mindfulness requires flexibility to embrace the ambiguity of the unfolding experience without controlling the process. Therefore, instead of forcing or imposing predetermined meanings onto situations, I had to be open to the unknown situation and focus on the unfolding events (Brummans, 2014). Mindfulness helped me bring myself back to the present moment and detach myself from my goals and agendas during the session. It also helped me detach from the need to engage in discussions while participants revealed their experiences. This was important because every time participants talked about weight management, I felt a strong need to discuss my experiences with them. I could also see clouds of thoughts (*"I was right", "this is the third person talking about weight gain", "After all, weight gain is the most concerning problem for people with psychotic disorders"*) trying to distract me from the process. I avoided projecting ideas and biases by not engaging with thoughts and feelings. Also, mindfulness helped me avoid engaging in inner dialogues and reflecting on my thoughts and experiences. Instead, I fully engaged with the participants and focused on participants' experiences to ensure what was co-constructed represented their version of reality.

For participants who wanted to construct their narratives verbally, I had to be active and present in the moment to engage in a conversation and take notes simultaneously. The mindfulness intervention helped me capture their experiences and balance between listening and

taking notes without getting distracted by my thought telling me that I would miss a reflection from the participant. Mindfulness helped me refocus my attention on what was said and let go of previous answers without getting caught on them. While I asked questions and clarified meanings, I was present and aware of my thoughts and emotions.

Mindfulness helped me be open to unknown situations and focus on unfolding events instead of forcing or imposing meanings onto situations (Brummans, 2014). Participants were only scheduled weekly for 90 minutes. Lack of organization and distraction would take away from the sessions. I made notes about distractions that arose during the sessions in the memos. Mindfulness helped me be present and less emotionally driven or distracted. However, sometimes distractions were outside my control. Mindfulness helped me be accepting and non-judgmental of the situation and refocus my attention on the present movement without getting caught on the past events. For example, participants answering phone calls took time from the sessions. Being mindful, I did not engage with any emotions (worrying about the time) or thought and was ready to resume activities without further distraction or delays.

As a qualitative researcher, I have established that my ontological stance is rooted in the assumption that what is seen as “real” is dependent on human perception, interpretation, and knowledge, which are mediated by external forces such as socio-cultural, economic, political factors. Therefore, unlike the conventional 'scientific methods' that consider researchers a source of bias to the objectivity and truth that resides in data, I support the position of Eakin and Gladstone in that in qualitative research, researchers are “a source of creative insight that [are] essential to the research task” (p. 4). According to Eakin and Gladstone (2020), “researchers add value to the research by interpreting data (assigning them meaning), by conceptualizing them (seeing them as instances of or types of more general or abstract concepts), and by “theorizing”

them (linking, explaining and accounting for data and concepts)” (p.3). Therefore, instead of claiming absence, I strive for presence because “data do not speak for themselves but have to be interpreted” by researchers (Eakin & Gladstone, 2020). However, reflexivity as an intervention during data analysis is recommended to ensure research findings are not dominated by personal perceptions and values (Carolan, 2003). Reflexivity is important for becoming aware of self and where researchers stand in relation to key participants and interests at play with research outcomes. Reflexivity can also help minimize gravitating towards unbalanced positivity or negativity (Fielden, 2012). The reflexive process was done by writing memos that signified my reflection on how I pre-understood participants' experiences based on my experiences. With reflexivity, I constantly questioned goals, values, and biases through an internal dialogue (“what I know” and “how I know it”) (Carolan, 2003; Clancy, 2013). Nevertheless, regardless of the level of engagement with mindfulness and reflexive processes, understanding and representing multiple perspectives independently may still raise questions about the validity of the findings. The use of teamwork was essential when endeavouring in an in-depth analysis to understand various perspectives (Cohen et al., 2000). The worldviews and preconceptions of the research team were used to understand, analyze, and present the results. Confirmability was enhanced by strategies such as biweekly investigator meetings, memo writing, reflective journaling, and an audit trail to track decisions made throughout the study.

Credibility refers to the degree to which inferences made in a study represent the actual phenomenon (Polit & Beck, 2012). A qualitative study is considered credible if the description of participants' views and experiences corresponds to the phenomenon's essence and is recognized by participants (Polit & Beck, 2012). Triangulation by different methods including, interviews and document reviews, can increase credibility by overcoming the limitation of individual

methods (Farmer et al., 2006). Using a wide range of stakeholders is suggested to enhance credibility and accurate presentation of the case (Farmer et al., 2006). To support the credibility of qualitative studies, member checking is usually used to verify data analysis and final construction of the themes with the participants (Lincoln & Guba, 1985). In this study, the digital stories were created in collaboration with the participants and could be recognized because they were made with them. However, for other parts of the study, a researcher not familiar with the data was involved as a second coder to read the transcripts, check the coding and the categorization process and discuss the findings. To ensure credibility, analysis was also conducted in collaboration with the supervisors in numerous meetings. I did not consider member checking for increasing the credibility of my study because the very subjective nature of inquiry challenges “the assumption that there is a fixed truth of reality that can be accounted for by a researcher and can be confirmed by a respondent” (Harper & Cole, 2012, p.5). In addition, “no interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge” (Van Manen, 1997, p. 237). I had captured the participants’ perspectives at a specific time, and the analysis process took over a year and a half to complete. The extended period between data collection and analysis could have resulted in new or conflicting perspectives on the analyzed themes requiring ongoing interpretation and analysis.

Dependability refers to the ability to follow the decision trail for data analysis and formulate comparable conclusions for similar participants in similar conditions (Koch & Harrington, 1998). To enhance dependability, the processes within the study should be reported in detail, thereby enabling other researchers to identify the constancy of the data over similar conditions (Tobin & Begley, 2004). In this study, the use of in-depth methodological descriptions and verbatim quotations support the dependability of the findings (Morse, 2015). A

data-oriented 'audit trail' is available to show how data were processed during the study and how it led to the findings (Bowen, 2009; Li, 2004). The written audit trail consists of the coded transcripts, data reduction process, synthesis products, produced codes and themes, and process and reflexive notes (Bowen, 2009; Li, 2004).

Transferability refers to the applicability of the findings to other settings or groups. According to Lincoln and Guba (1985), "It is . . . not the naturalist's task to provide an index of transferability; it is his or her responsibility to provide the database that makes transferability judgment possible on the part of potential appliers" (p. 316). Therefore, I provided a thick and detailed description of the context and phenomenon to help the reader compare and assess transferability to other groups or settings (Shenton, 2004). According to Denzin (1989), "Thick description evokes emotionality and self-feelings. It inserts history into the experience. It establishes the significance of an experience, or the sequence of events, for the person or persons in question. In thick description, the voices, feelings, actions, and meanings of interacting individuals are heard" (p. 83). Presentation of findings and analysis aimed to provide detailed description and interpretation in the form of written text. The worldviews and preconceptions of the supervisors were used to understand, analyze and present the results.

Chapter 5: Findings

This chapter provides details about the results of my study, including the content of the stories, the process of story-making and envisioning the impact of the digital stories by the story makers, as well as nurses and healthcare leaders. I present the results to align with each of the research questions.

- 1) What is the process of making digital stories with people with psychotic disorders about their physical health?
- 2) How do people with psychotic disorders express their physical health needs, concerns, and priorities through digital storytelling?
- 3) What are nurses' and healthcare leaders' reactions to the digital stories, including the format and the content of the stories?

Description of Participants

Eight potential participants (5 female, 3 male) contacted me to participate in the study, and 6 people completed the process. Of the two who expressed interest but did not participate, one attended the pre-interview meeting but did not answer follow-up calls, and the second person decided that he did not want to make a digital story related to the study. Six participants created digital stories; five female and one male, ranging in age between 24 and 64. Four participants had a diagnosis of schizophrenia and two schizoaffective disorder. The duration of their diagnosis ranged from 3 years to over 20 years. All participants lived in the community and in stable conditions (see Table 1). All six participants participated in the evaluation interview. Evaluation interviews were between 10 and 30 minutes.

Table 1) Demographic Characteristics of Storyteller Participants

Category	Digital Storytelling Participants
----------	-----------------------------------

	<i>N</i> =6	
	<i>n</i>	%
Sex		
Female	5	83%
Male	1	17%
Ethnicity identity		
White (Caucasian)	4	67%
Black	2	33%
Diagnosis		
Schizophrenia	4	67%
Schizoaffective disorder	2	33%
Duration of diagnosis		
<10	2	33.3%
10-20	2	33.3%
>20	2	33.3%

Digital Storytelling Process

Research Question #2: What is the process of making digital stories with people with psychotic disorders about their physical health?

After completing their digital stories, participants reflected on the process of digital storytelling and the decisions they had to make in collaboration with the primary researcher (LW). In this section, I present the outcomes of the process as perceived by the participants and provide details of my experience as the primary researcher who facilitated and conducted the digital storytelling sessions (see figure 1).

Figure 1: Digital Storytelling Process

Digital Storytelling Process	
➤	Constructing the story
○	Identifying/describing the physical health issue
○	Managing the logistics (pictures, music, etc.)
○	Managing risks (using personal photographs or other materials that could identify them)

- **DS as a powerful process**
 - Finding voice
 - Reconnecting with self (awakening, enlightening, rewarding)
 - Gaining a sense of accomplishment & strength
 - Providing a compelling representation of issue/concerns
 - Being an exciting & fulfilling experience

Constructing the Story

Data collection began as soon as the first participant was enrolled. While some participants rescheduled some of the meetings for personal reasons, most attended the weekly sessions on a regular basis. It took four to five sessions with each participant to complete each digital story after the preliminary meeting. Participants attended all scheduled appointments. Most participants completed the digital stories in less than 2 months; one participant required a long break (2 months) for personal reasons before coming back and completing the project. Data collection and recruitment were concurrent, and it took a total of 8 months to recruit and complete 6 digital stories and the evaluation interviews. Pre-interview (information sharing) sessions were mostly held at a coffee shop. For half of the participants (n=3), home was the most convenient place for developing the stories. The other half selected the University of Ottawa to develop their digital story.

Most participants were able to construct their narrative, select pictures/photos, and record a voiceover in collaboration with the researcher without difficulty. Participant 6 reflected, "I found the entire process to be pretty straightforward actually, so yeah, I didn't really find anything particularly difficult" (P6). All participants reported enjoying the project; however, not being familiar with the process, some participants reported experiencing feelings of uncertainty

and apprehension at the beginning. Participant 4 explained it as follows: "At first it was very nerve-wracking because I didn't know what was going to happen. But once we wrote it out and recorded it, a lot of my anxiety went down". Participants found that having a researcher who guided them through the process helped alleviate their anxieties and made them feel in control of the process:

The experience was great. I was a little nervous because I didn't know what to expect at first...but as you showed me and guided me along, and it was really good. You made it very easy. I was very comfortable with the whole thing so that, the whole process was pretty easy you know. I was really impressed with how it all came together. (P1)

Identifying/Describing Physical Health Issue. At the end of the pre-interview session, participants were asked to think about the most concerning physical problem they wished to discuss in a story and list their ideas in sentences or bullet form prior to their first session. The practice was optional, and they could brainstorm their ideas during the session as well. Two participants presented a draft of their ideas, and the rest brainstormed their thoughts during the session. Four participants presented one health problem for their story and two participants had more than one physical condition to explore. Therefore, during the session, we explored all their ideas to help them find their story. The two participants who presented with more than one physical condition were asked to determine which problem was most concerning or significant for them. For example, participant 1 had experienced cardiac, adrenal, and weight gain problems. However, the experience of weight gain (50 pounds in 4 months), had not been addressed for a long time, and that became the most disturbing and painful experience compared to other physical health problems. While she included all three physical health problems in her story, she decided to construct her narrative mainly around the experience of weight gain. Participant 3 presented two health problems of osteoarthritis and obesity. While both conditions were

concerning for her, she believed the occurrence of osteoarthritis to be related to the continuous weight gain that remained unaddressed for many years. Therefore, she constructed the story around the experience of obesity, and included osteoarthritis as a consequence of unresolved continuous weight gain. Once the participants determined the topic of their physical health concerns, we used the interview guide to construct the narrative.

Four participants decided to construct their narrative verbally with me and two participants chose to put it in writing. For the verbal narratives, I took notes as participants told their story. Participants were not interrupted so they could take time they needed to think through and restate something that was difficult to articulate. Participants who chose to write their narratives were encouraged to complete their writing during the session to receive continuing assistance with the editing, restructuring, and refining process. Participants could work on the narratives on their own time if they desired. Both participants found that working on the script at home provided a good basis for the narrative. However, working on their narratives on their own often led participants to get distracted from the main focus of their story, which resulted in narratives that were too long with information that was not related to their story or new information not previously mentioned. Participant 1 who selected to write her narrative and work on her narrative at home explained her challenges as follows:

I did work on it a lot at home, so I had a good base that I wanted to work from type thing [but] I didn't really know how much I was supposed to put in and what I really needed to say and what I should leave out and that kind of stuff, how it got too big. (P1)

The narrative of Participant 1 included extensive background information on the mental illness and the recovery journey. The participant was assisted in making the script concise. We focused on what the participant deemed to be the most important actions and condensed the script. The second participant (P3) constructed a written narrative about the experience of weight gain but

also included a story about being mistreated (handcuffed and taken to the hospital in a police car instead of an ambulance) by law enforcement personnel for reporting suicidal ideation. The narrative also included details about family members' physical and mental illness, as well as childhood abuse and neglect that were not previously discussed. After exploring details in the narrative, it became clear that the participant's sister had recently passed away from kidney failure due to lithium toxicity. She wanted to include that information to honour her sister, who had a mental illness and died from a side effect of psychotropic medication. Understanding her story in-depth helped us restructure the narrative. In addition, information that was directly or indirectly related to the participant's physical health concern was included. For example, the childhood experience of abuse and neglect was included in the story to give the audience an understanding of how those experiences negatively affected the participant's skills as an adult, such as cooking and exercising. We also included information about the participant's sister to honour her. Regarding the incident of perceived mistreatment by law enforcement, the participant had included this information to highlight the social stigma she had experienced because of her mental illness. After reflecting on the circumstances and the details of the incident, the participant concluded that the incident was less relevant to the story she wanted to tell and therefore was removed. However, the story was revisited in her evaluation interview, and that information was captured and included as recommendations for disseminating digital stories to help decrease social stigma towards people with mental illness (see Disseminating Stories).

While the process of restructuring the narrative and making the decisions to include or exclude information was done in collaboration, participants made all final decisions on what was relevant or irrelevant. If the information was important and perceived relevant by participants, it was included. For example, Participant 3 included the following details, which she considered

relevant and important in explaining her resilience and strength in overcoming the difficulties of life:

My father immigrated to Canada from South Africa, taking my siblings and I with him. Once in Canada, my father started abusing us. Looking out the window one day, I didn't know what was in store for my future (...) Learning to forgive my father and others made my fight to survive easier. I became a psychiatric survivor. In Luke chapter, verse 37, it says: "for nothing is impossible with God". Currently I am a published author, public speaker and an advocate. I also volunteer at [name of the organization] as a peer support worker and co-facilitate the conference trauma group and women's group. (P3)

Participants also determined what they wanted to share and include in their digital story:

Some of the stuff I haven't discussed. It has nothing to do with the project or research, it's just my own thing, it's private. So, what I discussed is what's pertinent to the project. What I haven't discussed is something that's private for me. And that's the same way I go with any situation with mental health, some of it I discuss with others, some of it I keep for myself because it's a very personal topic. (P4)

Of the two participants who wrote their narratives independently, one of them found the process somewhat challenging. Challenges included condensing the narratives and staying focused on the physical health concerns. Participant 1 described the process as follows:

The hardest part for me was just trying to compress it into like a three-minute or four-minute type thing. So, trying to word it and to keep it compressed, yeah. I was told that my story that I had originally written had like about eight stories in it, type thing. So that was, it was hard...trying to compress it but make sure that the important things were in there without cutting too much out. [other challenges] I guess to try to stay on course to the more physical illness side of how schizophrenia affects that type thing and what we do about it. (P1)

All participants who constructed their narratives verbally described being satisfied with the process. Participant 5 explained that constructing her story verbally was easy and helped avoid getting lost in the writing process:

I'm glad I didn't write anything because I literally would have written a huge essay on my life. I found...with your guidance, it was very easy. Thoughts came easily and kind of structuring it was really easy to just kind of fill in what my information was. Instead of just sputtering ideas that weren't really relevant. (P5)

Constructing a verbal narrative took less time and reduced the number of sessions that participants had to attend to complete their story. It usually took one session to construct a verbal narrative, whereas written narratives required at least two to three sessions to complete. The communication and interaction helped the process of constructing a verbal narrative to be short, simple, and straightforward in keeping with the principles of digital storytelling.

Answers to the interview questions provided a draft of the narratives. After completing the first draft, scenes were constructed. Participants identified the moment of memorable or dramatic events in their story, and some stories had more than one (abrupt and continuous weight gain, loss of employment, etc.). We established a chronological telling of events, in which the memorable events were positioned as the story's climax. Participants were encouraged to identify the emotions they experienced as they shared their story. They were also encouraged to convey their emotions using 'feeling' words, as well as audiovisuals. This process required a collaborative effort as participants asked for feedback. Participants' narratives presented their mental illness, followed by their physiological problem and its consequences on their social relationships including family, work and self. Narratives also unravelled deeper layers of their story's meaning, including loss of identity, and feelings of invisibility within the psychiatric system (see Content of stories). At the end, participants gave their stories titles. While participants were encouraged to select a topic that could help give context to the viewers, they made the final decision on the topic they wanted to use. Titles included: "Patient centered care" (P1), "Story of hope" (P2), "Through the eyes of God's child" (P3), "Hoping to be heard and recognized" (P4), "My struggles with fatigue" (P5), "The unacceptable side effects" (P6).

Only one participant (P6) found constructing a story about a physical health concern easy: "Working on the story, it was new but it wasn't difficult, because it's my life, I mean things

have happened. It's not like I needed to drum something up" (P6). Most participants of this study considered focusing on the physical aspect of their health somewhat challenging, partly because physical health had never been the main focus of their discussions with other people, including healthcare providers. For example, participant 3 noted: "Yes-that was a bit challenging. I didn't know what you meant at first, until you explained it. Yeah, because in my speaking engagements I have only spoken about the mental part, the mental health part, not the physical part". Another participant explained her challenges as follows:

I didn't know what physical effects my mental health had until we brainstormed together. Because this is not something that most physicians talk about, like, at least in my case with medication side effects that can be physical. I'm happy I helped shine a light on this topic. (P4)

Participant 5 reported that people were usually more interested in hearing about her mental illness, and she had been telling the same story repeatedly, which created a sense of comfort and familiarity. Therefore, talking about her physical health was something "new" for her:

It just kind of threw me through a loop... like I have to actually think now rather than just kind of explaining my life. I did find that [challenging] at the beginning. I was like, "Oh my god," ... but I think it's because we're so used to... like when you have a mental health illness, you're so used to talking about your mental health illness that it's almost second nature. Like if you ask me about my mental health from beginning to end, I could just run off the story without even thinking about it. (P5)

While Participant 2 found it "easier to focus on the mental health part" (P2), Participant 5 felt the process of creating a story with any topic, even mental health, would have been as challenging:

So I think that even if you were to ask me to like pinpoint on a specific issue in mental health, I think it'd be just as difficult. And I think that you just as easily could have asked if we'd covered everything but detailed on mental health. And I think that it would have been just as difficult. (P5)

Participant 1 also considered constructing a story challenging regardless of the topic because there are many aspects to any given topic:

I don't know if it would be easier [with any topic], because I know that, like the first one [draft] I wrote, had so many aspects in it. But you know, there are different areas even within the physical health or the practitioners area that maybe they don't understand or sometimes some things are handled as far as when you go in for something for your physical health, when you're dealing with a mental illness and they find out about that, like there's so many different [aspects]... you know? (P1)

Participants reported that being patient with them, explaining the project, and redirecting them to the purpose of the project facilitated the process of digital storytelling: "You [L.W] were very approachable and understanding. I found it easy enough to do" (P6). "I found it easy to write and like, with your guidance, it was very easy" (P5). All participants agreed that focusing on the physical health needs of people with psychotic disorders was important and necessary and suggested conducting more projects that use digital storytelling with people with such conditions. When asked to recommend other topics for future research, they suggested "social stigma" (P1), "peer-support" (P 4) and "mental health" (P3): "more research is needed on the concept of peer support and how we need more of it in Canada (P4)". For participant 3, this was an important step toward normalization and social acceptance:

They [stories] should concentrate on the mental health... because that's also powerful because the thing is the more people tell the story the better. There will be a society to accept us. To become the norm to talk about it. Just like diabetes or heart attack or stroke. Like there is still stigma out there. (P3)

Managing the Logistics. Most participants preferred to use available materials and images instead of creating them. Three participants provided personal photos for their digital story to identify themselves and highlight events that were important to them. For example, Participant 1 and 2 used their photos to depict before and after images of their weight gain. The

other participant (P3) used a graduation photograph to highlight the moment of change (when she was diagnosed with schizophrenia).

After reflecting, collecting, and selecting photos and images for their story, participants and I arranged them in order to visually organize the story. Most participants felt that the selection of images that resonated with the emotional components of the story was an easy task:

That was the easiest part because once I had the story in front of me and we recorded it, just picking something that matched to the different parts or aspects of the story was easy, that came much easier than recording itself. (P5)

The process of selecting images however was somewhat challenging for Participant 6 who decided not to view samples of digital storytelling in the pre-interview session:

I didn't know necessarily which type of pictures to go along with it. Maybe if I had seen some examples of digital stories, it would have allowed me to think about what type of pictures I could apply a bit better. (P6)

In addition, after uploading personal photographs of Participant 1 into the software, we noticed that some of the photographs were too blurry; therefore, she decided to replace them with other personal photographs that had higher quality: "the process [of selecting images] was good. Obviously ran into a few problems with the picture end of it, but it was more the quality of the pictures, you know" (P1).

In collaboration with the participants, we applied movement to images by panning and zooming to focus attention on an important element of an image. To make the visual narratives smoother, we used transitions between images to make going from one image to the other less abrupt. We used a number of special effects to more effectively convey the mood and story's sentiment, such as dip to color-dissolve, fade in fade out dissolve, ripple dissolve, and additive dissolve. The transition we used most of the time was the "cross-dissolve" transition, in which one image dissolved out as the next image dissolved into the frame. Viewers are most

accustomed to this type of transitioning due to its common use on television and in movies (Lambert, 2010). Participants decided how and where visual effects such as transitions, animations, or compositional organization of the screen were used.

The audio layers contained participants' recorded voice-over and music and/or ambient sounds in keeping with the principles of digital storytelling. Participants agreed that their recorded voice was powerful to bring their story to life and convey their message and meaning. Participants practiced reading their script aloud a few times on their own before recording their story. To help alleviate pressure and anxiety, I also gave them the option of recording their voice-over alone while I left the room. All participants wanted me to be present for the recording. While some participants reported feeling "nervous" (P1, P4, P5) and "self-conscious" (P4) with their voice, the performance of all participants was outstanding. For example, the process of recording took less than 15 minutes for all participants. Two of the participants recorded their audio once only. Others re-recorded segments of the audio to ensure everything came together in the way they wanted. Participants found the process of recording a voice-over "simple" (P1, P3) and "easy" (P2, P4). Participant 6 found the process "pretty straightforward" (P6), and Participant 5 felt that: "other than getting over your nerves of speaking into the microphone, I thought it was easy and simple... I feel like anybody can do it if they wanted to" (P5).

One participant provided his own music, and some participants (P3, P2) did not want music to run throughout their story. Participants made the decisions on the music, images, pacing and how they wanted the visual and audio narratives to complement each other. With their instructions, I performed all the audiovisual editing (removing background noise, amplifying

voice, pasting the re-recorded sections...etc.) after the session. Participant 5 expressed her experience with the editing as follows:

So I think you followed [my instructions]. You just encapsulated what I was thinking and put it on a screen. I don't think that you took anything away from what I was thinking. So I think you did a really good job. (P5)

The task of editing participants' audiovisual after the session took an average of 3-4 hours for each story. Participants provided feedback on the edited audio in the subsequent session and changes were made accordingly. As one participant noted: "I was always kept in the loop as to, you know, you would show me a draft if I didn't, something I didn't like, you would change it" (P1).

Managing Risks. Participants determined their comfort level with the possibility of being identified through personal photos and evaluated the risk of using personal images or other materials that could identify them. Participants were provided with options for anonymity. For example, they could use a pseudonym for their story and select a voice changing option from the software. Instead of using personal photos, participants had the option of using images or videos from the software or copyright-free sources. None of the participants in this study asked to be completely anonymous. However, they all stated being able to determine the degree of their anonymity gave them a sense of control and safety: "Not having to put my face necessarily to it and allowing me to be a bit anonymous, allowed me to speak freely about things" (P6). Being presented with options for anonymity in the recruitment phase of the study helped them decide whether they wished to participate and share their story in the context of focus groups. For example, Participant 4 expressed this as an important consideration:

For me I give permission at this point in my life to share it with the health care providers. Because part of why I did that, is because my face is not being shown... The researcher explained the process to me and it was explained that it could just be audio-recorded, it doesn't have to be images of myself, then it brought a lot of

my anxieties down. Had you told me we were going to be video-taped I would have backed out. (P4)

All participants used their own voice in association with their story. Five participants used their real names for their story and one person used a pseudonym. Three participants preferred not to be identified through personal photos. Participant 1 reported feeling slightly uncomfortable revisiting an old photo which showed significant weight gain stating: "That picture of my weight gain bothered me a bit, but I mean that's obviously the story. But, no, I don't worry about things now. Like yeah, that's long in my past" (P1). Participants 1 and 3 stated they were not worried about being identified in their story as they identified as public speakers and advocates: "it wasn't an issue for me because I am pretty open about things and I do a lot of advocacy work, so, my face is in front of people" (P1). Whereas Participant 2 did not want to be anonymous in her story because she was not worried about being judged by the viewers, who are all professionals.

All participants felt that being in stable condition was an important factor for enrolling and completing the process of digital storytelling. On the other hand, participants identified fear of social stigma as an impediment to participating in any projects. They suggested that introducing project through safe channels (social workers, in groups, etc.) could create a sense of trust and increase recruitment for future projects. Nevertheless, participants considered the timing of this project the most important factor in their enrollment. As Participant 4 explained:

But, also, the reason I don't have an issue with [participating in the study] is because I'm at this point in my recovery. Had you asked me a year ago, two years ago, three years ago, four years ago, or at the very beginning of my illness, I would have said no to the personal experience, no to a group experience, no to everything because at that point in my life I wasn't comfortable with myself and with the stigma, that I would be okay with this in any way, shape or form. So, it's timing and it's my own personal preferences which has made this process a little bit easier. (P4)

Participants recommended research of any kind be conducted with people in stable condition and recovery, especially when it involves technology. Participant 6 considered active symptoms of the mental illness to affect patients' ability and motivation, creating a barrier to participation and commitment to projects:

They might be not well and if they're experiencing delusions or paranoia the last thing they might want is someone recording them. So that's just one reason. Two, if they're experiencing anxiety as a result of, you know, living with schizophrenia, then they might just be too anxious to want to interact with someone or leave their dwelling if they feel the need to leave in order to get this done. A bunch of things illness related. It's nothing... it's not an affront. It's just they just want to be left alone. (P6)

Participants emphasized the role of the researcher and the flexibility of the workshop in overcoming the difficulties of the process. Participant 5 considered the format and approach of this research project accommodated the needs of people with psychotic disorder regarding flexibility, comfort, and convenience:

It was very flexible. You catered to the needs of people who have disabilities which is nice... You were very, very helpful, like very... I felt very comfortable with you. Like you're very open and caring and I think that you... like if anyone wanted stuff, they could just ask you. It was very flexible... I never felt like judged to cancel or afraid to be like, "Oh my gosh, what are they going to think?" I thought it was very well done and very accepting. you made it really easy for me because I have a car, right? I was going to say if someone didn't have a car it might be hard to get out here. But you made it really clear from the beginning that you would meet us wherever we wanted. So it was easy and simple and good. (P5)

According to Participant 3, "it wasn't like let's do this and it is like homework". Strategies such as providing refreshments were helpful in creating a friendly atmosphere and making the project less formal. Participants found the number and length of the sessions (one session per week; 60-90 minutes) and total number of sessions (5-6) for completing a digital story acceptable and easy to carry out. As Participant 1 explained: "all of that was really, really good. The flexibility, the hours...this place [conference room at the university] was very convenient for me. It worked

quite well, [you] showed me and guided me along, and it was really good" (P1). Participant 4 considered longer or consecutive sessions a risk for relapse or withdrawal from the project:

I think we also need those couple of sessions. Because if we were to do it all in one go, that'd be too long, too exhausting, both physically and emotionally and could potentially, either for myself or somebody else going through this process, be triggering. Because we talk about, at least for me, we talked about a difficult period in my life, and sometimes it was hard to go back to that, talking about it. So, it's good to break it up so that I can have a breather in between and prepare myself for what's about to happen. (P4)

Participants found the flexibility and accommodation in time and place important for their commitment to the project. Participant 6 stated, "Being able to meet the person in a spot where they feel comfortable is huge I imagine, like you did with me." Participant 1 considered the pre-interview meeting important for introducing the project, decreasing her anxiety, making her feel comfortable:

Also another thing that was nice, was at the very beginning [pre-interview phase], when we met at [name of the coffee shop], when we met for the very first time, because it made it comfortable. Like it was outside and that's where things were really explained in a good, in a good way, what it was all about. (P1)

Participant 5 emphasized the importance of the first impression at gaining her trust and interest:

First of all I don't like meeting new people. But right away you were like, "Let's hug. How are you? This is so great. I'm so excited." And right away I was like, "I'm so excited." Like oh my goodness. You were hugging me and this is so good. I was like had a really good time. (P5)

While few participants identified advantages of group-based sessions, such as receiving feedback from group members, most preferred individual sessions. Participant 1 considered individual sessions better at offering more privacy for speaking freely about emotions and concerns:

I think group might have been harder, like to zoom in on your, like to keep your mind on what you were doing. And then there's the confidentiality thing of it I guess. I think that would have been a little more difficult, maybe for everybody, as far as feeling at ease with divulging something that maybe someone isn't ready to, type thing. (P1)

Participant 4 preferred individual sessions because she felt comfortable with the primary researcher:

In my experience I liked this format [individual sessions]. But, it's because I could relate with the researcher involved. I don't think that for myself I don't think I would oppose too much to a group but at the same time, I'm not sure because I haven't gone through that experience. Like somebody else could be, just prefer a group or somebody else might not agree with the researchers so like, for me, I was lucky, I got a great researcher. (P4)

Individual sessions were also regarded as less distracting and anxiety provoking and helpful at building a trusting relationship with the researcher. Participant 2 stated, "You get all the attention and the focus is on you and it is not as anxiety provoking". Participant 3 who had previously written a story about her mental health recovery in a recovery-based group also preferred individual sessions because she was able to complete the project in a shorter period of time:

At the [name of an organization], I was taught how to tell my story and so once I wrote it out and told my story, I would get feedback from the rest of the group and like from the facilitator what to put but I think one-on-one, we got more done. (P3)

All participants were pleased that the researcher handled the editing software: "My personal preference is that the researcher did it because when it comes to editing software, I'm not good with that at all unless I'm specifically trained on it and have some practice with it" (P4). While some participants considered "it [to] be really interesting to know the platform" (P1), they perceived the process of being trained and gaining the technical skills time-consuming, difficult: "I am not computer savvy, so that would be difficult" (P3). Participants believed that managing the editing program by the researcher saved considerable time and effort and decreased the number of sessions they had to attend to complete their story:

I think it was awesome that you did it, I guess. It saved a lot of work (...) Because you knew what you were doing, you knew how it was supposed to work. Not knowing that process at all would have been really difficult. (P1)

Participants believed the collaboration in assembling the story was more important than learning how to work with the software and that leaving this aspect to the researcher did not diminish the quality of their story. Participant 5 explained this as follows: "I like that you did it. I don't think that you took anything away from what I was thinking. So, I think you did a really good job". In evaluating the process of digital storytelling, participants reflected on their experiences and provided feedback on the impact of the process. The next section will provide more details about participants' feedback on the digital storytelling process.

Digital Storytelling as a Powerful Process for Storytellers

Participants described their overall experience of participating in the digital storytelling process as positive, exciting and fulfilling. As one participant reflected: "That was actually really exciting. So I think having that experience is really interesting, really, really fulfilling. But also, it's just a lot of fun (...) It was just so good. I'm so excited that we did this" (P5). Participant 4 described being 'empowered' from her experience: "I'm not sure how I feel, I feel good, I guess I feel empowered, it's the easiest way to put it" (P4). Participant 5 described the experience of digital storytelling as awakening, enlightening, and rewarding. She reported that only after going through the digital storytelling process could she realize the importance of her physical health concern. The digital storytelling process increased her ability to be aware of her feelings and reflect on healthcare providers' attitudes and behaviours in addressing her physical health problem. This participant reported a transformation in her attitudes and behaviours towards her physical health needs as a result of the process. She also reported feeling empowered to take action to address her physical health concerns:

So seeing the finished piece of work, I feel like, almost awakened to the importance of taking care of my physical health when people kind of push it away. Watching it from afar, with music and stuff you're like, 'Actually this is a really big deal.' I feel, for myself, now...I feel like it changed me a little bit... like

I'm definitely going to bring it up and be like, 'Hey, after doing this [digital storytelling], I feel like...my physical symptoms are important. Is there a way that we can kind of address those?' ...I feel like now if a doctor or someone came up to me and was like, 'Hey, I think that this isn't a very big problem.' I'd be like, 'You know what? It is a big problem.' I feel like we should look into this more and try and find a solution that works for the both of us, not just for you. (P5)

The digital storytelling process provided participants with an opportunity to discuss their concerns and release their emotions. Participant 4 felt that the ability to voice concerns and emotions gave her a great sense of relief: "Yeah, it gave me a sense of relief because some of the feelings I talked about, I haven't really talked about because I never felt heard or respected" (P4). Participant 2 expressed feelings of empowerment: "it is not something that I have to hold back anymore". In addition to well-being and relief, Participant 6 also reported feelings of contribution as a result of the process: "I think having the final story and having gone through it, I feel like I've done my part to help the situation." (P6). Producing a story that could be shared with other people instilled a sense of ownership in Participant 2: "well I got a story to share. I can share it whenever I want [which] feels good" (P2). Participant 3 felt that going through the process and producing a digital story added to her list of achievements: "I got a sense of accomplishment out of it. It is just one more thing to add that I accomplished" (P3).

Going through the digital storytelling process and completing the project without withdrawing gave some participants a great sense of accomplishment as symptoms of mental illness and side effects of medications are often barriers to staying committed to projects. As one participant explained:

I actually finished something for the first time in like forever. Especially because when you get sick, I find that it's so hard to finish something because a lot of the times you're like, "Oh I have to" Like, for example, I dropped out of school twice. And just like every... I feel everything that I do kind of gets cut in half. Like I'm not able to finish anything. So like being able to finish something from start to end, I was like, "Yes." (P5)

Participants felt combining the visual and audio with their narrative was "neat" (P1), "inspiring and powerful" (P3) and had resulted in a compelling presentation of their issue that surpassed their expectations. For example, participant 5 stated:

I was really impressed with how it all came together. It was so much fun. It was like a lot more hands on and exciting and the end project was a lot better than I expected it. Like I don't know what I expected but it exceeded my expectations" (P5).

Most participants were willing to repeat the experience again, depending on the timing and circumstances and whether they could relate to the topic. Participant 2 wanted to repeat the experience "Because it was a good experience and [she] got a sense of accomplishment out of it". Participant 3 felt that producing more digital stories could help reduce stigma: "Yes, I like sharing my story with others, so other people will also share the stories to help reduce the stigma. That's the big part".

Many participants described that the focus on their physical health was a welcomed and powerful alternative to discussing their mental illness which was their main interactions with healthcare providers and other people. Participant 1 welcomed the change of focus: "I've never really zeroed into that aspect. Usually when I do my story, it is my journey (...) so it is kind of nice to have one that just does zero-in on how my physical health was". In addition, most participants had learned to "struggle in silence" (P3) about their physical health and suppress their feelings and concerns in relation to the side effects of the medication:

I've pushed down and like have been told to push down like my feelings about my physical health so often. I'd almost be super nervous to share it with my doctors. I don't like it when people don't feel like they're doing their job. And I feel like if you showed this to a doctor, being like, "Hey, you're not doing your job," they'd like get really upset. I feel like some of them would be kind of like be standoffish about it. You know what I mean? So and I wouldn't want that, personally. (P5)

Participant 5 highlights an important issue in her relationships with physicians, wherein she feels obligated to be mindful of their feelings regarding the quality of their care, even when such care does not meet her needs. Aware that sharing her concerns about her physical health (e.g., by sharing her story) could harm her relationship with physicians, she expresses not wishing to go down that road, even if it is to her detriment.

For most participants, digital storytelling was an opportunity to concentrate on their physical health concern, for the first time in a long time, if ever. As participant 6 stated: "digital storytelling combined with the fact that you're doing this allowed me to focus on just that [physical health concern], where I haven't done that before". The process of digital storytelling also created a sense of trust and a safe space for speaking and feeling of being heard. The same participant added, "I think the fact that someone like yourself is looking into the issue. The means definitely, as I alluded to before, helped in the sense that I could be anonymous and know that this was going to be heard" (P6). In addition, showing interest, attending to participants' apprehensions and supporting them throughout the process helped them disclose their concerns and reveal suppressed emotions. As participant 1 stated, "You know, that that's a really important part, is having someone that works with you and believes in you and tries to bring that out".

This section provided details about the digital storytelling process, including the construct of the narratives and managing the logistics and risks. While participants had to make critical decisions in relation to their anonymity and content of their stories, having the opportunity to voice their emotions and concerns, reconnect with self, and reflect on their problems provided them with feelings of accomplishment, well-being, and fulfillment. Digital storytelling was considered a powerful and safe process for participants to represent themselves and their realities

instead of being represented by someone else who may not accurately convey their needs or their message. The next section will provide details about the content of the stories.

Content of the Digital Stories

Research question # 1: How do people with psychotic disorders express their physical health needs, concerns and priorities via digital storytelling?

Obesity/weight gain and fatigue were the participant's most concerning physical health problems. Five participants constructed their stories about the physical health problem of weight gain/obesity and one about the problem of chronic fatigue. In their stories, participants talked about their physical health experiences and the role of antipsychotic medications in their etiology. They also revealed the consequences of the physical health problems on their social relationships, including family, work, and self. Analysis of the content of the stories revealed two overarching themes: 1) *Bodies as a contested site*, and 2) *(In)visible patient*. In the following section, I present the results for the content of the stories and participants' descriptions of their physical health problems, including their understanding of the etiology, consequences, and barriers to resolving them (see Figure 2).

Figure 2: Content of the Stories

Content of Stories
<u>Body as a contested site</u> ➤ Body as a biological entity in relationship with society • The body as a biological problem (mental illness) • The body amenable to a biological solution (pharmacological intervention) • The body in relationship with society <u>(In)visible patient</u> ➤ Paternalism ○ Lack of providers' concern for health problems ○ Physical health issues as a (small) price to pay ○ Ignorance or normalization of medication side effects ○ Exclusion from decisions ○ Not being heard

- Mental illness as the dominant entity
- Giving up, giving in, and accepting

Bodies as a Contested Site of Struggle

Participants described healthcare interactions based on limited understandings and explanations for their mental health issues, which led to treatments that focused almost exclusively on biological interventions. Later in this section, I suggest that such biological focus reveals contradictory considerations about participants' bodies and therefore posit their body as a site of contested explanations.

Body as a Biological Entity in Relationship with Society. Most participants started their stories by identifying their mental illness. For example, Participant 4 started her story as follows: "My journey with mental illness started when I was 16. I finally got diagnosed with schizophrenia at 22" (P4). Participant 6 started his story by stating: "I was diagnosed with schizophrenia in my late teens". Only one participant (P3) did not want to identify her mental illness because her diagnosis changed over the years with different psychiatrists. She reported that her initial diagnosis was bipolar disorder, which was changed to schizophrenia and then schizoaffective disorder. Therefore, she did not want to include this information in her story and only revealed the following information: "In 1980 at 21 years of age, I just managed to have graduated from college. I was hospitalized on the mental health ward" (P3). While most participants only identified their mental illness, Participant 2 also included the negative effects of her mental symptoms such as auditory hallucinations, lack of motivation and trouble with concentration and sleep. Participant 2 described her struggles as follows:

The auditory hallucinations started when I was 22 years old, about a month before I started college. I heard persecutory voices that criticized my past and ridiculed me. I tried to commit suicide. At college I felt very nervous. I had trouble with my

concentration especially with reading while I was hearing voices. My troubles with focus gave me worries of my ability to be a successful student at school. Once nighttime would come, I would have trouble falling asleep because of the voices and my worries. On my free time, I would spend hours on the computer on specific websites thinking someone was trying to communicate with me through pictures and text. The auditory hallucinations would sometimes go away for months at a time but seems to come back with stress. (P2)

Through their stories, participants described being prescribed high dosages and/or multiple medications for their mental illness. For example, one participant reported being placed on four different medications at the same time: "Olanzapine, Seroquel, Abilify and Latuda" (P4). Some participants were prescribed a "cocktail of medication" (P1) to control their symptoms: "I was taking too many meds to count, some for voices I was hearing, others for my mood and anxieties and still others to help to sleep" (P1). Participants identified antipsychotic medication as the main contributing factor to their physical health problems: "I was put on Olanzapine and Abilify. I gained 10 pounds with the Olanzapine in a month" (P2).

Participants talked about the consequences of receiving pharmacological treatment for their mental illness. For example, in her story, Participant 5 reported experiencing extreme fatigue that was not relieved by substantial sleeping and occasional napping: "Since being on medications, my symptoms are under control. However, I experience extreme fatigue despite getting what seems to be restful sleeps. I sleep over 12 hours a night, as well as occasional napping during the day". Five participants reported rapid weight gain in a short period of time after being started on medication, with one participant reporting gaining 10 pounds within a month, while others reported gaining an excess weight of 25 to 50 pounds in a few months: "In a very short period of time I had gained in excess of 50 pounds" (P1). For some, this was continuous, amounting to extreme weight gain:

I was put on high doses of antipsychotics at one point, 800 mg of Seroquel and I was told to double it if needed (...) I gained about 60 pounds in 4 months and it only got worse and I gained more and more. Now I am over 360 pounds. (P6)

This brought on additional health problems, as one participant described in her story:

I was in the hospital for 5 months and I became better with the correct medication. However, some of the medication caused fatigue, and excessive weight gain. In 2013, my weight spiralled out of control. I gained 257 pounds due to the medications. It affected my hips and knees. I was diagnosed with osteoarthritis (P3).

Introducing antipsychotic medications as a solution to their mental illness created consequences that had some participants "wonder if the cure is worse than the disease" (P6). For example, participant 3 reported losing her sister, who was diagnosed with a psychotic disorder to kidney failure as a result of pharmacological treatment. She dedicated her story to her sister and to her mother who died in an asylum, as well as those who are suffering as a result of their mental symptoms and medical treatment:

This [digital story] is on behalf of my late mom who died in an asylum and this is on behalf of my laid sister who died of kidney failure caused by a drug called Lithium. This is also on behalf of those who are struggling in silence. (P3)

Although antipsychotic medications helped manage mental symptoms, they often involved various consequences. Weight gain and fatigue led to changes in body appearance, energy level, and functionality of participants. For many, these changes created feelings of low self-esteem, concern, and even depression. One participant expressed how weight gain affected her on a personal level by stating: "I couldn't fit into clothes I would wear regularly (...) My self-esteem was negatively affected. It was so bad at times that I would cry myself to sleep" (P4).

Participant 2 had similar experiences and included this information in her digital story by stating:

I know 10 pounds isn't a big weight gain, but it did cause a lot of concern for me. It didn't help that I was bulimic at the time (...) My self-esteem had gone down with the weight gain. I had trouble exercising because of the ankle problem. The added weight gain didn't help. (P2)

Participants reported that their physical health problems also influenced their work and professional life negatively. In her story, participant 5 reported cancelling social gatherings and appointments due to her physical health problem:

This issue of fatigue has started to interfere with both my personal and professional life. When with friends I have had to sacrifice time with them to address my fatigue. Meetings, appointments, get togethers, and family gatherings are often cancelled because I am too tired. (P5)

Decreased physical activity and productivity due to weight gain led to loss of employment, income, and housing for participant 3:

My weight affected my self-esteem, loss of activities such as my residential cleaning business. I ended up getting depressed, losing my job and income. I lost my home and I was fortunate that my friend took me in for the summer. (P3)

Participant 6 was an athlete prior to gaining a substantial amount of weight and becoming obese. In his story, he reported that weight gain affected his athletic performance and decreased his ability to exercise and pursue competitive sports. He described the emotional burden of weight gain as follows: "I used to be athletic and I have done competitive basketball, soccer, and long-distance running. Unfortunately, I couldn't do it anymore because of the weight gain. My weight gain robbed me of my hobbies" (P6). While changes in physical and functional level were devastating for participants, sometimes family and friends did not understand their reality. For example, in her story Participant 4 stated: "It was very difficult to have to listen to family members constantly telling me to stop eating because I was gaining so much weight despite not having much control over it even with dieting" (P4).

Participants described attempting to address their physical health problems on their own by increasing their sleep or engaging in weight management strategies such as diet and exercise. However, these strategies were reported to be ineffective in the long-term. While most participants used approaches deemed to be healthy to address their physical health concerns, one

participant turned to harmful strategies for weight loss in a state of despair: "I have tried many times to lose weight using various of types of diets, exercise and I even abused amphetamines, but nothing worked long-term. I have only continued to gain weight" (P6). Participants felt their ability to address their physical health problems on their own was restricted by several impediments, such as limited community services tailored to the needs of people with mental illness. As participant 6 explained:

It is very difficult to go to a public gym where you are concerned about people judging you. That combined with anxiety and paranoia which create a huge barrier to addressing your weight gain. For example, if there was a gym for people with mental health challenges, I would be the first to be a part of it, because it is very difficult to go to a public gym where you are concerned about people judging you. (P6)

Other impediments included lack of skills in stress management, cooking and exercising. One participant who grew up in an abusive household described her challenges as follows in her story: "Due to my childhood struggles, I did not have the skills to learn about cooking, exercising, or coping with stress" (P3). The only effective strategy for resolving most participants' weight gain included discontinuing or decreasing the dosage of their antipsychotic medication. Participants shared those experiences in their stories as follows: "Finally they took me off some of the medications and I lost some of the weight" (P4). "I was taken off Olanzapine and the weight gain stopped" (P2).

Participants talked about their bodies as contested sites of struggle through descriptions of how they perceived their bodies to be biological entities that created struggles and consequences affecting every aspect of their life, including their social relationships. Participants acknowledged the negative effects of their mental symptoms, such as auditory hallucinations, lack of motivation and trouble with concentration and sleep on their life. However, introducing antipsychotic medications as a solution to their mental illness created negative consequences.

Participants reported that antipsychotic medications were the first line of treatment for their mental illness and described their failing efforts in trying to address their physical health problems by themselves. For some, this meant dealing with mental, as well as physical health problems. The next section will provide more details about participants' experiences in addressing their physical health concerns with healthcare providers.

(In)visible Patients

The content of the stories illustrated challenges that participants encountered and endured while trying to address/resolve their physical health problems with their healthcare provider(s). They also conveyed a feeling of loss of identity due to the mental illness which created challenges in having their concerns communicated and heard by healthcare providers. As they felt their concerns were mostly normalized and/or dismissed, some participants used different strategies for leveling the power imbalances and compensating for loss of identity to deal with their invisibility within the psychiatric system.

Paternalism. While participants hoped that healthcare providers recognized and addressed the physical needs of people with mental health conditions, they identified a gap between their aspiration and reality. Participant 4 stated, "I wish our physical concerns and life goals be as important to healthcare providers as controlling the symptoms of the mental illness itself". Most participants described practices and attitudes from healthcare providers that were akin to medical paternalism including, dismissing, overlooking, minimizing or normalizing their physical health concerns. Participants expressed that healthcare providers, especially psychiatrists, did not focus on patients' physical health concerns as much as they focused on the mental illness. In her story, for example, Participant 5 explained:

They haven't taken any further actions to address this issue even though it's affecting me very strongly. Although they are taking measures to deal with my

mental symptoms, my physical symptom of fatigue seem ignored. I wish that the issue would take higher precedence as it is a high priority for me, even if it is not for them. (P5)

In his story, Participant 6 explained that healthcare providers did not address his physical health concerns appropriately and did not provide realistic approaches to resolve them: "While there is growing concerns about weight gain, health care providers care more about stabilizing your mental health symptoms. They teach you about healthy lifestyles but don't necessarily provide you with tools and services to realistically achieve those goals". Later in the evaluation interview, Participant 5 revealed that she believed that her physical health condition of chronic fatigue was not addressed because healthcare providers could not see or measure the physical change:

I feel like when you go talk to a doctor, especially if you have a problem ... like an ongoing problem, that they don't see right away, that's not... like maybe it's a chronic illness or something like that, that they don't see or they can't grasp then ... they kind of like, it's like well if I can't see it and can't help it right now, then it's not important. Like it's not important enough...I think it's important to be, the fact that it's... like when it's affecting our lives even though you can't see it, it's still very important. (P5)

However, even when physical changes were observable and measurable, participants believed most healthcare providers still failed to recognize, discuss, and address them. In her story for example, Participant 4 claimed: "In a very short period of time I had gain in excess of 50 pounds. This weight gain was never discussed". In some cases, healthcare providers overtly ignored participants' physical changes or normalized them, something Participant 1 experienced firsthand: "I was told that I would definitely gain weight but not to worry about it, that it was just a normal side effect". Participants were also shocked by the side effects of the medications and described the process as "suffering in silence" (P3) and the effect as "worse than the disease" (P6). Most participants reported wanting to discontinue their medications on their own,

especially at the beginning of their treatment due to the side effects. Participant 2 included this information in her story stating: "I am very happy my weight gain stopped, otherwise, I might have tried stopping the medication myself". Participant 6 expressed his frustration as follows:

I didn't have much of a choice getting put on the medication in the first place but I wish I had known... or maybe... it was good that I didn't because I probably wouldn't have taken the damn pills... that this was going to happen...who knows.

This participant believed that when healthcare providers did acknowledge challenging side effects, they often framed them as a small price to pay for recovery. He expressed this clearly in his evaluation interview:

It's become the norm. Like it's just become acceptable that, yeah, the medication's going to cause a lot of people to gain weight and that's unfortunate but in order to treat the symptoms, they need to endure certain side effects and that's just okay now.

Some participants reported that their concerns were disregarded, ignored, and told they were normal by healthcare providers. Participant 5 described this experience in her digital story as follows: "I have discussed this [chronic fatigue] with my mental health team and they seem to think it's not related to the medication" (P5). Participant 4 had a similar experience, which she described in her digital story in the following way:

I told my healthcare providers at the time that I couldn't fit into clothes anymore and that weight gain was affecting my life. However, they failed to give it as much attention (...) Now I had to deal with both the symptoms of the schizophrenia as well as the weight gain. (P4)

In the interview, one participant expressed feelings of frustration and resentment towards healthcare providers for ignoring and minimizing their physical health concerns: "They're aware of it [side effects of medication] but they're at peace with it and I don't think they should be" (P6). This participant chose to give up and accept the situation, including pharmacological treatment and its side effects of physical health problems, because he felt powerless in making

any changes since he lacked voice, affluence, and power. In the follow-up interview he explained:

You kind of just accept the weight gain as a necessary side effect of the medication when you shouldn't have to. I've always felt it [weight gain] shouldn't be a normal side effect. It just... there's... I'm but one person, how do I go about making change to something...how do I go about making change to something when I'm not a doctor or anything like that. (P6)

On the other hand, participant 4 described compensating for her feelings of invisibility and not being heard by bringing a family member to appointments to advocate on her behalf and compensate for sense of loss of credibility, voice, and power. In her story, Participant 4 recounted her experience as follows:

I told my healthcare providers at the time that I couldn't fit into clothes anymore and that weight gain was affecting my life. However, they failed to give it as much attention as my mental health. I had to bring my father to appointments at times to advocate on my behalf because I thought my concerns were dismissed and I was deemed non-credible. When my father came with me to appointments, my concerns would get addressed. However, when I went alone, I felt the treatment was different. Finally, they took me off some of the medications and I lost some of the weight (P4).

While most participants reported receiving minimal attention and care for their physical health problems, one reported a different story. Participant 1 explained that after a long period of struggle with excessive weight gain and other unaddressed physical conditions, she was assigned to a new psychiatrist who treated her differently. This psychiatrist engaged in collaborative decision-making and provided compassionate and care that was felt to be patient centered. In her digital story, Participant 1 described the psychiatrist as actively listening, respecting her values and preferences, and building trust with her. This approach was described as a shift from traditional psychiatrist-driven care she had previously to a collaborative approach leading to meaningful and relevant solutions. The participant felt that the collaborative practice allowed both psychiatrist and the patient to share their expertise and knowledge to form a common goal

of restoring and maintaining her health. This equal partnership for decision-making created a better outcome and improved the participant's quality of life. In her story she explained:

For the first time, I was part of a team. Everything regarding my illness is explained and discussed together, including any medication changes, adjustments or side effects. He doesn't give me easy answers to my problems but rather explores them with me, allowing me to discover various ways to approach them. My questions are not only welcomed but encouraged. He ensures that my physical health doctors are kept in the loop in case of any medication interactions or interference. Due to his [psychiatrist] thorough and comprehensive approach, a tumor on my adrenal gland was discovered and the gland was subsequently removed. Seeking ways to help me have time away from my illness and looking for something that I might find enjoyable and that could help with my self-confidence, he came up with the suggestion that I might enjoy running. Well I tried it and it was love at first step. The combination of medication adjustments, my adrenalectomy and my heart surgery has helped immensely in my return to my previous weight and running has enabled me to keep it that way. My doctor's patient-centred care and strength-based approach has allowed me to benefit both mentally and physically. With all of his wisdom, understanding, compassion, and support, I can't imagine having a more motivating or inspiring guide accompany me on this journey. (P1)

While positive, the experiences of Participant 1 were unique among the sample in this study.

Participant 1 described the experience with this psychiatrist as unique among the many other psychiatrists that she had encountered over the years, stating: "I did go through psychiatrists who didn't involve me [in my care]" (P1). In her story, this participant recalled the treatment of the other psychiatrists as follows:

After many years which included several doctors, numerous meds and hospitalizations, things were going from bad to worse. I was taking too many meds to count, some for voices I was hearing, others for my mood and anxieties and still others to help me to sleep. No real explanations were ever offered about what each one was supposed to do or how any of them like interfered with my existing cardiac problem. The only thing that stands out for me is that I was told that I would definitely gain weight but not to worry about it, that it was just a normal side effect. And gain weight I did. In a very short period of time I had gained in excess of 50 pounds. This weight gain was never discussed. When things got really overwhelming, I would be hospitalized, where I would sleep a lot, meet with my doctor, my meds would be adjusted and eventually I would be released. Still I didn't understand why I was experiencing the things that I was and

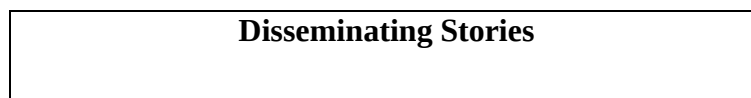
I was scared to death. Once again I was transferred to another doctor but this time, something seemed different. He wanted me to be included in my care. (P1)

The content of the participants' stories revealed the struggles they experienced as a result of their bodies being perceived as a vehicle to managing their mental illness. Participants spoke about their physical health concern and the negative effects their concerns had on self and their relationships, emphasizing that they did not have a voice that was heard regarding these concerns. All participants felt that their physical bodies were the venue for stabilizing their mental illness through pharmacological treatments without consideration of the physical health consequences. Participants described that they did not feel they had a voice, or their voices were not heard, which is consistent with Spivak's ideas of the subalterns' voice being silenced in systems of representation and power structures. In the present context, most participants considered themselves visible as a patient with a mental illness but invisible with physical health or other needs. Participants either accepted the situation because they did not have the power or authority to change it or tried to overcome the paternalistic approaches by bringing family members to advocate for them (i.e., the use of a family member as a voice to communicate with those in power). The next section will provide information about participants' perspectives about what could be achieved by digital stories.

Disseminating Stories

The results for "Disseminating Stories" illustrate participants' ideas about sharing their stories and potential use for their digital stories. (see Figure 3)

Figure 3: Disseminating stories



- **Using digital stories**
 - Education
 - Peer-support
 - Public awareness
 - Practice and policy change

Using Digital Stories

While the content of the stories conveyed feelings of lost identity and being unheard, participants' perceptions of the use of their stories were different. All participants considered digital stories to be a powerful medium for delivering a tailored message in an effective way. They did not express concerns or hesitation that a voice in the form of a digital story might be ignored or dismissed by the viewer. Participants questioned the extent to which digital stories of one project could result in fundamental changes. They however, expressed the hope that through additional digital storytelling projects, changes might become possible:

I know this is a limited project, but I just hope projects, the more projects like this that are shown, the more health care providers listen to people going through the system that way we feel like our perspectives matter. (P4)

They used words such as "hope" and "wish" to express their desires or doubts regarding the potential impact of digital stories:

I really hope that through sharing this with the professionals (...) it hopefully helps along some change. Hope it makes some people see what it's like to be on the other end. It might help them to understand and see that this really needs to be addressed and it's not okay and it's a big issue. (P6)

And in some ways, it's just, I hope they [physicians] increase their knowledge and improve their practices but it's in no way a judgement of the whole health care profession. Just hope. Hopefully health care providers see the different aspects of mental health, not just the mental health symptoms itself, but the whole person (P4)

Participants believed that many people would greatly benefit from watching digital stories of people with mental health problems including: "Nurses, psychiatric students, doctor students, social workers, psychiatrists, supervisors, policymakers, people who have mental illness, the public and companies like workplaces" (P3). Participants believed that healthcare providers should be targeted because they work closely with patients: "Medical professionals because well they are involved in the field" (P2). Participant 5 felt that "they [healthcare providers] might know that there are side effects with the medication. There are things that are happening but, they maybe do not understand how important it [physical health] is to the patients and how much it's [physical problems] affecting them" (P5). As explained by Participant 1, digital stories were perceived to have the potential to increase viewers' understanding and awareness about the struggles and needs of persons with mental health problems, increase empathy and therefore decrease stigma:

There is quite a stigma even among health care professionals when it comes to people with mental illness and especially with schizophrenia... outside of the psychiatric field, like on different hospitalizations, that when they found out I've had the illness, or you know, had this illness, or take a certain medication, or something, and how all of the sudden reactions are, you know, things are different (...) It [digital stories] can help health care professionals understand and be more understanding of and empathetic toward [us]. I think it was all good and it would be really interesting you know, to do something like this, somehow and have it zero-in just on how health care professionals can help, how we, as patients, can help health care professionals understand and be more understanding of and empathetic toward, which would help in a long way in the stigma that we often receive. I think it's [digital story] a good platform... I think it's really important that other medical professionals see some of the struggles that we have and how maybe they can help, that can help them better understand and help them to address it or confront it. It [digital story] lets them see that we should have a voice in what our care is. That doesn't mean, just poopooing everything a doctor says, but discussing it and having a voice in our own health. I think anyone can benefit from seeing how dealing with a patient and not just talking about a patient, but working with them type thing, is such a good thing to do. It gives that person, that patient a feeling that they're important, like it's their problem, but they're part of it, they're not just... I don't know how to explain that. (P1)

Participant 1 also emphasized that her digital story has an important message that could be beneficial for all healthcare providers, especially psychiatrists to help them see the person in the patient, acknowledge and hear patients' voice, and include them in decision-making:

I think that any health care professional should [watch my digital story]. I think firstly, probably I would think psychiatrists to start with because I did go through psychiatrists who didn't involve me and seeing how one who has really involved me, how that made such a difference and how that patient-centered care, how that made such a difference in my journey. Also, I would think that physical health professionals also because they do also, I think it's important that they do kind of work as a team and that they can take something away from that. That it's important that you know, they all work together, it also gives medical professionals who aren't in psychiatric field, it allows them to see that we're just people also...it's good for them to see, you know, we're, yes we have our problems but yeah, we can learn to manage them with the right care. When you're involved in your care and you have a medical team working with you instead of for you, type thing. Like you know, that it makes a big difference. Therefore, in my opinion, like doesn't have to just go by the book you know, sometimes it's just looking at that person who's suffering so much and doing what's best for them, even if that's not what's written in the manual per say, as to how to deal with things. (P1)

Participants believed digital stories have the potential to produce changes in attitudes and approaches to care. However, for foundational changes, participants considered exposure to policymakers as well as healthcare providers: "Health care providers, policymakers when it comes to treating the side effects of the antipsychotics" (P6). Exposing policymakers to digital stories was believed to be a more effective approach for changing practices:

People who deal with policies and procedures. I was going to say managers and like the people higher than doctors would probably be good too (...) like if you fix this problem from the top, it would be a lot easier to push it downwards. (P5)

Participants also considered the digital stories a tool for helping friends and family better understand the complexity of their health problems. Participant 2 stated, "Sharing it with people you know is to show them what you produced and also explain to them what you have been

through" (P2). Participant 4 envisioned benefits that could extend to care providers and also family members:

It's going to help health care providers see the different aspects of mental health, not just the mental health symptoms itself, but the whole person. I'm happy I helped shine a light on this topic. Because this [physical health] is not something that most physicians talk about, like, at least in my case with medication side effects that can be physical, or with their patients in a way that they feel empowered, or in a way that their families feel empowered. (P4)

Participants considered the embedded messages within a digital story to be a great tool for reflecting on and challenging problematic perceptions and attitudes. Participant 3 felt the dissemination of digital stories should extend beyond the healthcare system to help decrease stigma:

Police officers should see it. The way they treat people who have a mental health challenge. They always handcuff us if we call 911 and if we say we are suicidal, they handcuff us and sometimes they put you in a cruiser instead of the ambulance. Like I said I was suicidal and I said I had a knife to cut my wrist, this was in [name of the city], right and 6 cruisers came to my door and they handled me very roughly and they handcuffed me and they put me in a cruiser and the ambulance drove off and they escorted me into the waiting room and they stayed with me there until I saw the doctor and that was very embarrassing and degrading because you know what would other people think at the hospital. It was embarrassing. (P3)

Participants also considered digital stories a good tool for peer-support and raising public awareness:

People going through the system themselves that way they don't feel alone, some of the... what we discussed. Because that's what I felt like, I felt alone. Because being alone is something I encountered myself, something some of my, the peers I've met encounter and it's the biggest thing that can get in the way of getting help. (P4)

Because more people will come out telling their story. Because it is like everybody has someone in their family that has a mental health challenge, like if it is not a brother, sister, mom or dad, it is a cousin or a nephew or grandparents or uncle or aunt. You know what, we are all going to have one form of mental illness in our lifetime, whether it's not in our younger days or adult days or when we are in our 50s or 60s, we are going to have it when we are in 80s or 90s.

People go through depression when they are elderly because I worked with people who are elderly, or seniors and I saw it. They don't know much about the physical health of people who have mental illnesses. They [the public] don't know much about the psychiatric medications and they don't know much about the mental illness itself. (P3)

Participants reported that they would only share their own story with people they trust due to its sensitive nature. For Participant 4, this was a way to control exposure to stigmatizing attitudes:

I'm going to pick and choose who I share it with because weight gain is something that only a few people in my life know about which is what we discussed in the project. And my mental health is also something few people in my life know about. Not because I'm ashamed of it, it's because there's stigma out there and I don't want to open myself up to stigma. So with this final product I'm going to share it with the people I feel safe with. And that's been my policy with mental health from the very beginning. I will not share with you if I do not feel safe with you. (P4)

Some participants did not want to share their digital story with specific friends and family members because they felt they lacked empathy and understanding of their condition. Participant 3 feared receiving negative comments that could further damage her relationship with her brother: "I wouldn't want to share it with my brother because he never supports me in anything I do (...) the last thing I want is his negative comments about my story" (P3). Even sharing stories with empathetic loved ones was difficult, however Participant 6 stated: "I can think of other individuals...friends or family... who wouldn't get it, but they've been blessed to not have to deal with mental health challenges, especially when combined with medication and weight gain". Despite stories focusing on physical health, they still revealed participant's diagnosis of mental illness. Participant 4 found it important to reconcile the idea of having been diagnosed with a mental health issue (a stigmatized one at that) to be able to share the digital stories with others:

A few years ago I would have said no, I wouldn't share it with anyone, I probably wouldn't have made the video, but now, no, I'm totally transparent as far as my illness goes and everything that goes with it. (P4)

Stereotype, stigma, and negative consequences were participants' main reasons for not wanting to share their digital story with new people, potential employers, and current healthcare providers. Participant 2 expressed this concern as such: "I would be worried that they won't understand. They wouldn't understand the mental health part. There is also stereotype of people with psychosis being violent, which there are cases but it's a minority". Participant 5 did not feel safe sharing her story with her current physician because she believed her digital story expressed messages that could be perceived as insulting and offensive:

I feel like I'd almost be super nervous to share it with my doctors (...) some of them would be accepting but I feel like some of them would be kind of like be standoffish about it. Offended would be like a better word. And I feel like if you showed this to a doctor, being like, "Hey, you're not doing your job," they'd like get really upset. You know what I mean?

Participants talked about the importance of 'hearing' patients' experiences and subjectivity for empowering outcomes. While some feared negative consequences for sharing their digital stories with their current care providers, participants considered digital stories a powerful medium for establishing a line of communication with those in power to help increase awareness, empathy and understanding, counteract dominant perceptions, and potentially change practices and policies; a strategy Spivak (1999) considered important for overcoming subalternity and being "inserted into the long road to hegemony" (p. 310).

Second Step of the Study: Screening the Digital Stories

Research Question #3: What are nurses' and healthcare leaders' reactions to the digital stories including the format and the content of the stories?

Description of Participants

Two focus groups were held with a total of 15 participants. The first focus group consisted of a total of 7 participants who did not work in the field of psychiatry and mental

health. These included a pediatric nurse, a public health nurse, an intensive care unit (ICU) nurse, a general surgery nurse, a nurse counsellor and an emergency room (ER) nurse (n=2). Their working experience ranged from six month to 11 years. All nurses reported having provided care to people with mental illness including psychotic disorders at some point in their career, but these sporadic experiences amounted to less than six months of working experience as a mental health nurse with people with psychotic disorders. For example, a public health nurse had worked with homeless people and during this time had occasionally worked with people with psychotic disorders. Another participant had previously worked at a group home for people with schizophrenia and bipolar disorder as a mental health support worker, not as a nurse. The ER nurses also reported providing care to people with psychotic disorders on an occasional basis. The pediatric nurse reported occasionally providing care to people with psychotic disorders since the ages of care recipient in her institution ranged from birth to 21 years of age.

The second focus group consisted of 8 participants: 3 mental health nurses and 5 mental health managers including 2 point-of-care managers and 3 senior managers. The sample included 6 females and 2 males. The working experience of mental health nurses ranged between 3.5 years to 30 years. The working experience of managers ranged between 4.5 years to 22 years. Managers served a large population of people with psychotic disorders in tertiary and community settings across Ontario (see Table 2).

Table 2) Demographic Characteristics of Nurse Participants

Category	<u>Focus Group Participants</u>			%
	<i>FG1</i> <i>N=7</i>	<i>FG2</i> <i>N=8</i>	<i>Total</i> <i>N=15</i>	
Position				
Manager	-	5	5	33%
Hospital staff nurse	6		6	40%

Hospital mental health nurse		3	3	20%
Public health nurse	1	-	1	7%
Years of practice as staff nurse or manager				
1-5 years	4	3	7	46.7%
5-10 years	2	1	3	20%
>10 years	1	4	5	33.3%
Sex				
Female	7	6	13	87%
Male	-	2	2	13%

Reflecting on Digital Stories

The following section provides details about the results of the second phase of the study which included the nurse participants viewing the digital stories, reflecting on the content, and envisioning the impact of the stories. Participants perceived digital stories as a powerful process for patients and viewers/consumers. By placing the content of the stories within the larger context of mental health care, participants considered psychiatry an ideological system and a system of subordination. The results for envisioning the impact of stories revealed participants' perceptions on sharing and potential use of the digital stories. Participants reflected on the integration of digital stories as a form of evidence in psychiatry and the barriers and facilitators to using the stories to change practices and policies. Digital stories were considered a powerful tool for education, social advocacy, and peer-support.

Although members of both focus groups reflected on the format and content of the digital stories, participants of the first focus group which included non-mental health nurses (NMHNs) spent some time summarizing the stories and expressing their feelings about them:

I think a few of them [digital storytellers] kind of mentioned how like even when they [storytellers] did bring up these concerns to their health care professional, they were ignored, kind of brushed off. Like you know, this is to be expected. Or you know, one of them [digital storyteller] was saying that it wasn't... what was

the word she [storyteller] said... like it wasn't seen as, not valid but, like coming from her, like they didn't believe it. When her [storyteller's] father said it, it was like believable. Yeah, kind of like, 'you don't really know what you're saying because you have a mental illness.' That's kind of how it came out. (NMHN, 2)

I think that my take away is, what I'm hearing is that they don't feel like there's a holistic approach. Sort of like symptom management only and they have to kind of deal with the consequences that everything comes with is symptom management. Which is sad. I find that very sad. (NMHN, 7).

Members of the second focus group which included mental health nurses and leaders (MHNs) were able to immediately place the content of the stories within the larger context of the psychiatric system and their current practice (see Figure 4). They also provided examples from their respective practices that echoed the problems that were revealed within the digital stories. Both groups provided feedback on the content, process, and dissemination of the digital stories.

Figure 4: Reflecting on Content of Stories

Reflecting on the Digital Stories
➤ Psychiatry as system representation & subordination ○ Depersonalization and lack of collaboration ○ Subordinations of clients' preferences ○ Client powerlessness ○ Hospitalization as a threatening process ○ Stigma ○ Controlling the narrative of: ○ Who can/cannot speak ○ Who can/cannot be heard ➤ Psychiatry as an ideological system in need of solution ○ Not patient-centered care, not holistic care ○ Experiences and care taken out of context ○ Non-contextual quantitative approaches ○ Healthcare provider's practices are constricted ○ Conforming to protocols and standards without considering patient ○ Loss of autonomy

- Quantifying performance and care

Psychiatry as a System of Subordination and Lack of Representation. Participants and especially members of the second focus group (MHNs) were not surprised by the content of the digital stories which reflected feelings of lack of agency. As one senior manager mentioned:

with schizophrenia or the one with schizoaffective disorder, you can't expect you know, so much agency. How many people can say that they feel much control when they're taking these medications that make them gain 40 lbs in two months. Or develop these other side-effects. Sometimes they don't even tell us, 'well I haven't been able to have sex for you know, for ...' Weight gain is pretty obvious but then there's other things that happen from taking the meds that they don't even sometimes tell us. (Senior manager, 2)

Participants acknowledged that medication for people with no mental illness is a choice. For example, one of the NMHNs stated: "I'll present them with [the medication], 'okay it's important to treat your pain because of blah, blah, blah. You know, but it's your right to refuse, like it's your right to say no" (NMHN, 1). They felt "it would be nice if they [people with psychotic disorders] could have a choice of, yes; this medication and/or doing CBT [cognitive behavioural therapy] and having people make that decision?" (MHN, 3). However, lack of freedom of choice over treatment decision in psychiatry was a reality that was explained by a senior manager as follows:

One thing that strikes me is that every other medication as a treatment is a choice. Right? Based on the side-effects and if you want to be treated or not. It was imposed on them and the choice is back down to you, oh you need to do the exercise, you need to change the way you eat, you need to not be tired. You know, in psychiatry, the fact that they don't... it's almost like there's no choice here, it's like okay well you're sick and you're psychotic and you need Olanzapine. You don't need Olanzapine because you ... maybe hearing voices isn't as bad as

gaining 50 lbs. Right? There's that choice. There's a choice that should be made.
(Senior Manager, 3)

Participants acknowledged that in psychiatry patients are forced to take their medication and endure the side effects. Those who "decide not to take their medications" (MHN, 3) or voice concerns about the side effects, risk involuntary readmissions for non-compliance:

In my experience if patients speak to their psychiatrist about you know, a specific medication that they feel is causing them weight gain, then the risk of speaking with their psychiatrist about that is often a re-admission or to change the medication and is often unfortunately done as a threatening mechanism that they need to stay on their medication regardless if they're gaining weight. (Senior manager, 3)

Patients who express themselves or make decisions about their treatment can be also seen as displaying new signs of decompensation. Reflecting on the content of stories, one participant illustrated this risk as follows:

One [storyteller] was saying like how he was happy the weight gain stopped or he may have tried to stop the medication. So, that struck me, just thinking kind of ahead like how that would be really perceived as not compliant or like another symptom of the disease. (NMHN, 6)

A point-of-care manager shared a story from her clinical practice about how a patient was forcefully readmitted for not wanting to take her medication due to its side effects:

I was just talking to somebody [patient] the other day and they said, "I was prescribed Lithium and now I have acne scars on my face and it was to the point where I thought I was going to kill myself at one point because of it. So, I told my doctor I didn't want to take it and I was hospitalized against my will, I had to take it, my doctor told me, she actually spoke to the inpatient doctor and made me take it and now I'm here". And you know, she's got very significant scarring on her face so. (Point-of-care manager, 2)

Power differential between patients and healthcare providers was perceived to have diminished patients' sense of control and agency to voice their concerns: "the thing is that alone in with the psychiatrist in that closed door office the agency is not there. They feel intimidated. It's the psychiatrist against the patient. The message is controlled" (Senior manager, 3). Many

patients with psychotic disorders were believed to be "hesitant about sharing too much because they don't want to jeopardize the care that they get, which is unfortunate" (Point-of-care manager, 2). Power dynamics and fear of repercussion were also reported as possible factors that prevent patients from advocating for themselves or challenging decisions of healthcare providers:

There's a power dynamic that exists. And so I think it makes it difficult too for patients to advocate for themselves. Because it can be kind of seen like this physician is this person above them who is going to, like you know and I think it came up that might they feel like they're going to offend them or I don't know, they're not going to take good care of them if they like go against what they're going to say. (NMHN, 4)

A point- of care manager explained fear of repercussion for voicing concerns as follows:

And I think people do have concerns about if I'm not satisfied, if I'm taking the medication and I'm telling the person that I don't want to take it because I've got weight gain or I don't like the way it makes me feel, or whatever, there'll be some repercussions for that. (Point-of-care manager, 2)

Reasons for excluding patients from decisions were attributed to stigma and beliefs that people with a mental illness have poor insight into their situation: "the health professionals have stigma against these people. You know, like their own views, kind of like well you don't understand how important controlling your symptoms are. They are not as credible to make decisions" (NMHN, 2). One participant felt that in psychiatry, mental healthcare providers do not include patients in decisions because they do not respect the knowledge and expertise of people with a mental illness:

I think that for people with mental health concerns that we often don't respect the fact that they're experts in their own experience where we might for other conditions, like, more physiological conditions...something like a broken leg or something. We would take how they interpret that seriously. Where I wonder if that's maybe not as respected in the mental health community. (NMHN, 7)

Others believed that lack of empathy was a reason for not genuinely understanding the struggle of patients and being sensitized to their needs:

Yeah, that what they live with day to day, right? I don't live with what they're living with, I'm with them for a short period of time everyday and I'm hearing kind of those acute concerns, but I don't live their day to day. So, I just couldn't see it from their perspective even if I tried. Right? (NMHN, 3)

Not to criticize the health care professionals, but like a lack of empathy if you will. Like a lack of putting yourself in their shoes and kind of being like okay, like losing your house is important to them. You know, being... someone [in the digital stories] there was like, "I lost my hobbies", like that's like a big thing, like not being able to do anything that you like wanted to, you loved doing. Like that would devastate anybody, so. And I just think like there's this lack of empathy as well, kind of, whether it's because they have a mental illness, or I don't know, the health care professional's values. (NMHN, 2)

One of the participants believed that repeated exposure to people who have similar concerns may have diminished responsiveness to patients' struggles: "If you see 10 people in your office in a day, at the end of the day it's kind of just you know, a process at that point. And maybe you're a little desensitized at the experiences of those patients" (NMHN, 7). Participants also believed that patients are exposed to prejudice and discriminatory attitude as a result of labelling and "focusing on them as their diagnosis" (NMHN, 4). One of the participants explained some healthcare providers' stigmatizing behaviours as follows:

I think a little bit for me, just to accept that again like kind of label. And I have an Emergency Room background as well and I just, it resonated that you usually see people in crisis and so you have that different perspective and so, I think, sometimes it is terrible to say but that, these are functional people and that they're not their disease and I think that we have to go back to that. (NMHN-5)

Participants reported stigma towards people with a mental illness among some non-mental healthcare providers:

In hospital there's a lot of talk about psychiatric departments. I work in a community hospital, so all the other floors have these very elaborate, erroneous stories about what goes on in psychiatry and when they happen to get floated to our department, they walk in with their tails between their legs sometimes. But we

could reassure them and everything and you see after their first shift in psychiatry that it's pretty enjoyable. Patients are normal people and the team is great as well. So, it's all these weird stigmatic ideologies that people have outside the psychiatric department that can impact the care that they might receive in the ER or wherever else they may have seen. (MHN, 1)

Even one participant in the first focus group (NMHNs) acknowledged having misconceptions about the abilities and functionality of people with psychotic disorders prior to watching the digital stories:

I think as an emergency nurse I often see people with mental illness in crisis. When, and so this was a good reminder that there are people who are intelligent, articulate, they know themselves, they know their needs, they're able to say what they want and what they need. It was a good reminder for me certainly as a practitioner. (NMHN, 4)

The same participant appeared to be unfamiliar with the common side effects of antipsychotic medications and while she acknowledged her lack of knowledge, she casted doubt on the veracity of what was being said and also subtly discredited storytellers' experiences regarding medications' side effects:

I think it kind of gave me like a new perspective feel, because I think we often think that people who are obese, I think in my mind I was putting them in the same category as everyone who has obesity and kind of like that they have the same issues, like it's hard to go to the gym because... or you know, the things that obese people have to do and it kind of gave me this new perspective that okay, this is like more related to their medication or at least they are attributing it to their medication. (NMHN, 4)

Exclusionary and stigmatizing behaviours were not limited to non-mental healthcare providers but were also seen in mental healthcare providers as well:

At the Forensic unit, I don't think people would listen to them or be sensitized to them. The nurses might, the psychiatrists, it's true, they don't. I worked there during the summer and for three weeks a patient wasn't seen by a doctor, by his doctor, you know. (MHN, 1)

According to the participants, patients are maintained as passive objects with dependent agency in need of representation, instead of people who can recognize, express, and act on their

decisions. As one participant stated, "I think sometimes we feel like, 'okay well these people are at risk, so we have to advocate for them. And sometimes you forget that they can advocate for themselves as well'" (NMHN, 5). Patients' autonomy, priorities, goals, and preferences were perceived to be subordinated as result of healthcare providers' stigma and narrow approaches to care:

Medical views seem to be so narrow, like so focused on the actual symptoms. So, are we really giving the best care from like the perspective of the patient right? What's their priority, what's most important, what's going to be most helpful to them? What's going to be more detrimental to them? (NMHN, 6)

In reflecting on the content of the stories, participants considered factors such as stigma, lack of empathy and power dynamics as factors leading to subordination and representation of patients within the psychiatric system. Participants described structures of power and legitimacy and practices of domination and subordination such as forced treatment. For example, they considered psychiatry a system of representation in which certain voices are given authority and permission to speak while others are not. Participants talked about how patients can become passive recipient of pharmacological treatment regardless of consequences and through threatening mechanisms of readmission. Such practices and behaviours are akin to power structures that Spivak (1988) referred to in denying 'subalterns' from speaking and being heard.

Psychiatry as an Ideological System in Need of Solution. One of the participants perceived the risk of harm to self and others by people with psychotic disorders a reality: "With schizophrenia it's complicated too because it's more than just the client, it's the people around them. You're always worried about things like you know, harm to people around them, harm to themselves" (NMHN, 1). On the other hand, some participants perceived beliefs about mental illness and people with psychotic disorders ideological and only shaped by social norms and risk discourses:

we've come to this conclusion that having these hallucinations is bad and you know, being diagnosed with schizophrenia is bad, that you can't live with that and we want to get rid of it all together and kind of put it back to what we think you should look like. I think it, for myself, it's a good reminder kind of because I can see from the perspective of the health care providers that it's really easy to get wrapped up in kind of the mental health aspects and trying to make someone kind of conform to what we think a person's mental health should look like. Right? (NMHN, 3)

we're afraid of them because they're dangerous because they're schizophrenic or you know. Risk discourse as well I think. Society needs to be protected from mentally ill people. So, you know people will want to treat and have this strong will, you've got to be on your medication or else you're not doing your job. (Senior manager, 3)

The separation of patients' physical and mental health was highlighted by several participants as unique to the mental health context. One participant appeared to agree with such distinction, stating that in psychiatry "The goal is to stabilize their psychiatric medication. That's the primary goal" (MHN, 2). However, other participants saw such fragmentation as an issue. For example, one non mental health nurse was "struck by the differentiation between physical health and mental health" (NMHN, 4) in psychiatry. Moreover, one mental health leader critiqued the way mental health appeared to be better appreciated and respected in healthcare yet, paradoxically, physical health continued to be the main driver of care while mental health patients' physical health remained neglected:

something that stuck me really, is that in this era that we're saying, "Oh, mental health, we're increasing mental health and saying oh it's so important. It's as important as physical health." This total dichotomy between 'no actually for these people the mental health number one is the driver and the physical health is put aside, which is this big, big difference from the general population that the physical health is the... I mean there's changes right now, but physical health right now is the number one, right? (Senior manager, 3)

Participants confirmed that physical health is not well integrated into psychiatry, and it is not part of the routine care at their setting. One participant stated, "It's not integrated. As soon as there's

a Metformin which is pretty standard, I mean it's a very, very standard, some doctor, psychiatrists will not prescribe it" (Senior Manager, 3). Another participant claimed:

This speaks to kind of the metabolic monitoring work that I was doing prior to leaving [former managerial position in acute care]. Again, it was very basic, it was roles and responsibilities, and looking at what factors needed to be measured at what intervals. And which practitioner, is it the nurse, is it the doctor? There's certainly a lot of work in metabolic monitoring that came largely to nurses and so that was something that we were trying to work out in the fine details and I think sometimes that's a limitation, is just what is the regular process and the interaction of each of those visits? My belief is that it's largely just not integrated. The processes are not integrated in a way that makes it part of our routine. (Point-of-care manager, 1)

Participants criticized the fragmented care in psychiatry and found that excluding the complexity of human as biopsychosocial beings contentious:

But what's normal and what's acceptable for the patient are often different. Same with kind of pain scales. What they rate their pain and then what they consider to be an acceptable rating of pain, I think it's really interesting to see how patients have perceived what they've been told. And it's normal but it's not normal for them because that's not acceptable for them. (NMHN, 7)

There's kind of like this hierarchy of function. So, it was more important that they be kind of mentally functioning than functioning as a whole person. They weren't able to go out, meet appointments, see friends, do exercise, do any of these things but as long as they weren't hearing voices and able to kind of function then that was okay. (NMHN, 3)

But the issue of the whole person, it's not just the weight gain, it's the person. It's the fact that she can't talk to her doctor about the weight gain, she [storyteller] feels terrible, who wouldn't. But also what about the rest of her life? And some [storytellers] did mention relationships with families, of course the family says, 'what the heck's the matter with you, stop eating. You're gaining too much weight'. So, there's friction. But it's a total denial that we are people and we come to see our doc, we're full human beings, and if you [healthcare providers] can't see that, you should maybe take up another profession. Or if you've become so burnt out. I think we need as nurses to advocate for our patients that go before this kind of treatment. Anyways, I'm a rebel. (Senior Manager, 2)

The participant suggests that having a holistic perspective is somehow outside the norm, deviant in the current healthcare system, that it is so at odds with current clinical

orientations that embodying this view makes you “a rebel”, that raises questions about the ability of healthcare providers to effect change from within. In addition, the practice of healthcare providers in psychiatry was also perceived to be governed by methods which favour quantitative approaches to care in forms of standard tools and checklists. As one participant stated: "I think we went too much towards this depersonalized quantitative perception of the patient (...) even Mental State Exam is so banal, in my line, I just do it because it's there and it has to be done" (MHN, 2). Participants reported that objective performance measures by standard forms have been directing, informing, and enforcing healthcare providers' interactions with their clients:

often we're engaging with clients on a more regular basis, working with tools such as a mental health status and that might inform how we ask questions. And those forms of templates or checklists that are to be documented on, depending on what hospital you're working for, can influence a lot of the interaction we do have with clients. (Point-of-care manager, 1)

Conformity to objective measures, without taking into account patients' perspectives was perceived to have resulted in barriers to understanding their needs. As one participant explained:

In this era of counting and calculating, this is one tick box when ... even I was listening to [Fellow focus group member]. Wow, we've done this metabolic monitoring but what does that really mean? Does that mean that I'm taking a weight, a height, a BMI, and a waist circumference every four months and I'm checking the lipids and the diabetes and this and that every six months? Even those types of clinics we're missing the point with this video because these people [people with psychotic disorder] don't care about the 52 inches waist, that's not what came out of this. It's 'I'm not feeling heard by my psychiatrist about the effect of these medications on me.' It's way beyond these tick boxes and these... we're I think living in two different worlds. (Senior manager, 3)

This participant cautions that all these measurements are not substitutes or proxies for quality care, i.e., it is “missing the point”. They are not “care”. Participants considered collecting numbers and communicating care through standardized tools in isolation from their context

reduces patients to objects and can create inadequate and biased information by disregarding relevant factors. A senior manager explained this as follows:

Their inventory, in this era, and then the HQO [Health Quality Ontario] standards where we can just do tick boxes and oh yes, we're providing CBT to an X amount of people because there's 16 sessions and we've had 10 people in 16 sessions. Great, we've provided 160 sessions and we've treated this amount of people. This approach is totally against; it goes totally against it [quality care] (...) this is where it's gone. We get asked as ... in leadership roles, why your RAI [Resident Assessment Inventory] scales, why did your psychotic symptom scales for your patients that were discharged in 2015, why are you above the corporate average? Explain to me. So, here I am going back in the chart looking two years ago, why was my patient group, arbitrarily decided by financial quarters, are above the corporate average? It's numbers. Everything is driven... again it's the Board, right? Because these criteria are decided by the Board. And then my God, we got 10 suicides of our outpatient departments. This number has to reduce, why did we get 10 suicides? Right. It de-contextualizes everything. (Senior Manager-3)

Quantifying patients' and healthcare providers' behaviours through objective measures and use of numbers was perceived to have contributed to marginal space for subjective information:

Yeah because it's like number of aggressive incidents, number of you know, hours on CO [constant observation]. What does that really mean for somebody, you know, they don't have an idea about what's really happening with people. It's just like, well you have to decrease your number of restraints, and hours of restraints. That's what matters, not the person's story. (MHN, 2)

While participants voiced their concerns with evaluating patient care through quantitative approaches, they also expressed their dissatisfaction with the gradual elimination and disappearance of forms that collect patients' personal experiences:

When I was doing my consolidation at the [name of psychiatric hospital], I learned how to do proper notes and tell a story in my note as well. I used a lot of patient quotes to make it more personal. And when you read the note you actually say, oh you know, that's that person. It's easy to recognize without even having the name. Right? But now with the arrival of Meditech [electronic health record]...we lost that paper... that the person actually, they had the choice, they could write their story. Right? So, now they can't do that. They can do it on paper, they could type it, but hardly anybody does. So, we lost that. (MHN, 3)

With advances in technology, participants anticipated the trend of quantifying patients' care to be exacerbated. One participant stated: "In the future I could see, "Oh, this person came in, they were here for 14 days. We saw their voices, they had persecutory delusions 60% of the time at first and then they're down" (Senior Manager, 3). Participants considered restricting subjectivity can restrict scope of practice, creativity, understanding, compassion, and quality of care. As one participant summarized the effect:

Psychiatry is very context-based. Every situation, every person is different, right? So, I hate that use of numbers in Psychiatry and when they say to us sometimes, "You've had too many code whites this month". I'm like, that month that we had a lot of toxic psychoses that month so a lot of agitation, you know, it depends. (MHN, 3)

Care in psychiatry was perceived to be fragmented: "I think the disconnect is that lack of, like, looking at the person in a holistic way" (NMHN, 2). One participant considered the system not to be genuinely concerned with integrated, patient-centered and high-quality care, "I think that it's partly like that patient-centered, like patient inclusion is not very much valued in our health care system" (NMHN, 4). Quantifying experiences and care through standard approaches was perceived to have created a gap in healthcare providers' understanding:

Yeah, so we're doing that cause and effect. If I give you this medication, do you not hear the voices anymore? Yes, good, working perfect. And like I fixed the problem, that's good, I'm done. Like my work is done here, you know. And kind of like, I think they're missing the bigger picture. (NMHN, 3)

In addition, healthcare providers' beliefs, priorities, goals, and agendas were perceived to play a role in the type of care that they provided:

I feel like that also depends on the health care professional; they have to be kind of open. And they kind of have to value patient inclusion. If they're kind of like 'I'm the Pro', this is Best Practice, there's nothing better than these meds. Like you know what I mean? And I think often times, there's like a pressure from health care professionals, whether we like it or not, or kind of the way we present information is biased, our own views will be in there. You know, let's say, they might be like, well if you don't take these you're going to, like this is going to

happen, are you sure you want that? And so I feel like they kind of direct it. Their opinions kind of come in whether they like it or not. (NMHN, 1)

It's a personal thing. So, [name of a physician] took the time to go running with his patient. I doubt he's getting paid to go run with his patient. So, I could see, right now, 18 psychiatrists that work in the forensic psychiatry program, maybe one might do it, maybe. I mean, from the profiles I can see. I mean, it's sad to say, but money drives everything, right? Some psychiatrists won't come to meetings because they're not paid during that time and they would be able to see a patient and charge. I mean I've seen in team meetings where they're getting paid for the team meeting but instead of only getting paid for the team meeting, they chart on the patient at the same time and write 'patient seen' so they can be paid not only for the meeting, but they can also be paid through OHIP. (Senior manager, 3)

Participants believed that when healthcare providers have their own perspectives, agendas, and stigma they might close off other options (putting their priorities and agendas ahead of patients' needs):

I was going to say, I think when health care professionals approach a person, all that they might see is their own agenda, and automatically you close yourself off like, what other possibilities you can see here or like otherwise. I'm just saying again, like how we saw with [name of storyteller], how that different, like the physician, the approach of the physician, how it made such a difference in how she was able to participate and advocate for herself and made her needs known and work in collaboration. Just showed like it's all in the approach, that the possibility is there. (NMHN, 5)

our team rounds that we're having right now with the hospital, they're I don't know, 25 patients, one hour and a half, give or take. We've calculated weekly, it's around two and a half minutes per patient per week. And it's go, go, go. And the psychiatrists are waiting at the door and it's next, next, next. So, as soon as you want to elaborate on a certain patient, "No, no, no, we need to go. We have 20 others to go." And when you offer to the psychiatrist, well can we extend that? 'No, I have private assessments that are waiting for me in the office that are much more lucrative than sitting down here and listening to your stories'. (Senior manager, 3)

While some participants believed that healthcare providers "aren't sensitized enough to the idea of being more proactive to engage patients in their physical well-being in relation to their mental health well-being as well" (MHN, 2), others believed that healthcare providers' behaviours reflect organizations' dominant approaches to care and their implemented parameters of success

for quality care. According to the participants, when organizations dedicate most of their resources and budgets to address certain priorities, they automatically determine healthcare providers' priorities and agendas for care:

The organizations kind of prioritize certain things. And that's reflected in the way we can give our care...it can be that quality is measured as like "none of your patients have hallucinations, that's great"... Let's say, as a bedside nurse, I feel like the organization doesn't put a priority or doesn't value the kind of social care. Because they give me so many patients that I don't have time to do that...Kind of like the way it's organized on a bigger level is kind of impeding me from doing these super important things. They're [organizations are] in charge of kind of doing things a certain way which are like affecting the way I can provide care. I think even sometimes like it kind of comes up in the classes is like the way quality is measured. It can be that quality is measured as "none of your patients have hallucinations, that's great". (NMHN, 2)

They also believed that providers enter healthcare professions to help but fall into a reductionist approach to care which excludes the complexity of human beings as psychosocial:

When you do a root-cause analysis. So, why is it that so many psychiatrists practice this way? Is it that they don't know something else? Is it that they feel, say, powerless to ... I believe, [healthcare providers] went into psychiatry with a strong desire to be of service, but yet service has slipped into this very binary sort of, 'I tell you what to do and you do it and see you next week'. And you know, are you taking your meds, are you sleeping, are you and off you go. You sometimes have to look at, well how come things are as they are? What is it? How come they [psychiatrists] seem tone-deaf with regard in particular to the obesity with the drugs? I mean it's such a huge problem. But they must, perhaps I'm guessing, they don't know what else to do (Senior manager, 2)

Some believed that psychiatrist may have lost their autonomy by focusing on what they were originally assigned to accomplish:

it's easy to get wrapped up in kind of, "okay well you're having these mental health concerns, that's really what I want to focus on. I understand that you're gaining weight but" it's almost like you know, well what else can we do. You have to make a choice, like it's almost like making a choice. For the provider and for the client as to what you value more. If you can't have both then what do you value more? Because at the end of the day, there's no magic medication out there that I know of, where you can kind of be switching them to that they'll get everything that they want or everything that we want. Because we set expectations too. So, I think it's kind of, it kind of makes you think again about

just how difficult it can be for the client as well. And how it can be hard to make those big decisions with the client as to kind of what's valued in our society, what we see as important, what they see as important. (NMHN, 3)

Although I completely agree with all of these clients that weight gain is a significant side-effect that needs to be taken into account, I can also see that sometimes from the side of the service provider, if you've just witnessed someone move from an acutely ill phase into a less ill phase or a recovered phase you do feel like the problem is solved and sometimes it feels like someone's concern, even though you know weight gain is serious or important, it can feel less serious than it clearly was for these clients. (Point-of-care manager, 2)

Lack of time and resources were believed to be barriers to holistic and comprehensive care by healthcare providers: "I think, again, like one of the first things that comes up when you talk about changing practice and what not, is the concept of time and resources, right? It's like automatically put there as a barrier" (NMHN, 5). Participants explained how lack of time can become a constraint in addressing physical health of patients and providing holistic care:

I'm constantly thinking back to my work and you know, I'd love to give people all the time in the world you know, really explore and delve into all their physical and mental health needs but it's, it's really hard. And I think the practitioner side of it, like the nursing and doctor and whoever else, social worker, whoever it is, side of it is really that it's hard when time is so limited and when there's so much to do that it's easy to just throw things at the most obvious kind of thing that's going on and then let everything else slide. Because I just think how much time I have in a day and would love to sit down with my clients and you know, go through every physical health concern and go through everything that they're going through? Absolutely, but I probably don't have the time... no I know I don't have the time to do that and at the end of the day, the acute things that come up are going to be what I focus on. (NMHN, 3)

Others explained how organizations' lack of resources can be a barrier to healthcare providers providing a comprehensive and holistic care:

I'm coming from somewhere that was a tertiary care long-stay place and so certainly a challenge of me being here is that you know, a number of our clients only stay about two-weeks average and we don't have the resources, certainly we struggle with the resources at a regional hospital here to offer those same services (...) And so, even when the person had spoken of a gym being for people who have [mental] health problems, I was reflecting on how the [name of a hospital] does have a gym that is offered to inpatients and outpatients. And what that means

is when certain institutions are often, can be barriers to some clients in terms of two different levels of services and how that can be perceived and how services are split. (Point-of-care manager, 1)

Participants claimed that only few resources are usually dedicated to the physical health of people with mental illnesses in psychiatric organizations and when there is cutback in expenditure, these resources become the first target:

At one point we had an endocrine clinic we started at the hospital. So, anybody could come and they would see an endocrinologist and most of it was weight gain and he would see them and give them a couple of months, okay try to do it on your own, see if you can come down on your numbers and if not then we can talk about treatment. But then they cut it! 'Well we have to do cutbacks to budget, so we're going to get rid of the endocrinologist', who was only coming you know, on a Friday afternoon or something like that, it wasn't a lot of time. (MHN, 3)

The traditional biomedical model of care which mostly focuses on the biological processes of illness and treatment was perceived to be operating in psychiatry: "Patient care is the old medical model which is alive and well and very tragically in these stories" (Senior manager, 2). Changing the philosophy and approaches to care was perceived to be important for changing healthcare providers' practices. Participants also considered that healthcare settings need shifts in both funding schemes and organizational culture to address stigma and tokenism for true patient-centered care:

That goes to tokenism doesn't it. The risk of tokenism by forcing it say on your psychiatrists. They have to be, I guess they have to be ready or there has to be a culture shift or a funding shift... So, I think there's a big bias. So, my own research area is patient engagement in research and we know that there's a huge tokenism towards patient engagement, listening to the patient voice. So, I think it's just continuing to build the evidence base around this and ensuring that we're addressing concerns around tokenism as well that we've got researchers on board with this, policy makers on board with this. Because I think in the very scientific world that most psychiatrists operate in, I believe that this is a struggle. So, I think that there has to be more of an effort, more exposure out there to build on this. (Senior manager, 1)

Changing the educational paradigm in health education in general and medical education in particular system to acknowledge and incorporate other ways of knowing was reported to be an essential action in addressing the problem.

I would say teaching this [art-based] methodology in schools of nursing, in medical schools as well, which still operates under a very post-positivistic paradigm. So if we are serious about changing practice we really have to get this out there as an acceptable methodology. (Senior manager, 1)

Participants also suggested targeting the next generation of healthcare providers to have stronger impact on changing practices because students were considered to be more flexible, receptive, and accepting of new methodologies. Participants believed that digital stories should be incorporated in students' assessment, treatment, and plans for recovery. As explicated by one participant:

And yeah, if you can get the nurses while they're in school, I know for me and the people I was in school with, there's a lot ... the next generation is really into activism, they're against inequalities and you know, people not being heard and I think if you can reach them then that's the next generation going to hospitals, that's where you can make an impact. I think people who have been working the same way for a couple of years, for 20 years, for 30 years if we're talking about physicians, I think it's very hard to tell them... even if you can tell them this is happening... it's very hard to switch like this and be like, okay I'm going to be patient-centered care, I'm going to do this, this and this. Whereas new nurses, they are learning right now. (MHN, 1)

Quantifying performance in psychiatry was reported to be harmful in depersonalizing patients. Placing objective performance measures to improve the health care system was perceived to be counterproductive to its original purpose of producing quality care. Restricting subjectivity and the knowledge that matters was perceived to be damaging not just to persons with mental health issues but also to clinicians. Healthcare providers were believed to have lost their autonomy as practitioner while trying to comply with a system that objectifies care and depersonalizes patients. To overcome these limitations and prevent restricting practices,

participants believed that patient' experiences, subjectivity, and sense of agency should become a priority. Participants believed that organizations' mission should enforce the incorporation of qualitative as well as quantitative data for patient-centered care. In addition, cultural, philosophical, and financial changes were indicated as important factors for changing practices to become inclusive and patient centered. In other words, participants encouraged deconstructing practices, structures, ideologies and behaviours that work together to silence 'subaltern's voices'.

Viewing Digital Stories

Participants reflected on the process of digital storytelling and considered the process to be powerful for the digital storytelling participants and themselves as consumers of the stories. (see Figure 5)

Figure 5: Viewing Digital Stories

Viewing Digital Stories
➤ Powerful process for patients ○ Empowering ○ Finding voice ○ Tailoring messages to be heard ○ Controlling messages ○ Therapeutic effects ○ Compelling representation of concerns ➤ Powerful process for viewers/consumers of digital stories ○ Better understanding of patients' perspectives ○ Powerful emotional experience ○ Reflective process

A Powerful Process for Patients

Participants considered the approach of digital storytelling in-line with the "recovery-oriented care" (Senior manager, 3), and "found the videos excellent" (NMHN, 1) and the process of digital storytelling "very powerful" for patients (MHN, 3). Participants explained that digital storytelling "gave some power to their [storytellers] side of the story and what was important to them" (NMHN, 2) and they "got to put everything that they could say, or they felt weren't heard on, in a video"(MHN, 1). The process of digital storytelling was also regarded as empowering for patients by allowing them to "feel validated in their care. To be seen as an equal in the circle of care, where they can take the time to prepare the message" (MHN, 2) and verbalized their needs without interruption:

I was just going to say that I found the imagery in the videos very powerful and very good at kind of showing from their perspectives. I think that the fact that there's not the opportunity to interrupt them. That could, you have to listen to the whole story and you, like, it's, it can't be a conversation, you know. It kind of juggles into what they have to say, and you can listen to it. Not that I'm thinking about responding because there's not a person to respond to, like I'm just taking in what they have to say. I think that made a difference. (NMHN, 1)

Digital storytelling was perceived to provide a safe and supportive process for patients to voice their concerns and express their emotions authentically and in a way that is meaningful for them:

No censor, no sugar-coating anything and very authentic. A good platform for empowerment for your patient. And I just feel like these patients, they have probably, until they figured out what the problem was, a lot of them maybe they haven't talked to anyone about it. They felt maybe stigmatized, it's very taboo and I feel like the videos, what you did with them, was giving them a platform to speak. (MHN, 1)

Participants suggested that digital storytelling gave time back to patients to formulate their thoughts, tailor and amplify their message, and represent their concerns in a compelling way:

Depending on the personality type, not everyone's ready to just go out there and say their message to their physician. So, it gives them time to formulate the thoughts, to collect their thoughts, and we know that antipsychotics can also have

an impact on their cognitive abilities long-term. So, maybe giving them that extra time to think about what they want to say could be good. The stories can be used for that...They can have all of their concerns addressed in a way that is meaningful for them. (MHN, 2)

People with psychotic disorders were reported to often struggle to find their voice in a creative outlet:

I come from a community mental health [background] where we know our patients for like 20 years sometimes. We've never discharged people unless they actually get better. So, we follow them long-term. And I think we try a lot of different sort of rehabilitative activities and we have a lot of clients that are very creative but struggle to find their voice in a creative outlet. (Point-of-care manager, 2)

Therefore, the process was perceived to offer participants a forum to express their voice in a creative way: "I just think it's really powerful. Yeah. And it would be a good way of allowing the client the space and creativity and their voice to speak away from them and then let them see it kind of separately" (NMHN, 4). The fact that digital storytelling gave patients control over their message and their representation was identified as an additional benefit:

I feel like if I'm controlling the message then I feel more empowered. I think it's important to capture their voice in the way they had, I had a sense that they had control over the message... which is not something that everybody gets all the time. So, just to be able to do their story, say it the way that they wanted to, in their own words, you know, that's powerful. That's like a ... you feel much more invested and your message is getting through the way that you want it to. You feel more in control. (Senior Manager, 2)

According to participants, patients "might get stage-fright or forget to mention certain things. It might be an intimidating relationship with the physician"(MHN, 3). Going through the digital storytelling was perceived as empowering because patients could "deliver the message the way that they decide. Not necessarily be stuck in this [patients/physician] dynamic behind a closed door with one person" (Senior Manager, 3). Therefore, digital storytelling was believed to

provide patients with a platform to find their voice outside constricting and stigmatizing structures and interactions:

Because I think when you're in the presence of a health care provider it can be intimidating and maybe you don't say all those things that you were saying in the beginning even though that's the way you feel (...) I think it kind of goes back to power dynamic, being able to do this without someone, like a health care provider staring at you, and you're able to express yourself without having somebody staring you down as you say it is a big thing. And being able to kind of explore kind of the pictures that you feel relate and the music that you think relates to what you're trying to say or even being able to hear the inflections in their voice, where they kind of emphasize things and de-emphasize other things. Whereas if I were reading that on a piece of paper, it wouldn't have the same impact. (NMHN, 4)

Participants further considered going through the digital storytelling process and exploring, expressing, and reflecting the innermost feelings, thoughts, beliefs, and experiences could "build confidence" (Senior manager, 3) and be a form of therapy for patients:

I think as well, just again, kind of thinking back to my work, I've seen quite a number of the people that I work with that there's a lot of trauma in the past that goes along with the mental health that they're experiencing now, and so I think that it could be a great way for them personally to work through things like trauma. Be able to speak out loud about it and either share or not share it, whatever they kind of wanted to do. I think that would be an incredible way for them to work through things and be able to listen back too, to themselves. And then share it if they wanted to, or not. (NMHN, 3)

A Powerful Process for Viewers/Consumers

According to one of the participants, the stories were "totally non-judgemental. They were just there; it could have been one of us today telling a story. And the idea that it was a story ... we weren't reading a chart, or we weren't hearing it that way (Senior manager, 2). A MHN found the digital stories "more personal than those check boxes or those electronic forms that we do" (MHN, 3). The process of viewing digital stories was described as "a mini-Ted talk" (MHN, 3) as audiovisuals employed within the stories provided a powerful and compelling

representation of experiences and helped connect the viewers on an emotional level for new ways of seeing and knowing:

What struck me is you know, just the language and the emotionality and the way that the stories were told. I think this is a really powerful medium because it attacks all your senses. So, you're seeing the visual images, you're hearing the voices, so I'm thinking that this is more powerful than somebody reading a story or somebody sitting there. (Senior manager, 1)

Digital stories were perceived to help better understand the perspectives of patients, "it kind of gave the patient's perspective of the situation, kind of like what was important to the patient, which I think health care providers should do more of" (NMHN, 2). Participants indicated that presenting experiences through a digital story helped make meanings more tangible to the viewers:

I really liked the format that we heard these stories in. I thought it was impressive how quickly it really brought home how vital and critical this issue was for these clients in a way that I think it doesn't always come out in clinician and service-user conversations. It can be a little too easy maybe to take some of those things less seriously, to not understand their true impact. (Point-of-care manager, 2)

Participants also believed that digital stories can help enhance empathetic understanding for improved outcome:

Yeah, especially if you're working maybe as a psychiatrist or a mental health nurse. It kind of brings you back down to reality, like it's not all about the mental health, it's about how you live, like your life in general. And how you feel your quality of life is and how you feel your health is and is your idea of health in your mind, is that what you're living out right now? Maybe that means that you're on less medications, you still have some mental health concerns that still exist, but you don't gain weight. Maybe that's more important. But I think that that's not often what health care providers see as important. Maybe that is what's important. (NMHN, 3)

Really powerful in [understanding] goals of care, like how often their healthcare providers and nurses, physicians are seeing things through, you know, controlling mental health issues, symptoms, but not really addressing the main concern of the patients. (Senior manager, 2)

Digital stories were perceived powerful at challenging problematic perceptions of viewers. "I think that these digital stories help to see the people amongst us who you know, have schizophrenia or bipolar [disorder]. So, I think it's a great sort of demonstration of normality" (Senior manager, 1). The digital stories increased participants' ability to identify and challenge some of their behaviours and attitudes in the following way:

It's easy to see people as their diagnosis, so you know, and I'm guilty of doing this, where I'm describing someone in rounds, you know, with the other nurses and maybe they're new or something like that, kind of the first thing I do is just say their name and age, but then I start to list off the different diagnoses that they have. And then again, there's different reasons why, because it's important that my colleagues know, kind of the health concerns so that if anything were to happen they have the context. But I think it's easy then to focus on, okay they have schizophrenia, so it almost turns into, it's awful but, that they are schizophrenia because that's what they have, like you focus on that. And I hate to say that because I think it's awful and I try so hard to not, but I can see how it happens and where it comes from. Very much the medicalization of kind of narrowing in on someone as like a disease. Like when somebody comes into Emerg and they are, you know, they are a broken leg. We know that they aren't literally a broken leg but that's what they turn into with us, right? Because that's what's going on right now. So I think that's part of it. (NMHN, 4)

Viewing digital stories was considered powerful at creating desire for change and innovation. As a result of watching the digital stories, some participants identified having their ways of thinking disrupted:

I think we all can become jaded and turned down and think oh the hell, I, whatever. But these kinds of personal stories, they go right in your heart. And you think, I'm not going to see another patient without you know, having the opportunity to hear them out... I think if the nurses saw them and felt the impact that we felt today with those beautiful stories, I think they in their own ways would interact with patients in a more meaningful way. (Senior manager, 3)

Because we are so clinically preoccupied, I think sometimes, that we may not get to those intimate moments with all clients. So, that was nice to see and I think it was certainly something that I'm reflecting on going forward, engaging with patients, I think we all try to be mindful of it but I think that just helped to solidify the importance of key factors in the forefront of our minds. (Point-of-care manager, 1)

Viewers Envisioning Impacts of Stories

Participants discussed what could constitute potential use of the digital stories. The next section will provide details about their perceptions of both their use and impact. (see figure 6)

Figure 6: Viewers Envisioning Impact of Stories

Viewers Envisioning Impact(s) of Stories
➤ Using and sharing digital stories ○ Digital stories as a form of evidence ○ Changing interactions & communication ○ Educational tool ○ Peer-support & raising public awareness ○ Tool for social advocacy

Using and Sharing the Digital Stories. Participants considered digital stories to have the potential to present, communicate, and share feelings and experiences with friends and family members to increase understanding and empathy:

I think that this is such a strong tool for families. I think would really resonate with families. Because families for the most part are trying to control a mental health, you know, the chaos that that sometimes brings home and in family life. And it seems that these stories are all about being heard. And so in some way, and I speak as the daughter of a mother who has very severe schizophrenia and I think that this is a very powerful... this would have been a very powerful medium for her to have received you know, a story of an experience, whether it's my loved one or somebody else. But from sort of that family lens I think it was sort of quite powerful to see these stories. (Senior manager, 1)

Therefore, digital stories were recommended to be used with family members: "we could use them in family groups that we run for people's families to give people a sense of what was going on" (MHN, 2). Digital stories were also believed to be a beneficial tool for peer support, "to inspire other people" (MHN, 3) by raising public awareness about a particular issue:

For peer support groups as well. Like to make sure that this [medication side effects] is not normal, I think that it's not normal but it's something that's

happening to someone else. I'm not the only one gaining 50 lbs in three months (Senior manager, 3).

Participants also reflected on the possibility that going through the process of digital storytelling and producing a digital story could be therapeutic. One participant suggested using digital storytelling as a rehabilitation activity in recovery groups in the following way, "I can see this as a rehabilitation activity that we could take on and do as a yearly group where people had opportunity to create these sorts of videos" (Point-of-care manager, 2).

Participants believed that digital stories can be used to capture healthcare providers' attention and sensitize them to the needs of their patients: "I think because we don't see this medium so often, explaining the experience with the patients that it kind of catches their attention more" (NMHN, 7). One participant summarized the potential effect as follows:

I think that this can touch on some people, you know, make some people see that kind of maybe I should hear my patients out more and I think it might even be relevant to other situations as well, like not just mental health. When people see that my treatment might be affecting my patient in a certain way and that this might be important to them but I'm neglecting to... like I think it can open people's eyes in other pieces as well. (NMHN, 6)

Participants recommended using digital stories as an alternative method of communication with the healthcare team:

The one-on-one interventions behind closed doors can, I mean, it might be with these stories, right? To be conscious, to be able to be behind a closed door or be conscious of these, what's really happening with the person. Because what I find sometimes is when I work in an inpatient unit and oftentimes the patient will tell me some of the concerns regarding the medication or certain side effects and I encourage them to discuss it with their physician during the interview. And after the interview I ask them, "Did you talk about that?" And they often say no, I forgot. So, I'm not sure what's going on in the interview with their physician. It might be an intimidating relationship with the physician. They might get stage fright or forget to mention certain things. So, I think maybe for those, even inpatient or primarily the outpatient, the people can maybe use these videos or these stories at home to voice their concerns and then share it with their team afterwards. (MHN, 1)

I think it's interesting if they would be able to submit these stories to their health care professional before an appointment. And it's unfortunate that they kind of have to do that rather than have the proper communication during the appointment but like, I don't know, for them to sit and listen to what they are saying I think might hopefully be helpful. (NMHN, 3)

I think that it would be good to enhance communication between providers and patients. I think that everyone should do some... I want to do this with all my clients, I think it's great. Yes. So, and also, it's hard because I know that at the anonymity piece, it would be of course up to them and what they would want to do but if you had people of course who were up to sharing things with the public, educating the public, that would be amazing. (NMHN, 2)

One of the participants suggested presenting to the psychiatric system with a digital story as a way of communicating needs and expectations. While this participant acknowledged the fear that patients might have for disclosing certain information through their digital stories but considered nurses a safe channel for sharing such information:

if people have the option to do their digital story of their life, when they come in to service to be like an assessment or just telling what they've, what's happened to them. And more than just like right now we do EMRs [electronic medical record] so we have this electronic thing and right now we still have the patient's story, we still do their 15 questions. Yeah so what's important to you and what's happened to you, and what do you expect the nurses or the team to do for you and you know, if your problem was gone, what would it look like? You know, what needs to happen for that to happen? So, if people had the opportunity to do digitally I think it would be very... not everybody is going to want to do it, but it would be very interesting to see the effects of doing it, who they would want to show it to and how people would react. And I think people do have concerns about if "I'm not satisfied, if I'm taking the medication and I'm telling the person that I don't want to take it because I've got weight gain or I don't like the way it makes me feel, or whatever, there'll be some repercussions for that". So, there's still people that are hesitant about sharing too much because they don't want to jeopardize the care that they get, which is unfortunate. But being a nurse, and not prescribing medications, we get the chance to hear those stories about the good and the bad and people can tell us. (Point-of-care manager, 2)

Participants considered the digital stories beneficial as an educational tool for students, clinicians, staff, administrators, and family members: "These videos can be used in orientation for new staff at hospitals. I think that that's very grounding, for teaching purposes, teaching

undergrad but as well in the workplace" (Senior manager, 3). One participant emphasized that digital stories made with people who have a mental illness should not be limited to mental health nurses and should be seen by all nurses, "I also think that when we think about this for nursing education it shouldn't just be seen as for the mental health nurses. You know, it really needs to be really every, every nurse needs to see these" (Senior manager, 1).

All participants agreed that digital stories provide a form of evidence: "obviously we all agree it is [evidence]" (Point-of-care manager, 2). While some viewed integrating digital stories as evidence at all system levels feasible, others perceived integrating the stories as a form of evidence to change practices and policies within the psychiatric system difficult, if not impossible:

To me there is no greater form of evidence than that. I mean, who are we to sit here and talk about our research papers when people are experiencing this. I have a background in policy, and I think things like this would go really far with policy makers. Because oftentimes policy makers are so far removed from the clinical realm. Not always, there's some times that they're still involved, but sometimes they are so far removed that you tend to forget kind of like the person behind what you're doing, the person behind the policies that you're creating. (NMHN, 2)

I do think it can be used as evidence absolutely, just at the patient or person or service user and provider relationship. I'm not sure that, I don't think that the system can necessarily change in that direction. I think it's hard to integrate such models that are not such easy check boxes and in this age of doing everything that's electronic. Maybe I'm pessimistic. (MHN, 2)

MHNLs were less confident with use of digital stories as a form of evidence in psychiatry because "It's not tick boxes" (Senior manager, 2), and "you can't measure it" (Senior manager, 3). They believed that in psychiatry, quantifiable and measurable evidence remain dominant, and stories do not have the same impact or value because they are "incredibly nuanced", "very individualized" and "changing from client to client" (Point-of-care manager, 2). A point-of-care manager summarized the limitation of digital stories as follows:

I'm thinking from a clinical perspective it's much easier to change clinical perspective when you can say, you know, this was the outcome for these 300 clients and this was the outcome for these 300 clients and it's binary information and that therefore you decide to do this. Whereas this kind of nuanced information doesn't lend itself to the creation of new pathways or it has to be about responding in an individualized way to individual patients. And that requires the buy-in from the practitioner and a whole soft-skill set that's hard to define. (Point-of-care manager, 2)

These participants believed that integrating stories as a form of evidence require changes in the system and buy-in from leaders and practitioners: "It's numbers. Everything is driven [by numbers] ...again it's the board, right? Because these criteria are decided by the Board. And I think those videos would be very interesting at the Board meeting" (Senior manager, 3).

Suggestions to help use digital stories to inform/change practices and policies included exposure of leaders and policy makers to digital stories: "Because I think if you're serious about changing a system and you're serious about policy change, it's about exposure to policy makers" (Senior manager, 1). Due to a hierarchical system, participants believed that change should start from higher level such as board of the executive for hospitals and community health centers. They suggested presenting the stories at the board meeting to help increase awareness and create change:

Unfortunately we live in this kind of hierarchical system. In terms of trying to shift culture sometimes you have to start at the board or the executive level. So, I'm thinking that often there's a patient's story or a client's story or a service user's story given at the board. But often it's read. I think this is a really powerful medium because it attacks all your senses. (Senior manager, 1)

Targeting the leaders and policy makers who decide on the budget, programs, and initiatives was also perceived to be important for creating and reinforcing change. As one participant stated: "So, at the Board and at the Executive level because ultimately, they're the ones that are deciding where the money goes to fund what programs, what initiatives. And so, it's about driving it sometimes at that level" (Senior manager, 1). Participants also suggested that in order to use

digital stories as a form of evidence in psychiatry buy-in from frontline practitioner, especially nurses were required:

So, it's the movement of our front-line nurses, it's the movement of our front-line allied health staff as well as the movement at the board and policy levels. So, doing a two-pronged approach, having nurses seeing these videos, but also making sure that the boards, hospital boards, community health boards, and the executives throughout are. (Senior manager, 1)

One participant also suggested using digital stories as a tool to inspire nurses to advocate for their patients: "I think there's a lot more nurses than there are physicians and if you reach them then they can make a difference and they can be the voice for their patients" (MHN, 1). Most participants perceived nurses to be more open and accepting of digital stories as evidence "because nurses listen more" (MHN, 3). Therefore, they considered nurses to be at the best position to use and advocate for patients to create change:

the whole metabolic aspects of the medication isn't necessarily addressed unless you have a very proactive nurse who is going to look at that other patient, make a care plan and everything. I think we need as nurses to advocate for our patients that go before this kind of treatment. (MHN, 2)

One of the participants provided an example from her practice in relation to a patient's story and the role of the nurse in creating the change:

I had a nurse ask me about metabolic monitoring and medications and everything, and she said, "You know, we're seeing a lot of people that they're on these medications and suddenly they're gaining weight, even in the geriatric populations. So, she was like, what exists for metabolic monitoring? You know, we shared information with her and she's like, yeah I'm going to the doctors and saying, hey, look at this and pay attention to this because until we started measuring it we didn't have an idea but maybe it was becoming more and more prevalent. So, she was that voice, that advocacy. She heard the story of the person and she related it to the doctor. And started taking, on her own, figuring out what they had to do. (MHN, 3)

Participants however considered buy-in from physicians more challenging since most operate within the biomedical model and its reductionists approaches:

Because the way that physicians are trained, they are trained to you know, the way that they have to be trained, is they're trained by body systems. Most med schools do that now, where they look at, they start with GI [gastrointestinal system] maybe and then they move on to neurology, and then they move on to whatever, whatever. And psych is like one component of one course. So, the way that they are going to have-- the barriers that they're going to experience are not going to be the same as nurse. Where most of our nursing programs are not like that anymore. So, I think it really depends on who you're dealing with. (NMHN3)

Therefore, participants suggested more exposure and effort to help advocate for digital stories as a valid form of evidence to be integrated into routine care. According to a senior manager, "in the very scientific world that most psychiatrists operate in, I believe that this is a struggle. So, I think that there has to be more of an effort, more exposure out there to build on this" (Senior manager, 1). Therefore, as an integration process, participants recommended using digital stories in conjunction with other dominant forms of evidence. Rather than competing with these, participants considered integrating various types of information and knowledge helpful to improve care. As one participant explained:

As I was saying in research we don't want to use, like pit different types of knowledge against each other. Rather they should be used together. Right? To improve the outcomes of care for people. That's the ultimate goal, right? So, if you find a way to use these stories as a way to improve the client's experience of their care, make sure that they're validated in their care, along with the other types of research that will show like the statistics behind obesity and weight gain and diabetes and all that stuff, will be used in conjunction with this story. Can help the person better understand what's actually going on and help the physician also understand what's going on. Get a more global picture of the entire situation. (Senior manager, 3)

Digital stories were believed to have the components to create emotions, provoke empathy and become a priority "these videos are very important because they go get you, as [a fellow participant] was saying. They get you here. And if you're able to touch people then it becomes a priority" (Senior manager, 3). Therefore, they were considered a useful tool for influencing policy and decision makers to create change:

from an advocacy point of view it definitely has an effect (...) advocating for how are dollars coming into hospitals and how are hospitals spending those dollars? For example, [a patient with schizophrenia] was very strongly advocating that when fundraising was being done in relation to her own runs or for other schizophrenia causes that those funds should then be directed back to the schizophrenia program that assisted her. And so that just goes to show the power politically and monetarily you know, where we're at as a society and what impact those kinds of very honest and emotional stories can have on decision making processes. (Point-of-care manager, 1)

Participants did not consider difficulty in influencing policy makers because they felt that policymakers are open to hearing people's stories:

Just in terms of the policy level, I think we're inviting people to speak and to tell their stories, if we look at the inquest into a murdered and Aboriginal women [The National Inquiry into Missing and Murdered Indigenous Women and Girls] or the Truth and Reconciliation commission [Truth and Reconciliation in Canada], we're really looking to hear people's stories (NMHN, 4)

One participant provided an example of how policymakers have been using personal stories to raise public awareness and create change:

I think we're trying. Like I look at what's been going on with the opioid crisis, and there has actually been effort from the government, from the provincial government to bring in people with lived experience, who are living through the crisis right now, to speak and to say, sit down and say, please tell me your story. (NMHN, 1)

Participants believed that stories have been used to change certain laws in the past and therefore can be used to change practices and policies if the right approaches are taken. For example, one of the participants stated:

I think that as kind of opening the gate right now for using the storytelling in policy making more to the theme of what has happened. Kind of like what [Name of fellow participant] was saying about the Aboriginal Women and just domestic violence in general. So, any laws that use the person's name, like Clare's Law, that was recently kind of brought forth after someone was murdered by a person who had a domestic violence history and now being able to disclose that information. So, I think that by telling those types of stories we have seen change in the past, and that if this kind of gains more momentum it will be influential for policy making based on the lived experiences of patients and the overall consensus of patients as well. (NMHN,7)

Therefore, digital stories were considered a powerful tool with the potential to help implement changes to current practices to help empower patients in psychiatry:

I also have a bit of a background in policy and I think that the modality can be used as a tool to just say that these patients are legitimate stakeholders and just to be able to spend the time and policy and people involved in policy that are maybe closer to the actual practice and also like managers that are looking for resources to be able to change and impact the way that care is delivered. (NMHN, 5)

Most participants considered the format of the digital stories to have all the required and desirable elements and qualities, to be impactful, including being short, concise, and attractive.

Suggestions by some participants about the format of the stories included providing more background:

I guess the only thing is I would have liked them to be a little bit longer. I don't know how feasible that is but knowing a little bit more of their background would have been nice. Like some of them did describe their background and I found I really liked it and it gave me more context and understanding to the story. otherwise I thought they were really good. (NMHN, 3)

Other suggestions on the format of digital stories included shorter clip edges, and showing the person earlier in the video to help make it more personal:

If you could take some time off the intro and the exit, like maybe get a few more seconds, anyway of story right? Like there was only three or four words on the screen. It doesn't take you very long to read them, so you can kind of... and it was I think it was like 25, 30 seconds of that intro screen. If you can do that in like 15 seconds at each end and then you get another 30 seconds of story. With the same length of video. (NMHN, 1)

I guess this is also dependent on the participants, like what they're willing to do. But, having their faces, kind of sometimes earlier in the video, because it was nice, like when I did see their faces, it was nice to kind of like put a face to the voice. It kind of made it more personal or maybe kind of like see, kind of understand who was speaking here. (NMHN, 2)

Digital stories were perceived to be an ideal medium for patients to tailor their message and voice their concerns through a powerful presentation. Participants considered digital stories to have the potential to help share experiences and concerns that are difficult to communicate.

Compared to face-to-face communication and in-person meeting, digital storytelling as a method of communication was perceived to help overcome the physician-patient power dynamic and any fear or anxieties of directly talking to their psychiatrists about their concerns. Digital stories were perceived to convey patients' messages in a clear, powerful, and concise manner which could potentially change the interaction and communication with healthcare providers, especially with psychiatrists. In other words, participants' feedback suggested that digital storytelling can provide a line of communication between patients and those in positions of power ("circuits of citizenship or insitituionalty"); an important step in overcoming subalternity and being "inserted into the long road to hegemony" (p. 310).

Chapter 6: Discussion

Findings from this research brought forth stories that spoke of deep struggles people with psychotic disorders experience in addressing their physical health concerns within the psychiatric system. Story makers embedded their experiences with notions of powerlessness and despair and the associated negative impact this had on significant aspects of their life. By reflecting on the digital stories and placing the content of the stories within the larger context of the psychiatric system and current practices, nurses were able to expose power relations and structures that exclude patients' experiential knowledge in the health care system. Meanwhile, reflecting on the stories exposed nurses' passive stance in challenging and resisting the dynamics that exclude patients' voices at every level of care. In this chapter, I discuss the subaltern identity, status and voice of people with psychotic disorders and the role the psychiatric health care system plays in maintaining patients' subalternity. I then propose digital stories as a tool for resistance, transgression and political action. By discussing nurses' role in maintaining or disrupting the subalternity of people with psychotic disorders, I emphasize their need for knowledge of political action. I draw a close to the discussion by presenting the limitation and implications of this research for nursing, including research, practice, education, administration, and policy.

Subaltern Identity of People with Psychotic Disorders

Antonio Gramsci first introduced the term "Subaltern" in his Prison Notebooks (Srinivas, 2013). He used the term "subaltern" to refer to those with a "subordinated" identity. The term was then used in humanities and social sciences to refer to marginal, dominated, and powerless attributes expressed through class, age, gender and other forms (Guha, 1988). Spivak used the term "subaltern" to refer to the most excluded citizens, who are "removed from all lines of social mobility" and relegated to the margins of society (Spivak, 2005, p.475). Participants who built

their digital stories described identities that shared many commonalities with what Spivak described as “subaltern”. They expressed great concerns about stigma towards people with mental illness and recollected experiences of discrimination (e.g., ignorance, disrespect) by the public (e.g., police officers) as well as healthcare providers. For instance, one participant recalled how the behaviour of healthcare providers at an Emergency Department became degrading (e.g., doubting her physical symptoms) as soon as they found she had a mental illness. Another story maker had to bring her father to appointments to address her physical health concerns because she felt “non-credible”. Story makers described these experiences as discriminatory, demeaning and humiliating, leaving them feeling invisible, devalued and dismissed. Research also shows that most people with severe mental illness feel devalued, dehumanized, and dismissed upon interaction with the public (Clarke et al., 2007; Hamilton et al., 2016; Taggart & Bailey, 2015). Recognizing that dominant ways of thinking operate implicitly, individuals may not be aware of their negative personal biases (Arboleda-Flórez & Stuart, 2012; Sukhera & Chahine, 2016; Ungar et al., 2016). According to Medina (2013), mechanisms of oppression “are ‘put out of cognitive reach’ of privileged people and those in positions of authority” (p. 33). Research indicates that most healthcare providers do not recognize or acknowledge they have stigmatizing beliefs and behaviours towards people with mental illness until they have received anti-stigma training or interventions (Knaak & Patten, 2016; Sukhera & Chahine, 2016). Being exposed to behaviours that made story makers feel non-credible, devaluated and dismissed reiterated patients’ precarious position and inferior identity.

Story makers in this study acknowledged that having a psychotic identity exposed them to discriminatory behaviours. They believed that degrading stereotypes such as being “violent” and “non-credible” often associated with psychotic disorders are widespread. Nurse participants

expressed that demeaning and patronizing interactions with people diagnosed with psychotic disorders are prevalent because many healthcare providers are “not sensitized” to care recipients' needs and doubt their credibility, judgment, and insight. Interestingly, one of the nurse participants expressed stigmatic attitudes by suggesting that people with psychotic disorders indeed pose a risk of violence to themselves and society. Another nurse revealed misconceptions about the abilities and functionality of people with psychotic disorders before watching the digital stories. Spivak argued that subaltern citizens could be so oppressed and neglected that they have limited ability to challenge the established views held by those in power. In this study, story makers also felt powerless in challenging widespread derogatory stereotypes, stigma and discrimination. By withholding information about their mental illness and hiding their psychiatric identity during interactions with the general public, story makers tried to avoid prejudice, stigma and discrimination, a strategy they could not use with health care providers.

Spivak's theory of subalternity focuses on what she called “epistemic violence”, violence inflicted through thoughts, speeches, writings, and decisions that exclude subaltern voices. In other words, Spivak considered excluding, silencing, and representing the subaltern a form of violence (Spivak, 1988). Story makers in this study described stigmatizing practices and attitudes from healthcare providers akin to medical paternalism, including dismissing, overlooking, minimizing or normalizing their physical health concerns. Fricker (2007) explains that healthcare providers' stigmatizing behaviours, such as dismissing physical health concerns as described by story makers in this study, as identity prejudice. Identity prejudice is “the injustice that a speaker suffers in receiving deflated credibility from the hearer” (p. 4). Identity prejudice “distorts the hearer's perception of the speaker” and can result in willful ignorance, dismissal and silencing of the communicator (Fricker, 2007, p. 36). According to Potter (2020), “Not having a voice, or not

having one's communications taken seriously, frequently involves treating the communicator as lacking credibility" (p. 274). Potter (2020) further explains that "[t]o render speakers/writers/communicators not-credible in virtue of their perceived group memberships (e.g., mentally ill, racialized, classed, gender-nonconforming) is to do epistemic violence to them" (p. 274). Being exposed to prejudice and silencing as a form of epistemic violence suggests that people with psychotic disorders share similar features to those with a subaltern, subjugated, oppressed and subordinated identity.

A central premise to most critical theory is that identities are socially constructed and defined through dominant discourses and hegemonic norms (Abbinnett, 2003; Ingram, 2017) (REF). As explained by Voronka (2016), "We are not 'born this way,' but rather, through a multiplicity of ways, we come to be and continue this process of becoming through encounters" (p. 192). Identities have a form of power attached to them (what it is or means to be man or woman, non-binary or binary, "sane" or "insane" and so on) (Voronka, 2016). This is "a form of social power which is directly dependent upon shared social-imaginative conception of the social identities of those implicated in the particular operation of power" (Fricker, 2007, p. 4). Identity power can be social or structural and may work in favour of a person or against them through control, constraint, and oppression (Fricker, 2007, p. 16). The process of identity production is also considered political and discursive because various forces and strategies can be used to assign inferior or superior identities to people (Scott, 1991; Voronka, 2016). In analyzing the modes of operation of colonial systems, Said (1978) argued that by stereotyping differences such as skin colour, ways of living, religion, gender, and identity and enforcing hierarchical dominance, colonizers were able to systematically push down the identity of the native people and force them to comply to new ways of being and living. In geographic colonization,

domination was accomplished through reduction and dehumanization in which the colonized were categorized as less than human (Lugones, 2012). In other words, European powers justified dominance through, amongst other things, enforcing an inferior identity through imperial binarism (Said, 1978).

Similarly, scientific modes of inquiry that focus on biochemical imbalances and dividing practices such as sane vs. mad), have imposed a “psychotic” identity on care recipients, despite lack of consensus on the biological basis to mental illness (Deacon, 2013). While some psychiatrists claim a biochemical basis to psychiatric disorders (Shorter, 2011), other psychiatrists, such as Frances (2013), believe that "psychiatric diagnosis still relies exclusively on fallible subjective judgments rather than objective biological tests" (p. 111). Kato (2011) stated that "psychiatrists should be aware that we cannot identify “diseases” only by interviews. What we are doing now is just like trying to diagnose diabetes mellitus without measuring blood sugar" (p. 199). Through scientific discourses, the medical model created superior and inferior categories and paternalistic and colonizing relationships between healthcare providers and care recipients (Sutherland, 2017). Since the biomedical model of care focuses on patients' limitations, visibility and expression of people with psychotic disorders that move beyond limitations (competency, ability, curability) of their condition became difficult, if not impossible (Gilman, 2014). In this study, story makers and nurse participants believed that focusing on a person's mental illness diagnosis and symptomatology resulted in stigma and dismissive behaviours towards patients' physical concerns. Research also shows that healthcare providers' stigmatizing, dismissive, and incompassionate behaviours are associated with focusing on the mental illness and failing to see the person behind their diagnosis (Knaak & Patten, 2016). Most participants of this study considered it challenging to address the physical aspect of their health,

partly because it was never the focus of their discussions with healthcare providers. Nurse participants also considered patients' mental health a priority at their setting, explaining that resources, protocols, and checklists for care were designed to prioritize patients' mental health with difficulties moving beyond a pathologizing lens.

Most psychiatrists have adopted a strict adherence to the medical model since the 19th century to help maintain their status and the status of psychiatry within the medical profession (Gøtzsche, 2015; Handerer et al., 2021; Kato, 2011). In the United States, the director of the National Institute of Mental Health (NIMH), Thomas Insel (2010), stated that neuroscience would “lead to more targeted and curative treatments” (p. 51) and “the distinction between neurological and psychiatric disorders will vanish, leading to a combined discipline of clinical neuroscience” (Insel, 2007, p. 757). According to Deacon (2013), the use of the biomedical model in psychiatry remains the dominant model of care in psychiatry and “those who publicly question its legitimacy are swiftly and vigorously criticized by its advocates” (p. 847). By serving as the main explanatory framework for personal experiences, in psychiatry, the biomedical approach to care is believed to have reduced patients to mental symptoms and, therefore, their psychiatric identity (Rocca & Anjum, 2020), which Potter (2020) considered “colonization” of the “body and mind” (Potter, 2020, p. 273).

Spivak (1988) emphasized that dominant power in unequal power relations determines the behaviours, knowledge, discourses, relationships, culture, and language that are legitimate and superior and which ones are not. Similar determinations exist in psychiatry, where norms and expectations around actions and behaviours (what is allowed/not allowed to be said) are assigned in “relation to the authorized (and some might argue, colonizing) mandate of that institution” (Sutherland, 2017, p. 432). Psychiatry has conferred an identity on all members

(mental health nurses, patients, psychiatrists, family members, etc.) and being on the “underprivileged end of this hierarchy”, people with psychotic disorders have an identity of being “distrusted, ignored, and silenced by virtue of their modality - subaltern or ...psychiatric communicat[ors]” (Kamens, 2020, p. 260). In other words, in this study, story makers’ psychiatric identity continued to act as signifiers for their lack of discursive power, rendering them as unreliable/noncredible narrators and subjugating their knowledge as symptoms (Kamens, 2020). Thereby, psychiatry patients’ identity, which is “essential to a sense of agency, autonomy, and citizenship” continues to be suppressed under “the gaze of pathology” and their self-representation and expression are continually subjugated through psychiatric discourses (Sutherland, 2017, p. 5017).

Subaltern Status of People with Psychotic Disorder

Spivak’s ideas about the limits on decision-making, voice, and agency of subaltern were shaped through her experiences with women of low social status (Riach, 2017). She examined how social hierarchies and practices, and policies of exploitation and dominance through colonization and patriarchy systematically deny self-representation opportunities for those assigned an inferior position in society due to age, gender, or other reasons. Spivak’s theory, which has emerged in response to legacies of epistemic violence, provides a critical tool for understanding how power differential in clinical encounters between persons in different positions of authority and privilege (status) can render patients’ voices irrelevant or meaningless.

Nurses in this study talked about the powerlessness of patients in the institutional hierarchy. They expressed concern about lack of patient-centered care, freedom of choice over treatment decisions, involuntary readmission for voicing concerns to pharmacological treatment, power imbalances between healthcare providers and patients, fragmented approaches to care

including neglected physical health, stigma, and lack of resources and time to address patients' health goals and concerns. Nurse participants believed that power dynamics embedded in institutional spaces and practices made it difficult for patients to express agency. According to Jacob et al. (2016), "any institutional space gives rise to discursive, material, and symbolic elements permeated by diffuse power relations" (p. 152). Nurses referred to such spaces as mental health institutions and dialogical spaces "behind closed doors", where patients could be exposed to exclusion from decisions, inferior treatment for physical health concerns, stigma and coercion (e.g., threats of involuntary hospitalization for lack of compliance). Nurses also talked about patients "controlling their messages" and believed that expressing agency and voice in a space loaded with power imbalances and fear is difficult, if not impossible. According to Sutherland (2017), psychiatry's hierarchical space makes it difficult for patients to be seen in a non-judgemental way because the space is established and tied to the gaze of pathology that determines how patients are defined and treated. Sutherland (2017) additionally referred to psychiatric institutions as "colonial space" (exclusionary and oppressive), in which care recipients' "beliefs and identity is partitioned off or excluded as part of healing" (p. 433). Fricker (2007) further argued that "even if we are personally innocent of prejudiced beliefs, still the social atmosphere in which we must judge speakers' credibility is one in which there are inevitably many stray residual prejudices that threaten to influence our credibility judgement" (p. 5).

Spivak (1988) argued that social hierarchies of dominance create subalterns and subordination, disempowerment, and silencing conditions. Stigmatizing beliefs about the character of people with psychotic disorders are not isolated incidents but a profound problem embedded in the healthcare system (Abbey et al., 2011; Ross & Goldner, 2009; Schulze, 2007;

Stuart et al., 2012; Thornicroft et al., 2007). For many centuries, labels attached to people with psychotic disorders such as “dangerous”, “unpredictable”, “violent”, “incompetent”, and “non-productive” have created the belief that these people have lives that are not worthy (Astier, 2007). Psychiatry as a “discursive regime” has specified a “normative domain of relevant action” (Gergen, 2007, p. 5) and has forced psychiatric measures on people with mental illness to rehabilitate, re-socialize and lead what is socially and economically regarded as a meaningful life (Astier, 2007). People who show signs of mental illness and who display “abnormal” behaviours/ thoughts/ actions are placed in a mandatory relationship with hierarchical structures of psychiatry to be monitored, controlled, and treated (Kamens, 2020). The hierarchy dictates “who controls access, who sets the agenda, whose interests are served, and how those lower in the socio-institutional hierarchy are treated in ways that continually ‘remind’ them of—and keep them in—their ‘place’” (Poland et al., 2005, p. 172). In other words, psychiatry as a social, clinical, discursive, legal, political, and historical system is built around patients deemed to be deviant, unreliable, risky, irrational, and violent subjects. Interventions for rehabilitation aim for conformity of behaviour, action, and thought to what is considered the acceptable norm, constraining the extent to which people with psychotic disorders can speak and be heard beyond the structures and practices of psychiatry (Astier, 2007). This reiterates Kamens’ (2020) comment that the “voicelessness” of people with mental illness is the result of “contemporary psychiatric discourse and practice” (p. 253). According to Porter (2015), people with mental illness are not heard because understanding patients’ perspectives require “recognition of the worth of the patient’s perspective. This kind of recognition entails a reversal of the type of power disparity and conditions of oppression” (p. 5).

Story makers in this study felt powerless to have their physical health needs addressed because their concerns had to be processed through “the lens of the expert/authorizing diagnostician and the psychiatric institution, and the person herself, being already positioned as ill, cannot (or, cannot easily) refuse that positioning. We might call this the colonization of a person’s body and mind” (Potter, 2020, p. 26). In addition, the strategies that story makers used, such as giving up, giving in, or bringing a family member to advocate for them, suggests a position of powerlessness in an institutional hierarchy that appears to have “a philosophical tension between the person focus of recovery and the patient (or disease) focus of psychiatric medicine” (Buchanan-Barker & Barker, 2008, p. 94). The digital stories suggest that most healthcare providers were using what Duggan et al. (2006) explain as “doctor-centered” and “disease-centered” care as opposed to patient-centered care. With the former, healthcare providers’ agendas dominate the encounter and push aside patients’ concerns and needs. In “disease-centered” care, a reductionist approach to care ignores various aspects of patients’ lives in favour of labels affixed to pathological processes (Duggan et al., 2006). Based on the stories and feedback of the nurse participants, the point of view of people with psychotic disorders, unlike other care recipients, is filtered through providers’ worldviews, is ignored or controlled. Care is assumed to be patient-centred because it is organized around patients - but with an objectified and subjugated patient, the understanding, evaluation and management are mediated by disease and doctor-centered care.

While shared decision-making in psychiatry has been shown to result in better outcomes for recipients, many, if not most psychiatrists, do not use this approach in their clinical practice because it is considered time-consuming and requires specific training and skills (Lee et al., 2015). A meta-synthesis review on participation and shared decision-making in mental

healthcare found that, while healthcare providers and leaders considered including patients in decisions important, they did not accept that patients should have control over decisions in practice (Stomski & Morrison, 2017). The review found that only patients who reflected healthcare providers' and leaders' approaches and standards were included as consultants. Patients' suggestions were integrated when compatible with providers' decisions and perceptions of appropriate care. Those who disagreed or questioned the authority or expertise of healthcare providers were often labelled as "difficult patients" (Stomski & Morrison, 2017). In other words, those in a position of power were reconciling patients' values and needs with their defined "objective", "gold standard", and "best evidence" care (Bergqvist, 2020). This finding points to the risk of including only these patient experiences that align with systems of domination which could consist of biomedical investment (Deacon, 2013; Gorman, 2013), but it also suggests that patients' credibility as knowers and experts over their bodies depends on their compliance with dominant views. In other words, patients' capacity to escape the subaltern status and "buy back" their place in mainstream society requires the uptake of dominant discourses that define and impose upon them their identity and status. Findings of this study, including strategies that story makers used to compensate for healthcare providers' dismissive behaviours towards their physical health, suggest that the status of people with psychotic disorders share similarities with that of subalterns: inferior, constrained by dominant structures that confer narrow possibilities for self-expression and social participation, and powerlessness.

Subaltern Voice of People with Psychotic Disorders

In her essay, Spivak (1988) questions the benevolent intentions behind banning the Indian Sati practice of widow sacrifice because the concept of Sati was forged without the input of women. Spivak's analysis of the social and political implication of Sati emphasizes the

importance of elitist opinion (professional opinion) in decision making and helps understand how voices of women as subaltern were discursively and materially removed from discussions of practices and policies, and therefore rendered “non-relevant” and “unimportant”. According to Joseph (2016),

In mental health, we can see similar hegemonic practices that privilege the voices of psychiatrists, lawyers, and expert opinion leaving the subaltern voices of [those] diagnosed as mentally ill as the terrain upon which these issues are discussed while leaving little space from which this subaltern group can speak or be heard. (p. 91)

Story makers in this study talked about different struggles regarding their physical health and their consequences, such as loss of employment and relationships. In the stories, the problem of being "invisible" and "unheard" were consistent across all stories. Spivak emphasized that voicelessness is at the core of subaltern status and people with mental illness “are excluded, again in various ways, from hegemonic power structures—and thereby rendered ontically deprived (or without basic resources) as well as voiceless within the dominant discourses” (Kamens, 2020, p. 259). Potter (2019a) identified passive and active mechanisms that mental healthcare providers can use to dismiss or silence those who have a mental illness. Passive behaviours include belittling or ignoring patients’ concerns, nullifying their experiences such as attributing physical symptoms as psychosomatic, and only acknowledging patients’ concerns when caregivers are present or only recognizing and talking to the caregiver in patients’ presence (microaggression) (Potter, 2019a). Active silencing could include threatening behaviours that jeopardize patients’ privileges, freedom, and treatment (Potter, 2019a). Involuntary admission and treatment are examples of active silencing of people with mental illness. While story makers talked about passive forms of silencing and dismissing, nurse participants in this study reported both active and passive forms in their clinical practice. Nurse participants claimed that those who decide not to take their medications or voice concerns about side effects risk involuntary

readmissions for non-compliance. A point-of-care manager witnessed one such occurrence when a patient was forcefully readmitted for not wanting to take her medication due to side effects. Nurses also believed that patients who express concern about their physical health concerns (primarily associated with antipsychotic treatment) could be seen as displaying new signs of decompensation. This, according to Kamens (2020), “demonstrate[s] the existence of hierarchical, universalist, and indeed hegemonic and discursively colonizing practices in psychiatry that subjugate the interpretation of content” (p. 259). According to Jacob et al. (2016), places are governed by rules that can exclude, forbid, suppress and silence voices. Interaction in such “space[s] (physical locale) are rife with power relations” (p. 152), and psychiatric organizations that are built “around the absolute power of the psychiatrist” can undermine patients’ self-agency (Foth, 2013, p. 283). Psychiatry is also notorious for being a place of exclusion (Federman, 2012), seclusion and control (Muir-Cochrane & Gerace, 2014), coercion, restraint, suppression and punishment (Papadopoulos et al., 2012). Therefore, it is essential to provide a safe space (outside threatening power dynamics and structures) for patients to formulate and deliver their thoughts in a creative, self-driven way to be heard.

Disparities in how the physical health needs of people with psychotic disorders were acknowledged, addressed, prevented and treated remain a global problem (Saxena & Maj, 2017). A report on the second round of the National Audit of Schizophrenia in the UK in 2014 indicated that only 39% of people with schizophrenia feel they received adequate and understandable information about their psychiatric medication (Royal College of Psychiatrists, 2014). A Canadian study by Munshi et al. (2017) auditing the physical health assessment and examination of people with mental illness in a 40-bed inpatient hospital in Ontario demonstrated disparity in services. The initial auditing of a physical assessment template, designed and implemented

before the audit, showed that only 54% of patients received assessment and screening for their physical health. This number was decreased to 33% on the second audit, which indicates that physical health assessment and screening of people with mental illness remains grossly insufficient (Munshi et al., 2017). Studies show that when care is sought, healthcare providers are more likely to ignore patients' physical health complaints or incorrectly assess their physical symptoms as psychosomatic, delaying diagnosis and treatment of physiological conditions (Muir-Cochrane, 2006; Saxena & Maj, 2017).

There also continues to be limited research on the perceived experiences of people with psychotic disorders in relation to their physical health or the quality or availability of physical health care services (Happell et al., 2016; Melamed et al., 2019). Surprisingly, most research in relation to the perception of people with severe mental illness on barriers to accessing physical health focuses on the perspectives of healthcare providers and not the care recipients (Chadwick et al., 2012; Nash et al., 2021). This focus can contribute to the erasure of patients' perspectives/experiences and voice and implicitly skew the available evidence to develop sound care policy and processes. Care providers' views can remain the norm, while patients are structurally and discursively relegated to the margins. The limited literature investigating the perspectives of people with psychotic disorders about their physical health also reiterates Spivak's claim that the dominant group has a false belief that their values are universal, which justifies the dismissal of the subaltern's values, beliefs, knowledge, and desires. Spivak highlighted the operation of discourses that worked through the violence of colonization and cultural practices that silenced the subaltern groups as a way to civilize, manage, and regulate those deemed uncivilized. In her essay, she accused Western politicians, leaders, and academics of ironically rehearsing the task of imperialism through 'epistemic violence' or violence imposed through discourses (Spivak,

1988). She spoke “to the discursive violence and development of hegemonic, academic, and professional disciplines that forged on a complete knowledge of the Other” (Joseph, 2016, p. 7). Being influenced by Said’s Orientalism, Spivak (1988) argued that by producing ontological and epistemological differences between the orient and occident, colonialists not only claimed superiority over and expressed contempt towards the orient but set themselves as experts who know Orientals better than they know themselves. According to Joseph (2016), professional hegemony, hierarchy, dominance, and claiming to know the Other better than they know themselves continue to exist within biomedical psychiatry.

Although it is tempting to say that story makers had no voice and were not heard, findings of this study reveal that they were heard when they endorsed their psychiatric identity and interacted accordingly with care providers. Healthcare providers took measures to address participants’ mental symptoms, and concerns or voices about their mental illness were heard. Story makers reported that care providers were mainly interested in hearing about their mental illness. For example, some were invited to speak about their recovery in public engagements organized by psychiatric organizations. This shows that narratives that fit with the script of psychiatry and relayed patients’ “insight” into their mental health disorder were deemed legitimate. Nurse participants acknowledged that the psychiatric system is designed to mostly privilege, accept, acknowledge and integrate patients’ messages that are consistent with clinicians’ worldview. Nurses in this study also explained that patients only reiterate messages that fit psychiatry’s dominant discourse and practices because they feared repercussions and negative consequences. This fear was echoed by story makers who were reluctant to share their digital stories about their ignored physical health condition with their current psychiatrist, resulting in reiteration of the psychiatric discourse which patients feel compelled or pressured to

adopt for fear of being further disqualified. Story makers, therefore, remained visible as psychiatric patients but invisible as patients with other health needs. Thus, while the concept of “voice” in this context is different from what Spivak envisioned and theorized, I suggest that people with psychotic disorders have a voice of subaltern which is structurally and discursively ignored, dismissed, and silenced, and their epistemic agency is seriously compromised.

Digital Stories: Towards Epistemic Justice

Epistemes are defined as “blueprints that shape our bodies of knowledge: who we count as knowers, what we count as evidence, who we count as credible, and who determines the structure of various practices” (Potter, 2015b, p. 3). Epistemic violence is the central concept of Spivak’s theory which refers to a form of violence inflicted through representation of subalterns by powerful people in society. Spivak (1988) argued that the limits and possibilities of communicating and being heard (episteme) are underpinned by systems of power and control in which the dominant voices can draft their own narratives and claim legitimacy and authority. She also claimed that representation by powerful people in society had prevented subalterns from achieving self-representation since representation takes place within the discourses of hegemonic power that serve the dominant classes. Foucault (1991) also claimed that “the formation of knowledge and the increase of power regularly reinforce one another in a circular process” (p.224). Systems of knowledge are systems of power and control as they determine boundaries of thoughts in a given domain and period and define norms of behaviour and deviance (Potter, 2019a). Scientific discourses and institutions have the ability to subjugate the knowledge of people with psychotic disorders as “naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity” (Foucault, 1991, p. 82). Therefore, they can create, define and redefine “regimes of truth” and “general politics” through systems of

knowledge that can be scientific, academic, and clinical (Foucault, 1991). When falling within the purview of psychiatry, there “is an attempt to maintain and instrumentalize that hegemony by exacting rigid control over the origins of writing and discourse” (Kamens, 2020, p. 263).

Therefore, psychiatry has also been accused of resisting knowledge that challenges its practices and character (Potter, 2015b). The discursive hierarchy of psychiatry usually achieves control over discourses and episteme by powerfully impeding the capacity for self-representation of people with mental illness, subjugating their knowledge and voice, while elevating the voices of those in power (Karmen, 2020; Potter, 2020). I argue that this constitutes epistemic injustice which I hope to expose through this doctoral work.

In this thesis, epistemic injustice is being used to refer to exclusion, silencing and systemic distortion of one’s knowledge, meanings and communications. In re-establishing epistemic justice, I aim to disrupt the subaltern identity and reframe systems of knowledge (i.e. whose knowledge counts, whose knowledge is authoritative and legitimate and whose is not). Self-representation counteracts mechanisms of oppression, exploitation, marginalization, powerlessness, and epistemic violence (Joseph, 2016; Kamens, 2020; Potter, 2020, Porter, 2020). Movements such as the Antipsychiatry movement, Mad movement, Psychiatric survivor movement, critical psychiatry, and the Recovery movement are all movements of resistance against the harmful identity conferred on people with mental illness. These movements work to help people with mental illness reclaim their identity, voice, power and agency because they recognize the crisis of representation in contemporary mental health systems and challenge the epistemic authority that excludes patients’ experiences within both the arenas of clinical practice and scientific inquiry. Foucault (1991), for example, talked about the power relations and values embedded in psychiatry that can create categories of “subhumans” for people who are not

entitled to the same rights, consideration, respect, value, and privilege of “normal” citizens. Therefore, digital stories are a way to help healthcare providers learn from those whose knowledge, expertise and voices are currently silenced, discredited or misunderstood and challenge current mental health practices. The literature also shows that marginalized people, such as those living in poverty, with addictions, or mental issues are at risk of being inadvertently and systematically excluded within mainstream decision-making, including healthcare institutions (Conrad & Sinner, 2015). Therefore, the first step to promoting epistemic justice and overcoming subalternity is self-representation (Spivak, 1988). Advocates working towards fostering epistemic justice and addressing oppression (e.g., liberation and rights movements) pay special attention to making it easier and safer for disenfranchised people to express their perspectives and experiences (Meadows, 2003). As O’Donnell et al. (2009) argue, “Much of the analysis of mediated communication is modeled on a politics of expression, that is, of speaking up and out, finding a voice, making oneself heard” (p. 423). In this research, participants spoke about losing control of their narrative in the psychiatric system, which is consistent with previous research literature (Chadwick et al., 2012; Happell et al., 2016; Melamed et al., 2019). I argue that digital stories provide an opportunity for people with psychiatric conditions to disrupt the mainstream epistemic injustices. In areas of social justice, digital stories have gained prominence because of their power at capturing, amplifying, and presenting marginalized and disfranchised voices (Beltrán & Begun, 2014; Booth & Booth, 1996; de Jager et al., 2017; Ellem, Wilson, Chui, & Knox, 2008; Garden, 2010; Gubrium, 2009; Gubrium et al., 2014). According to de Jager (2017), “Rather than focussing on representations of colonised or minority groups from the dominant culture, DST [digital storytelling] necessarily involves self-representation—a story ‘from the inside out’” (p. 2550). By using digital

storytelling, the construction and validation of knowledge shifts from the voices of those in positions of power to those of the marginalized. Digital storytelling provides story makers with an opportunity to represent themselves and their realities instead of being represented by someone else who may not accurately convey their needs or their messages. Storytellers are fully engaged in every stage of the process and as such are better able to control the narrative.

Stories of the participants in this study talked about their suffering in relation to unaddressed physical health problems that left some wondering “if the cure is worse than the disease” (P6). Story makers talked about their exclusion from decisions in treatment, exposure to dismissing behaviour, and being left to deal with the side effects of the treatment on their own. They either accepted their situation of having poor physical health because they did not have the power or authority to change it or tried to overcome healthcare approaches by bringing family members as a representative to communicate with their psychiatrists. Nurse participants also believed that relationships between psychiatrists and people who experience mental health issues are permeated with power imbalances. Gøtzsche (2015) emphasized that,

Although psychotropic drugs have many harmful effects, doctors tell their patients very little or nothing about the side effects when they prescribe them, or they say there are no side effects to worry about, which is never true...patient values and preferences are almost totally ignored. Patients and their relatives are rarely listened to, particularly when they complain about drug harms, and patients are subjected to forced treatment with drugs even when they know it will harm them” (p. 223-269)

In addition, in mental healthcare, people with psychotic disorders are often considered as less credible (Potter, 2019). Thus, it is important to create spaces that are emotionally safe from judgement and stigma to help people with mental illness achieve higher control over how they communicate their experiences and how those experiences are interpreted (Potter, 2019). Digital storytelling is known for its inclusive approach that can support safe contributions and power-sharing (Conrad & Sinner, 2015; Gonzales, 2012; Hancox, 2012; Lenette & Boddy, 2013). In

this study, story makers found the process safe for speaking, and they appreciated that they could be anonymous. By showing interest, attending to participants' apprehensions and supporting them throughout the process, they could disclose their concerns and reveal suppressed experiences and emotions. Participants further expressed that the process left them feeling supported, trusting, and experiencing a form of kinship. Nurse participants also felt that through digital storytelling, participants were less vulnerable to negative consequences that they could encounter if they voiced their physical health concerns within constricting and stigmatizing interactions within the psychiatric system. They believed that story makers were able to formulate their thoughts, tailor and amplify their messages, and represent their concerns and problems in a creative way that was meaningful for them. Nurses also felt that story makers were able to voice their needs more openly and authentically in a private and supportive space, outside patient-provider power dynamics.

According to Potter (2020), people with psychotic disorders “mourn the experience of having their credibility repeatedly and violently questioned. They mourn erasure [...] The haunting and the mourning indicate both suppression and expression of what is lost and grieved over when one falls under the psychiatric gaze” (p. 275). In this study, story makers talked about their inability to have their concerns related to their physical health needs addressed because they were repeatedly dismissed or ignored. Story makers believed that their unaddressed physical health concerns resulted in additional burden such as psychological/ emotional (decreased self-esteem and depression), interpersonal (social isolation and conflict with family members), and social problems (loss of home and employment). For example, in his story, Participant 6 reported that weight gain affected his athletic performance and decreased his ability to exercise and pursue competitive sports, leaving him feeling “robbed”. Most story makers attempted to address

their physical health on their own using conventional strategies such as diet, exercise and napping but also through harmful methods such as ingestion of methamphetamines. In addition, while most story makers suffered in silence, they expressed feelings of helplessness, frustration, and resentment towards healthcare providers for ignoring and minimizing his physical health concerns, which were extremely important to them. It is important to acknowledge that epistemic injustice in psychiatry, such as the inability to be heard as participants described in this study, “not only affect[s] agency and freedom” of care recipients but also their “safety, their health, their sense of self, their relational experiences, their material opportunities, body compartments, and their relationships to other groups” (Potter, 2019b, p. 309). The process of digital storytelling was considered empowering because story makers had the opportunity “to control their message” and bring their ideas to light to a broader audience. All story makers considered their digital story a powerful and effective way of delivering their messages. They were not concerned that their voice in the digital story might be ignored or dismissed by the viewers. Participants expressed faith that the digital stories could change providers’ attitudes and considerations regarding their practice and approaches, but some felt less sure how practical and realistic they were.

Story makers found the process of exploring and voicing their thoughts, beliefs and experiences through digital storytelling empowering, awakening, and rewarding, reporting feelings of relief, enlightenment, contribution, and accomplishment. Story makers felt that they were able to express their needs more freely and felt that they were being heard, acknowledged, and respected by the researcher. Nurses also believed that digital stories gave power to the story makers’ side of their story. They compared the digital stories to “mini-Ted talks”, which are meant to be inspiring, meaningful and impactful conversations and stories. Nurse participants also believed

that going through the digital storytelling process and expressing one's innermost feelings, thoughts, beliefs, and experiences could be a form of therapy for patients. This is significant because digital stories may not only help restore epistemic justice but may help reverse some of the psychological damages caused by epistemic violence such as exclusion and censorship.

According to Fricker (2007),

The psychological damage of epistemic violence consists in losing sight of one's sense of self as a knower—especially about one's own experiences. The service-user/survivor may distrust the things she believes or may lose intellectual courage. Such experiences are damaging because they undermine one's very humanity. (p. 44)

Indeed, research on the therapeutic use of digital storytelling has shown beneficial outcomes with different populations across a broad range of issues such as trauma in veterans (Tuval-Maschlack & Patton, 2015), adults (Cohen et al., 2015; Hancox, 2012), and children (Anderson & Wallace, 2015); adolescent sexual health (Gilliam et al., 2012); self harm and stress in adolescent girls (Goodman & Newman, 2014); healthier response to stress in children and adolescents with poor social behaviour (Sawyer & Willis, 2011), disruption of historical trauma with Indigenous communities (Beltrán & Begun, 2014), and stigma experienced by HIV positive youth with negative beliefs about self (Cowan et al., 2013). For example, Willis et al. (2014) who evaluated the process of digital storytelling with 12 youth with HIV positive diagnosis in Zimbabwe reported the process to be therapeutic for participants. Interestingly, digital storytelling has been reported to be therapeutic for both the creator and the viewer of the stories (Sawyer & Willis, 2011; Stenhouse et al., 2013). In Canada Ferrari et al. (2015) used digital storytelling as a knowledge to action tool to transfer the knowledge about the experiences of patients, their families, and healthcare providers in early intervention program for psychosis, wherein digital stories were screened with policy makers and healthcare providers. The process of digital storytelling was then evaluated for its healing potential using a survey. Participants,

which consisted of people with lived experiences of psychosis, their family members, and point-of-care staff reported the process to be therapeutic, promoting reflection, healing, and voicing troubling emotions (Ferrari et al., 2015).

Self-expression, ownership, reflection, sharing and releasing troubling emotions, and connecting with others are by-products of digital storytelling (Hardy & Sumner, 2014). Research shows that participants often find digital storytelling a life-changing experience and describe the process as relieving, cathartic, and empowering (Shea, 2018). Self-reflexive and recursive process of digital storytelling is shown to help participants make important intellectual and personally transformative moves (Benmayor, 2008; Brushwood Rose & Granger, 2013; Burgess et al., 2010; Cunsolo Willox et al., 2013; Wijnen & Wildschut, 2015). Engaging in the process provides opportunities to storytellers to critically reflect and think differently about an emotional experience that has shaped them (Lundby, 2008). For example, researchers using digital storytelling to capture experiences of resilience among single refugee women in Australia found that participants had feelings of well-being, pride, accomplishment, and empowerment because they felt heard and acknowledged (Lenette & Boddy, 2013). Having a coherent digital story is shown to help story makers feel confident to share their concerns without fearing discrimination (Shea, 2018). Story makers in this study were also confident that they would be heard through their digital story, suggesting that policymakers, healthcare providers, and students could watch and engage with this particular medium to better promote patients' participation in the care environment. Therefore, digital stories have the potential to provide forms of knowledge that promote epistemic justice and counteract the damaging effects of silencing people that undermines a person's humanity. As a tool for political action, resistance, and transgression,

digital stories have the power to inform and disrupt dominant approaches to care and knowledge creation.

Digital Stories-Overcoming Subalternity by Establishing a Line of Communication

Spivak initially suggested that to achieve justice, it is not enough to let subaltern people speak because structural practices and dynamics disqualify their voice. She suggested that power structures that exclude members of society and create subalternity must be deconstructed through practices of self-representation and decolonization. Spivak later nuanced her original position, stating: "when a line of communication is established between a member of subaltern groups and the circuits of citizenship or institutionality, the subaltern has been inserted into the long road to hegemony" (Spivak, 1999, p. 310). The change in Spivak's position is important to this research as it suggests a way for subaltern people to have a voice without dismantling established power infrastructures. This nuance suggests subaltern people work with existing power structures and reconfigure power dynamics.

Although digital stories have the potential to influence approaches to care in psychiatry, I am not suggesting them as a tool to dismantle the system because, along with Porter (2015), I believe that "The nature of psychiatry is not fixed. Psychiatry can act as a colonizing force, a force that facilitates subjugation and exploitation. And psychiatry can act as a liberating force that mediates the suffering associated with subjugation and exploitation" (p. 1). I acknowledge that some people with mental distress and have benefited from psychiatric interventions to manage their mental distress and increase their quality of life. One of the story makers in this study talked about benefiting from appropriate psychiatric care. Such care included active listening, respecting her values and preferences and forming common goals of restoring and maintaining all aspects of her health. She described her psychiatrist's approach to care as

collaborative, holistic, comprehensive, patient-centered and as leading to meaningful and relevant solutions. Through equal partnership in decision-making, the healthcare team helped this story maker enhance her mental, physical and psychological health, improve her quality of life and achieve meaningful goals such as running a marathon and becoming a public speaker and advocate.

Recognizing that most mental healthcare providers are well-intentioned and deeply committed to helping their patients, they can be influenced by dominant ideologies, practices, and policies embedded in the psychiatric system that subjugate and subordinate patients' voice, knowledge, and agency. Since we are all fallible knowers and vulnerable to endorsing and/or reproducing harmful practices, those who practice in psychiatry must adopt a critical stance and evaluate and question taken-for-granted practices. Harding (1993) refers to this act as "strong objectivity", by which scientific communities examine their practices, biases, assumptions, and interests, tools, and measures towards care recipients. Keep critical thinkers and practitioners have provided critical analyses of psychiatry, the work aimed at identifying and transforming its oppressive features is ongoing. According to Potter (2015a),

An examination of colonizing forces in psychiatry...is meant to encourage mental health care workers to take seriously some of the problems in the institutions of psychiatry and related fields while, at the same time, to open dialogue, inquiry, and critical reflection. By taking into account critical studies in colonizing practices, people who care for the mental distress and mental health needs of these populations can not only provide better treatment but live out an ethical imperative to not replicate past historical and systemic harms. (p. 1)

Therefore, I suggest that digital stories can help identify areas for change in both the professional, and disciplinary domains of psychiatry and help expose, understand, and challenge entrenched and (in)visible problems. I placed the impacts participants envisioned for digital stories within the broader literature to demonstrate the potential of digital stories for influencing

and potentially disrupting systems of ideologies, practices, and policies upon which psychiatric systems are based.

Digital Stories-Disrupting Dominant Ideologies and Practices

In this study, story makers and nurse participants believed that excluding patients from decisions was due to stigma and beliefs that people with a mental illness have poor insight into their situation. Stigma and prejudice continue to be one of the main barriers to the poor physical health of people with psychotic disorders because they prevent them from receiving integrated, effective, and holistic care (Knaak & Patten, 2016). Research shows that stigmatizing, dismissive, and incompassionate behaviours among healthcare providers compromise the relationship between patients and healthcare providers, creating delays in seeking care and barriers to quality care for physical as well as mental symptoms (Clement et al., 2015; Henderson et al., 2014; Krupa et al., 2009; Leucht et al., 2007). Chadwick et al. (2012) undertook a literature review regarding the perceptions of people with severe mental illness on barriers to accessing physical healthcare came to similar conclusions. Their review of 9 intervention studies identified the following barriers, which are similar to what participants in this study expressed: not being taken seriously; hurried atmosphere; lack of knowledge, education and information about their illness and treatment options; disrespectful and non-caring behaviours on the part of the clinician; misattribution of physical symptoms to their mental illness; lack of follow up; and powerlessness (Chadwick et al., 2012).

Digital stories have been used to challenge stigmatizing beliefs around differences in race, culture, gender, sexual orientation, and physical and mental abilities (Castleden et al., 2013; Luchs & Miller, 2016; Vivienne & Burgess, 2012). For example, *The Re*Vision Centre for Art and Social Justice* in Canada used digital storytelling to help transform stereotypes and advance

social inclusion and health equity through self-representation of people with disabilities (Rice et al., 2015). The centre is an art methodology research hub that Dr. Carla Rice founded in 2012. It investigates the power of art, specifically stories, as an approach to tackle systematic injustice in various sectors, including healthcare. The center provided technological tools and methodologies, including digital storytelling to activists and storytellers (Rice, 2015). Through a CIHR funded project called *Re*Vision*, over 100 digital stories were produced from a wide range of people living with disabilities as well as healthcare providers to help overcome stereotypical perspectives that create barriers to healthcare. According to Rice (2015), "the disability arts movement is an indication that disabled people have agency, are creative, and come together in community, which provides a powerful counter-narrative to the assumption that disabled lives are lives not worth living" (p. 516). As a counter-narrative to the dominant and problematic social beliefs and perceptions of disability, the project aimed for inclusion, justice, and an alternative presentation of difference (Rice et al., 2015).

Digital storytelling has also been used to help create changes in the viewer's attitudes, knowledge, and behaviours. For example, Wexler (2011) used digital storytelling with seven youth to improve Alaskan people's resilience and cultural identity. Youth, elders and adults who watched the stories believed that digital stories provided a helpful advocacy tool as they increased awareness of the needs of youth in the community. They also believed that digital stories could be used as a suicide prevention tool for youth in their community (Wexler, 2011). Wexler et al. (2013) then conducted a larger scale study in which they used digital storytelling to help provide a suicide prevention tool called "Hope kits" to youth living in northwest Alaska (Wexler et al., 2013). In this project, 566 digital stories were created by 432 youth, highlighting

positive aspects of youth's lives by reflecting on important relationships and achievements as well as personal assets and reasons to live (Wexler et al., 2013).

Story makers in this study felt powerless in counteracting stigmatizing beliefs and dismissive behaviours of healthcare providers in relation to their physical health. However, they remained confident that messages in forms of digital stories could have an impact. For example, they considered the embedded messages within a digital story to be a tool for reflecting on and challenging problematic perceptions and attitudes and the stories powerful tools for peer-support and raising public awareness. The potential power of digital stories at challenging stigmatizing beliefs was also evident when some nurse participants acknowledged their misconceptions about the abilities and functionality of people with psychotic disorders. Nurse participants reported that digital storytelling increased their ability to be cognizant of their disrespectful and dismissive feelings and attitudes and challenge their own beliefs and behaviours. In this study, story makers strongly believed there was a need to transform healthcare providers' approaches to care for more holistic, integrated and patient-centered care. They asked to have a voice in their own health needs and wanted their physical health to take higher precedence. Some nurse participants believed that mental health remained the priority in psychiatry and that patients were exposed to exclusion from treatment decisions because healthcare providers were narrowly focussing on their mental illness diagnosis and failing to see the person in the patient. They considered the traditional biomedical model, which focuses on biological processes towards illness and treatment responsible for dismissive behaviours of healthcare providers. The implication that psychotic disorders can only be understood and treated as biological phenomena has been scrutinized as a form of ideology that can subjugate and oppress within psychiatry (Rocca & Anjum, 2020). Biomedical dominance in psychiatry is believed to be an epistemic authority that

delegitimizes other ways of knowing, shifts resources, and reinforces paternalistic practices and policies (Ibrahim & Morrow, 2015). In addition, the rigid application of the biomedical framework leaves no epistemological space for the social context in which mental disease emerges and impacts the lives of particular individuals (Ibrahim & Morrow, 2015). The medicalization of psychiatry and the use of the biomedical model are believed to have ramifications regarding epistemic authority. The biomedical model of care in psychiatry is grounded in a positivist epistemological approach to knowledge that neglects patients' experiences of the illness or the side effects of the treatment (Joseph, 2016). Lewis (2011) noted that when clinicians are open to other explanations (e.g., de-emphasizing the neurochemical explanation of mental illness) such as those experiences through sociopolitical, spiritual, economic factors, they are less likely to exclude patients from decisions and marginalize them in clinical encounters. However, dogmatic emphasis on epistemic authority, in which the person believes they are the only ones who hold valid knowledge, can create a space of oppression and coercion (for example, in the form of forcing patients into treatment) (Lewis, 2011, Deacon, 2013; Porter, 2015).

Victoria (2016) contends that with their esthetic, moral, and personal ways of knowing, digital stories can augment scientific ways of knowing for high quality, safe, and ethical practice. Story makers emphasized that their digital stories had an important message that could be beneficial for all healthcare providers, to help them better see the person in the patient, acknowledge and hear patients' voices, and include them in decision-making. Nurse participants also found that digital stories have all the required and desirable elements to impact beliefs, practices and policies. One of the nurses used the word “attack” to describe the capacity of digital stories to shake viewers to their core. For example, in a quasi-experimental study,

Coleman et al. (2010) used digital stories to assess the effectiveness of digital stories at reducing the prevalence of binge drinking among young people (14-15 years old) living in a relatively deprived and rural area in south Wales in the UK. The intervention was received in three community-based sites, and the fourth site was used as a control site. The first part of the intervention included screening four digital stories of young people discussing the consequences of binge drinking, including physical illnesses, hospitalization after accidents, getting into trouble with law enforcement personnel, and imprisonment (Coleman et al., 2010). After viewing the digital stories, discussion groups were formed and reactions to the stories, including attitude and knowledge, were explored. Self-reported questionnaires examining behavioural changes and predictors of the behaviour change such as attitude and intention were conducted prior, immediately, and six months after completing the stories (Coleman et al., 2010). The study indicated that the intervention increased participants' knowledge about the effect of binge drinking and had a small impact on preventing drunkenness. The effect of the intervention was however short term and did not sustain long-term (Coleman et al., 2010). In another quasi-experimental study, Goodman and Newman (2014) examined the effect of digital and oral storytelling processes on depression, anxiety, stress, and anger among young female adolescents in the U.S. Two groups of female adolescents (n=60) evaluated the intervention using pre and post survey. Participation in digital storytelling was shown to reduce all measures of depression, anxiety, stress, and anger (Goodman & Newman, 2014). Although the impact of digital stories on participants in this study was not evaluated in an intervention, digital stories have been shown to have the potential to disrupt beliefs, values, and practices.

Digital Storytelling- Disrupting Dominant Ways of Knowledge Creation and Education

Spivak (1988) emphasized the importance of deconstructing elitist and authoritarian approaches to knowledge generated mainly from the perspective of the researcher to include the perspective of the researched. As mentioned previously, I decided to conduct this research because there was limited research exploring the physical health needs of people with psychotic disorders. In addition, the few studies that investigated patients' perspectives reported barriers and factors that were not reflected in the weight management strategies, such as social isolation, lack of energy, poverty, side effects of the medications and symptoms of the mental illness (Abed, 2010; Vandyk & Baker, 2012). The literature also shows that the scientific knowledge in identifying, diagnosing, and treating patients in psychiatry is mainly built around the biological factors with low emphasis and research on social factors that influence mental health and incidence and duration of mental illness such as economic equality, acceptable housing, good education, and employment (Handerer et al., 2021; Priebe, 2016). In addition, while the application of genetics and neuroscience research in practice is lacking (diagnoses are based on clinical interviews and not biochemical and neurobiological markers), the neurobiological paradigm itself, a component of the biomedical paradigm, continues to be the most valuable and prominent for knowledge creation, education, research, practice, and policy in psychiatry (Priebe, 2016; Deacon, 2013). In the past two decades, billions of dollars have been allocated to neuroscience research that has put forth various theories suggesting that individuals' "diseased", "abnormal", "peculiar" behaviour have an underlying physiological and, more specifically, brain malfunction which will be ultimately discovered (Deacon, 2013; Handerer et al., 2021; Priebe, 2016). The methodologies used to uncover these brain anomalies consist of randomized control trials in genetics, biochemistry and neuroscience and are not concerned with patients' narratives

(Deacon, 2013; Handerer et al., 2021; Priebe, 2016). According to Frese (2001), the scientific approaches to care, including evidence-based approaches, have excluded patients' experiences and perspectives. By preventing attention to the whole, the dominance of the reductionist approaches continues to subjugate patients' knowledge and expertise in psychiatric discourses (Handerer et al., 2021). Various advocacy movements have accused "psychiatry of colonizing areas of life where medicine does not properly belong" and have criticized the use of biomedical epistemology in education, practice and policy (Porter, 2015, p. 1). The importance of challenging the use of the biomedical model in psychiatry was explained by Porter (2015), who emphasized that:

so far as these critiques fail to challenge mainstream ontological assumptions about the nature of mental disorders, they will fail to address important sources of colonization within psychiatry. The demand that real mental disorders be conceptualized as facts of nature that transcend questions of social interest has a particularly pernicious effect on psychiatry. If these assumptions are not challenged, unjust imbalances of epistemic authority within psychiatry will never be addressed. (p. 1)

Combating authoritarian practices in scientific inquiry requires moving towards and attending to the needs of those who are affected by "scientific" research. Participatory research is believed by numerous scholars to provide the road to emancipation and empowerment and an optimum way to recover and amplify marginalized voices.

Digital stories have the potential to tackle some equity issues arising from epistemic battles and thereby level the epistemic field. Because they encourage critical thinking, moral reasoning, creativity, imagination, debate, reflection, and discussions, Victoria (2016) suggests that digital stories are one of the best ways to create knowledge with marginalized groups and connect students and healthcare providers to care recipients. The use of digital storytelling with healthcare students has been shown to strengthen professional identity and increase their capacity of self-awareness, insight and ethical approach to medical education and practice (Victoria,

2016). Encountering and reflecting on patients' experiences of suffering, pain, and fear often transforms the viewer's perspectives about a given situation (Victoria, 2016). Therefore, through professional development and patient-centered education, digital stories have the potential to transform healthcare to deliver compassionate and humane care (Hardy, 2017). Furthermore, in 2007, the Royal College of Nursing partnered with Patient Voice (an organization conducting workshops since 2003 to help produce and distribute insight from within organizations through digital storytelling) to create an online learning resource of digital stories to improve continence care in-home care. Ten digital stories highlighting the impact of incontinence on patients and their caregivers were produced. The stories provided a greater understanding of the struggles and challenges of patients and their caregivers, which helped bridge the gap between healthcare providers' clinical and empirical knowledge and personal ways of knowing (Victoria, 2016). While stories initially served as a learning resource for professional development, the Royal College of Nursing was motivated to change the following way. Instead of limiting the use of the stories to professional development and education around incontinence, the college was prompted to "develop education around the stories, trying to get people to think about specific situations rather than conditions, treating patients as individuals, rather than treating conditions" (Hardy, 2007, p. 24).

Story makers suggested using digital stories as an educational tool with students, nurses, residents, psychiatrists, supervisors, policymakers, and the general public. As a thought-stimulating tool, digital storytelling helped nurses in this study engage in reflective debates and challenge their thoughts and actions. Some nurses also reported committing to change in attitude and behaviour from that point forward due to watching the digital stories. Nurse participants also considered the stories an effective educational tool for students, clinicians, staff, administrators, and family members. They believed the videos could be used in orientation for new hospital

staff, practicing healthcare providers and undergraduate students. By increasing viewers' understanding and awareness about patients' values, preferences and priorities, digital stories were perceived to help increase knowledge, empathy, and compassion of healthcare providers to see the persons in the patients and include them in decision making. Digital stories have been used for educational purposes as well as for knowledge translation, preserving cultural heritage, participatory approaches, and social advocacy (de Jager et al., 2017). For example, digital storytelling was used as a reflective method with British undergraduate medical students in their final year to deeply reflect on critical moments in their clinical practice (Hardy, 2017). Participants found the process unique and empowering as it enabled them to receive feedback and learn from the team members, stating it provided students with great self-awareness, personal transformation, and a profound understanding of their role as a physician. They reported becoming more aware of themselves and realized the need for more humane and compassionate care in which patients are seen as individuals and not solely as their disease or diagnosis. The process also resulted in change in attitude and behaviours of some of the participants (Hardy, 2017).

A recent systematic review on the use of digital storytelling in health professional's education indicated that studies about learning had been conducted with professionals and students from various disciplines, including medicine, community health workers and health aids, midwives, and social workers; however, most studies focused on the undergraduate level and nursing students (Moreau et al., 2018). Moreau et al. (2018) also reported that some studies used digital storytelling as part of their curriculum/educational program and investigated learning about creating their own digital stories (Cueva et al., 2016; Cueva et al., 2013; Gazarian et al., 2016; Price et al., 2015; Walsh et al., 2010). Examples of studies using digital storytelling for

teaching purposes included a wide range of topics such as palliative care concept (Price et al., 2015), patient support and advocacy with nursing students (Gazarian et al., 2016), issues around oppression and diversity in society with social workers (Walsh et al., 2010), and provision of cancer care with community health workers (Cueva et al., 2016; Cueva et al., 2013). All studies showed that digital storytelling had a positive impact on the learning of healthcare providers through self-reflection. The review indicated that only a few studies had investigated the use of digital storytelling on healthcare providers' learning and changes in behaviour. For example, in two different studies, Cueva et al. (2013, 2016) used digital storytelling as a cancer educational course with community healthcare workers in Indigenous communities. Participants created digital stories related to smoking cessation, screening, survivorship, end-of-life care, and self-care. The study found that the digital storytelling process increased self-care practices among participants and the community they served, including healthy dietary intake, increased physical activity, and increased screening exams (Cueva et al., 2016; Cueva et al., 2013).

Digital Stories-Disrupting the Development of Policies and Reforms

Spivak (1988) questions how patriarchal and colonizing systems and politics, with their various forms of oppression and marginalization that work together to determine subalterns' position in a society's hierarchy, can allow subalterns to speak and be heard. This questioning is critically relevant to the present study in light of gaps in the healthcare system that nurse participants identified. Nurse participants suggested that healthcare professionals enter the profession to help but fall into a restrictive system that forces them to follow protocols and priorities grounded in binary views of illness and wellness. According to Jacob (2016), “Places of discipline where power, discourses, practices, and space come to be aligned in the regulation of individual and group behavior” influence emotions, behaviours, and understanding of self and

others (p. 153). Healthcare providers working as individual agents usually become “instances, nodes, or switch-points in the operation of an anonymous apparatus” (Holmes & Murray, 2014, p. 36). While they work toward meeting the institution’s specific objectives, they are forced to incorporate practices whose ethical, legitimacy and effectiveness they question (Holmes & Murray, 2014). Counter-discourses put forward can become the target of attack, and individuals can encounter negative consequences and reprimand for criticizing established practices (Caplan, 2014). For example, the founder of the Critical Psychiatry Network, Dr. Duncan Double, was suspended as a psychiatrist working in mainstream psychiatry for not agreeing with all aspects of care and practicing differently (e.g., by using less medication and being less concerned with formal diagnoses). Therefore, by expecting compliance with rules and regulations, the system becomes more rigid and more difficult to disrupt because a culture of compliance is established. Care providers can also be unaware of their own participation in promoting repressive care structures, especially in an environment where interrogating values and assumptions, challenging social structures, exposing injustice, and engaging in social action is prohibited or severely punished (Jacob et al., 2016) and even more so when dominant practices are believed to be in the best interest of the patient, evidence-based and ethical. Suggestions for a need to restructure or rethink practices could be considered as undermining “essential” and “evidence-based care”. Therefore, providers can perpetuate oppressive practices and inequities when complying with institutional policies and procedures.

Nurses discussed how certain “priorities” and “goals” that reflect disciplinary “agendas” are enforced through organizational context culture, resources, education, and budget and practices, protocols, checklists, quality measure and guidelines. For example, nurses claimed that only a few resources are dedicated to the physical health of people with mental illness in

psychiatric organizations, and when cutbacks in expenditures occur, those resources become the first target. By dedicating most of an organization's resources and budget to addressing mental health symptoms, the system effectively redirects healthcare providers' priorities for care towards psychiatric symptoms. Providing care through medical directives, protocols and guidelines, and measuring quality through checklists geared towards patients' mental illness further reinforces mental health priority. Therefore, healthcare providers come to understand that by focusing on patients' mental health problems, prescribing medication as a first line of treatment, and teaching patients how to comply with their medical regimen, they are providing therapeutic, appropriate, and high-quality care. Concerns that do not reflect those institutional priorities come to be understood as less important. This may explain why nurses in this study considered physical concerns (e.g., obesity, weight gain, fatigue, joint pain and their associated consequences) as "non-acute" and "not a priority" and can also help explain research that demonstrates a 15-to-25-year mortality gap resulting from poor physical health compared to persons who do not have mental health issues (Collins et al., 2012, Kisely et al. 2007). Therefore, by deciding on what counts as a problem worthy of time and resources, the system maintains persistent inequities in physical health care for people with mental health issues (Masters et al., 2016). According to Drake et al. (2001), mental health services should go beyond outcomes of compliance to treatment and rehospitalization to include factors of value and importance to care recipients such as social relationship, employment, independence, and quality of life.

In addition, by only focusing on the mental health aspect of care, institutions are reconfiguring healthcare providers' understanding of what good care is. Healthcare providers might conclude that privileging mental symptoms means providing optimum care but that any deviation from this thinking is reprehensible (Bernheim, 2016). For example, one of the senior

managers called herself “a rebel” after suggesting, “we’re full human beings, and if you can’t see that, you should maybe take up another profession. I think we need as nurses to advocate for our patients that go before this kind of treatment” (Senior manager, 2). Viewing herself as a “rebel” reflects that holistic perspectives are something outside the norm and deviate from current clinical practice. Embodying this view in psychiatry may put one in a precarious position in care settings that claim to provide holistic and patient-centered care. Disconnecting mental health from physical health as reflected by lack of integration of services and funding can also lead to healthcare providers dichotomizing health, positioning physical and mental health as an either/or situation. As a result, patients’ and healthcare providers’ goals may seem antithetical, as suggested by one of the nurses in this study, highlighting the difficulty they had in appreciating what is important to patients compared to what is important to providers.

Story makers believed digital stories have the potential to influence and create change. They considered digital stories being exposed to policymakers a more effective approach for changing practices, a view that reflects an understanding of care settings as top-down organizations. Nurse participants also believed it to be essential to target leaders and policymakers who decide on the budget, programs, and initiatives to create and reinforce systemic change. By engaging the viewers emotionally, digital stories were considered a tool for presenting concerns as a priority. They believed that stories had been readily used to change certain laws in the past, and therefore digital stories could be used the same way to change current practices and policies in psychiatry. One of the nurse participants referred to Clare’s Law, established after Clare Wood was murdered by a former domestic partner, who was known to police for being dangerous. The change in the law allowed public members, including a partner, to request information from police about potential abusers. Nurses suggested presenting

the stories at board meetings to help increase awareness and promote systemic and organizational change. The literature indicates that stories have provided opportunities for conversations between decision-makers and laypeople that were not otherwise possible through traditional research engagement (Baden & Wimpenny, 2014; Cox et al., 2014). Digital stories have helped voices of marginalized and vulnerable people to be heard in policy and decision-making (Booth & Booth, 1996; Ellem et al., 2008; Garden, 2010). For example, Walsh et al. (2009) used digital storytelling to engage Canadian homeless women in community-based research to explore how the target group understands the notion of 'home' and help practitioners and policymakers better address their needs (Walsh et al., 2009). In response to the study's findings, The Calgary Committee to End Homelessness collaborated with the participants and established a 10-year plan at the municipal level and with corporate and service agencies to end homelessness in the city (Walsh et al., 2009).

In the UK, digital stories were also used to improve mental health services, which rated low for satisfaction with dignity and respect. In the cities of Manchester, Bolton, Salford and Trafford, a care Trust providing mental health services to people who live with mental health issues formed a 5-year collaboration with Patient Voices to hear the voices and experiences of the persons they were serving (Cahoon, Haigh, & Sumner, 2018). Nearly five years later, 11 digital storytelling workshops were conducted to create digital stories with service users and care providers about their experiences of care. Stories were used at every board meeting and during recruitment interviews to recruit those who met the organizations' mission and vision. They also served for education and training, raising awareness about mental health issues in the community, decision making at the board level, clinical practice to help understand care quality from patients' perspectives (Cahoon et al., 2018). This project transformed the operations of this

organization by increasing awareness of patients' and healthcare providers' preferences and priorities. Digital storytelling helped identify poor practices and plan for improvements. The project was reported to result in improved care, reduced claims of clinical negligence and complaints, increased patients' and caregivers' satisfaction and involvement with the Trust activities and increased savings (Cahoon et al., 2018). This experience lends further support to digital stories' potential to disrupt and change exclusionary, stigmatizing and ineffective policies in mental health services and that policymakers and decision-makers constitute appropriate and effective consumers of these stories.

Nurses' Ambivalence with Political Agency

We have seen thus far how using digital stories as a tool for resistance and political action in education, practice, and policy shows promising results. However, we need to be cautious when proposing digital stories as an approach for disrupting beliefs, practices and policies in the mental care system because it implies that patients must build digital stories and accept that these will be screened and disseminated. Suggesting that the system might change as long as patients produce stories and accept being exposed through them revealing sensitive information about themselves, assumes that patients must be ready to take on the responsibility for this change and shoulder much of the burden and risks it entails, which perpetuates inequity. In this research, story makers were acutely aware of the risks brought on by their disadvantaged position in the care structure. In particular, they expressed fear of offending care providers and experiencing repercussions. The risk of stigma was also a persistent concern for participants. This led them to simultaneously advocate for broader dissemination of digital stories in the public sphere and the restriction of disseminating their own story. Dissemination entails exposure and risk of stigma, which made some participants feel unsafe. Participants, therefore, suggested a need to be

strategic in how, if at all, their story should be shared, a deliberation that could lead to both establishment of boundaries regarding acceptable use of one's story and self-censorship as a risk management strategy. Therefore, we need to be mindful of the very real harms that can result from forcing a "power position" on patients in a system expressly built around making patients overly visible as a target of interventions. The pervasive and profound effect of the system has socialized them to a state of defeat and excluded and discredited identity (Holmes & Murray, 2014).

Spivak indicated that we are responsible to "work for the bloody subaltern...against subalternity" (De Kock, 1992, p. 46). She emphasized that it is not enough to let the subalterns speak from their position of subalternity and that we challenge and change structural power that excludes voices of subaltern and creates subalterns (Chakravorty, 1999). In re-establishing epistemic justice, the responsibility and burden of building and disseminating stories should not rest solely on care recipients in a mental health care structure that remains monolithic and difficult to change. Actors within this structure, such as care providers and administrators, should not wait passively to be convinced that changes are indeed needed. Therefore, we need influencing actors such as nurses to be part of that change process to acknowledge, accept, appreciate and integrate this new form of evidence into their practice. According to Jacobs (2016),

Reform is not in the interests of the major players in the mental health industry. This means that reform can only be brought about by persistent pressure, threat, and disruption from below, i.e., from the vast majority of mental health professionals who are not psychiatrists and who presumably do not have a vested interest in medical dominance of the mental health industry. (p. 295)

Nevertheless, the findings of this study show that several assumptions and contradictions were embedded in how nurse participants viewed possibilities for change and who change leaders

should be. They perceived various groups of actors within care organizations as homogenous. They suggested targeting the next generation of healthcare providers to foster greater change (i.e., students were deemed more flexible, receptive, and accepting of new ideas). Nurse participants also presumed that newcomers in nursing programs were more “naturally” geared toward social justice and activism and were ready to fight. They assumed that new graduate nurses would be immune to the problems that make current nurses unable to effect change, such as lack of time, resources, and heavy patient load. Finally, they also implied that current healthcare providers were not “patient-centered” while removing themselves from this category of workers, despite practicing at the time of data collection. Nurse participants also called for more holistic and patient-centered care while suggesting that structures that make the system non-holistic and non-patient-centered remain intact. The literature also shows that the majority of nurses fail to challenge policies and structures that affect the health and well-being of patients and do not participate in policies that impact safety, quality, affordability and accessibility of care (Safari et al., 2020; Shariff, 2014; Turale & Kunaviktikul, 2019). Nursing's lack of involvement in politics is believed to be caused by lack of knowledge, repression, and the need to uphold a trusting image (Des Jardin, 2001; Shariff, 2014; Turale & Kunaviktikul, 2019). Historically, nurses did not have the autonomy or power to make decisions since they were believed to have no knowledge of their own (Turale & Kunaviktikul, 2019). Behaviours such as self-sacrifice and submissiveness were praised, and any conflict or deviation was severely punished (Turale & Kunaviktikul, 2019). Thereby, lack of self-esteem became a well-accepted characteristic of nurses. Bent (1993) argues that, as a result, this type of system and education produced nurses who “fail to believe in their own judgement, their own worth, or their own ideas” (p. 298). The only acceptable position for nurses was to subsume their needs and desires

under that of patients. As Perron (2013) explains: “This particular attitude of self-negation (which continues today) has been linked with a conscious will to reject all forms of desire and ambition, except those that correspond to patients' own needs and aspirations” (Perron, 2013, p. 156). Despite the phenomenal professional growth and the astonishing achievements in advancing the practice of nursing, this profession continues to struggle for recognition, autonomy and leadership due to difficulty in engaging with involvement in political action (Bent, 1993; Perron, 2013).

In addition, some nurse participants did not envision that digital stories could bring systemic change, and instead shifted their applicability to the level of individual nurses, while also acknowledging that current challenges in care setting made it very challenging for point of care nurses to enact such changes on their own volition. Interestingly, nurse participants casted nurses as a safer channel to go through for change and advocacy compared to psychiatrists. Yet, at the same time, most nurse participants suggested that nurses were dominated by the “system” and unable to change institutional priorities. Several participants endorsed the widespread idea that nurses are the strongest patient advocate without questioning its accuracy. In this study, nurse participants suggested that nurses are more open and accepting of digital stories as evidence “because nurses listen more” (MHN, 3) and considered nurses to be in the best position to advocate for patients to create change. Such idea deserves critical scrutiny, as it has been suggested that nurses often do not have their own voice in relation to professional concerns (Perron, 2013). The literature also shows that while nurses are touted as the backbone of the health care system and best advocate for patients, they continue to work long hours in an increasingly difficult work environment and often with lack of resources despite clear evidence of negative impacts on patient care and safety (Garcia et al., 2019). They continue to experience

high rates of emotional exhaustion, absenteeism and burnout and feeling of ineffectiveness, detachment, cynicism, and low productivity (Garcia et al., 2019). In addition, nurses face many ethical dilemmas caused by unchallenged policies that are implemented by those who do not necessarily take into consideration nursing knowledge and theory (Fyffe, 2009; Sharif, 2014).

In addition, nurse participants called for changes in funding schemes and organizational culture to address stigma, tokenism and lack of true patient-centered care. Some believed creating more evidence in this area would be an indispensable step towards change. On the other hand, they also acknowledged that significant evidence already exists about the importance of patient inclusion and patient voice in the literature and that such evidence was acknowledged and accepted by clinical experts, researchers and policymakers. Suggesting a need for additional research to build on the already available evidence for change represents a simple stance that overlooks the fact that despite the significant amount of evidence already available, changes are not occurring as they should, and there is little reason to believe that additional evidence would change that.

In lieu of face-to-face communication and in-person meetings, nurses in this study suggested using digital stories as a method of communication with healthcare providers to challenge physician-patient power dynamics and help alleviate or overcome fear or anxieties associated with directly talking to psychiatrists. Some nurses also suggested that patients should enter the psychiatric system with a digital story as a way of communicating needs and expectations. While suggesting to replace patient and healthcare providers' interaction with a digital story speaks to the powerful effect of digital stories, it can also show the extent to which voices of patients in interactions with healthcare providers are unheard or silenced. Nurses did not seem aware of some of the risks identified by story makers about sharing their stories with

their immediate healthcare team, especially psychiatrists. In nurse participants' narratives, the psychiatric system emerged as an inevitable point of passage for these patients. And while their propositions seemed to focus specifically on patients' voluntary interactions with mental health services, they did not touch on contexts where overt coercive dynamics are at play (e.g., involuntary admission) that already reflect epistemic injustice.

Interestingly, findings in this study reveal that leaders and point-of-care nurses did not take ownership for change. The paradox of separating and distancing themselves from the process of change and resting it on the shoulder of others in the healthcare system reveals the power of psychiatry in creating a culture of disengagement extending to healthcare providers. During focus groups, nurses and nursing leaders distanced themselves from the harms reported in digital stories as well as the problems they identified in their workplace, such as stigma, lack of resources to address physical health needs, etc. Though they proposed solutions fit for the current system, they did not challenge the structure of the system itself. For example, nurses believed that integrating stories as a form of evidence would require buy-in from leaders and practitioners. They also believed that change should come from the higher levels of their organization, such as executive boards for hospitals and community health centers, in keeping with existing hierarchical structures. While they suggested presenting the stories at board meetings to help increase awareness and create change, they did not question existing structures such as the board itself, funding schemes, hierarchies, or the influence of select groups of individuals removed from patients' experiences, such as psychiatrists, policymakers, and executives. In other words, rather than viewing digital stories as tools to challenge hierarchies of power, they suggested fitting the digital stories in the current system in a way that would leave power dynamics intact. Spivak (1988) emphasized that structures and power dynamics that silence subalterns need to be

challenged. All nurses in this study also confirmed that digital stories constitute a form of evidence. Through this authoritative positioning, nurse participants challenged the institutionalized “conventions” for identifying and implementing “best evidence” and decided that digital stories constitute a form of evidence on their own assessment of the stakes. However, their decisive discursive move contrasts the research realm because “what counts as evidence” is not decided by consensus or even nurses but “identified experts” who are deemed to have the credibility and rigour to make these authoritative calls.

Findings of this research also reflect that nurse participants did not conceive of themselves as responsible for changing practices or policies that they perceived as restrictive or oppressive. They considered digital stories a powerful tool for empowerment, tailoring and controlling messages, hearing patients’ perspectives, and changing practices and policies. However, they did not position nurses or themselves as authoritative actors within that system to be part of the change process and embrace and integrate digital stories as a form of evidence into their practices and their own workplaces. Instead, they moved the discussion in relation to change processes outside their personal responsibility and control, a discursive move that may undermine their political agency. Nurse participants were concerned with the over-reliance on quantitative approaches to care, lack of resources for addressing physical health concerns of patients, exclusion of patients from decisions, and lack of freedom of choice for patients about pharmacological treatment, despite documented harms. At the same time, they also considered current healthcare providers powerless in making changes because they need to fit into the system and comply with and conform to its processes and priorities. This requires a deeper examination of the disconnect that may exist between their understandings of their political role within the nursing profession and within care organizations more broadly. Therefore, while much

of this thesis turned a critical gaze onto the use of digital stories in disrupting psychiatric practices or policies, it also offers an opportunity to focus on nurses' knowledge of and engagement with political action that can support such action.

In this study, nurses, some holding leadership positions, were not taking ownership of change, which significantly contrasts from dominant discourses of leadership and advocacy change in nursing. According to McMillan (2018), "Political agency is understood as nurses' recognition that they are entangled within a complex web of power and politics, and they have a responsibility to choose how such political discourse will shape their practice" (p.281). The Canadian Nurses Association (2018) defined advocacy as "exercising your voice...speaking out against inequity and inequality...participating directly and indirectly in political processes and acknowledging the importance of evidence, power and politics in advancing policy options". A few years later, the Canadian Nurses Association (2021) further emphasized that leadership in nursing requires that nurses use critical thinking, expanding the boundaries of their practice, addressing social justice and broad determinants of health and services that cause disparities:

Nursing is a practice discipline and it is a political act. Nursing leadership is about critical thinking, action and advocacy-and it happens in all roles and domains of nursing practice...nursing leadership is about helping nurses lift their practice so they see nursing not solely as a series of acts of scientific caring that can change individual lives but also as a lifelong commitment to political action for system change. (p. 1)

The social mandate of nursing is to foster social justice, uncover inequalities, and give voice to subjugated voices by examining systems and structures that exert a discriminatory and oppressive power (Kirkham & Anderson, 2002). This includes a critical examination of dominant discourses that exclude patients' voices from informing research, practice and policy (Kirkham & Anderson, 2002). If nursing integrates oppressive principles (e.g., ignoring care recipients' requests or values, excluding them from decisions about their care) into its agenda

without questioning them, it becomes part of existing oppressive processes (Holmes et al., 2008b). Nurses need to identify and challenge ideologies and conditions that serve organizational interest but affect nursing's knowledge and practices (Mill et al., 2001). According to McMurray et al. (2010), “in organizations the ethical subject is always a political subject” (p. 541). Nevertheless, nurses usually struggle to enact political agency in places with complex relations of power (McMillan & Perron, 2020). They often envision political action in the realm of citizen life and outside the workplace instead of being embedded within and central to nursing practice (Perron, 2013). They also continue to be uncomfortable discussing politics and remain invisible in policy development and political action (Perron, 2013; Perron et al., 2014). Invisibility and lack of involvement of nurses in health policy have contributed to the challenges faced by nurses and patients today (Adams & Nelson, 2009).

Nurses should learn not to carry the burden and shortcomings of the healthcare system. They can accomplish that by becoming visible and involved in political actions that affect their working conditions and their patients (Turale & Kunaviktikul, 2019). As Fyffe (2009) explains, “addressing the challenges requires an increased nursing contribution and influence in healthcare policy across clinical, management, research and educational areas” (p. 699). If nurses want the implemented policies to reflect their needs and values, they must participate and develop and shape those policies (Fyffe, 2009). Nursing needs knowledge of political action to fulfill its ethical obligation of advocating for the public and improving the quality of care, maximizing its potential and overcoming some of the challenges that the profession is currently facing while also advancing as a discipline (Shariff, 2014). Nurses are accountable and responsible for advocating for themselves and their clients and supporting their profession's goals related to the population's health. However, voices of advocacy must be powered by political knowledge.

Hence, it is crucial to acquire the required understanding of political action to participate in policymaking processes to influence change (Safari et al., 2020).

Implication for Nursing

Exposing and disrupting power relations that marginalize certain groups at every level of the health system is essential to help bring forth disempowered voices. Through epistemic injustice, practices of knowledge production continue to marginalize and exclude the voices of people with psychotic disorders (Byskov, 2020). Questioning the continued exclusion of experiential knowledge of people with psychotic disorders that profoundly impacts their health and longevity through “critical research is not only illuminating but potentially empowering.” (Mercer, 2014, p. 264). As Campbell and Bunting (1991) explain:

if one's epistemology involves belief that the purpose of knowledge is to release the individual from domination (emancipate) and further autonomy and responsibility, as is the case in critical theory, then one exposes hidden power imbalances and enlighten agents about how they ought rationally to act to realize their own best interest. (p.5)

The issue of epistemic injustice emerges in all spheres of nursing practice. Representation of people in clinical practice, education, policy and research is a way of maintaining and advancing discourses to confine authority to a particular discipline, profession, and form of knowledge (Joseph, 2016). Spivak (1988) emphasized that subalterns cannot speak because those in power exclude them from conversations and speak for them. Representation often occurs within the discourses of hegemonic power, which serves the dominant classes in society has prevented subalterns from voicing their concerns (Spivak, 1988). Expertise and knowledge of people with psychotic disorders are often disregarded as irrelevant through academic knowledge and organizational practices and policies (Joseph, 2016). Epistemic injustice remains the least analyzed aspect in psychiatry; therefore, understanding the harmful effect of epistemic injustice

on people with psychotic disorders and offering alternatives can make a difference in resisting the reproduction of oppressive practices (Potter, 2015b).

Research

Overcoming subalternity means combating authoritarian practices in scientific inquiry and moving research, practices, education and policy to serve community interests (Lewis, 2011). This is important, especially because medical research, practices, and policies in psychiatry have been accused of following the interest of pharmaceutical companies (Porter, 2015). Research can be a means to amplify voices, needs and interests of marginalized, oppressed and disfranchised communities and has been viewed as part of a process of emancipation. People with psychotic disorders have an important yet neglected role in challenging unjust imbalances of epistemic authority (Sutherland, 2017). In 2005, the WHO identified the poor physical health of people with mental illness as a serious international problem needing attention. A decade and a half later, the problem remains a global concern in need of urgent action. Yet, there is limited literature exploring the perspectives of people with psychotic disorders about their physical health. It is unclear how this problem can be addressed if the voices of those most affected by care (or lack thereof) are excluded. Therefore, it is essential to examine dominant discourses that continue to marginalize the voices of people with psychotic disorders in light of the 15 to 25 years mortality gap caused by physical health conditions, namely cardiovascular diseases, diabetes, and cancer. In this project, the construction of knowledge originated from the standpoint of care recipients, who are usually overlooked as passive consumers of “evidence-based knowledge” in the forms of guidelines and protocols (Holmes et al., 2008; Gøtzsche, 2015; Whitaker, 2016). Therefore, more research is required to help bring voices of people with psychotic disorders forward and challenge and disrupt power

structures that exclude their experiential knowledge about their physical health in practices and policies.

It is imperative to reiterate the importance of nursing research that focuses on people with psychotic disorders as participants because they are marginalized in many aspects of contemporary health care. Moreover, engaging in ways that allow a more accurate representation of the complexities in people's lives is crucial. In this research, I found that story makers considered that sharing their experiences with others was highly anxiety-provoking, even if they have similar experiences or problems. Fear of public speaking and judgment can create barriers to disclosing personal experiences in group sessions. On the other hand, individual interviews may lack the element of trust-building with the researcher that marginalized people require to express their concerns without fear. In addition, co-developing knowledge with marginalized people requires making space for and understanding all realities, including those that differ from the norms and expectations determined within hegemonic social structures and discourses (Caxaj, 2015). Therefore, more research using participatory approaches and art-based methodologies with people with psychotic disorders is required. Through the use of emancipatory approaches such as digital storytelling, researchers can promote epistemic justice and examine and challenge the status quo. As discussed throughout this chapter, digital storytelling can help marginalized groups find and articulate their voice by providing them with an opportunity to present stories that meaningfully depict their experiences (Gubrium, 2009). Having their stories heard and acknowledged as a legitimate form of knowledge helps shift the balance of power from researcher to storyteller/participant; this, in turn, creates trust and creativity to find solutions to complex problems (Gubrium, 2009). The nature of digital storytelling provides a commitment from researchers to hear and understand the voices of

marginalized people. The process of digital storytelling can create a safe and supportive space, establish a trusting relationship, promote confidence, and decrease anxiety and fear. It can also empower participants to reflect on their experiences and represent themselves in a powerful and compelling way through a process that allows ownership and self-determination of their narrative. This process is flexible and can be tailored to participants' schedules and needs. This research showed that using digital storytelling was a powerful process for capturing the voices of story makers. Since there is limited research using digital storytelling with people with psychotic disorders, such approach constitutes a fertile and promising area of nursing research. The process provided a powerful means for engaging with participants and understanding the complexities of their lived experiences and needs. I also recommend conducting research that use digital stories as an intervention in practice and evaluate the outcome.

Practice

The findings of this study have several implications for the clinical practice of healthcare providers. Digital stories enabled story makers to voice their experiences about their physical health concerns and needs and identify and challenge stigmatizing attitudes, behaviours, and practices among healthcare providers. Stories showed story makers' struggles resulting from clinicians emphasizing biopharmaceutical interventions to manage their mental illness. Reflecting on the digital stories helped nurses expose barriers to hearing patients' voices, including stigma, power dynamics between patients and healthcare providers, lack of time and resources to address physical concerns, quantifying performances in psychiatry and lack of integration between physical and mental health services. Nurse participants in this study cast all these problems as falling outside of their responsibility. For example, while some evoked nurses' role in advocating for a different management of patients' pharmacological regimen (e.g.,

requesting that medication dosage be lowered or that other measures such as psychotherapy be used), they continued to speak as though it is up to “others” in the healthcare system to address this problem. Nurses need to explore options and help patients make informed choices; this is standard practice for all nurses, including psychiatric nurses (Canadian Federation of Mental Health Nursing [CFMHN], 2014). Nurses should create an empowering environment, identify personal biases, and advocate for patients and “for continuous improvement to the organizational/systemic structures consistent with the principles of safe, ethical, and competent care” (CFMHN, 2014, pp. 11-12). The *Canadian Standards for Psychiatric-Mental Health Nursing* (2014) encouraged nurses to ensure client needs remain the focus of their therapeutic relationship (CFMHN, 2014). It mandated nurses to act as clients’ advisors and collaborate with other healthcare members to discuss and address client preferences (CFMHN, 2014). Based on the findings of this study, nurses need to be more involved in informing care recipients of the side effects of antipsychotic medications. Research establishing the harmful side effects of antipsychotic medications, including morbidity and mortality, is widespread (Harrow & Jobe, 2018; Harrow et al., 2017; Moncrieff, 2013; Muench & Hamer, 2010; Peluso et al., 2012; Reist et al., 2007; Schneider et al., 2005; Whitaker, 2016). Even recommendations of the *Canadian Guideline for the Pharmacotherapy of Adults with Schizophrenia Spectrum* (Canadian Psychiatric Association, 2017) allude to harmful side effects of the medications. The guideline instructs practitioners to provide regular monitoring to assess the side effects and patients’ responses. Medical professionals are also encouraged to keep the pharmacological treatment simple (once a day), the dosage within the normal range, and not using more than one antipsychotic medication at a time. Interestingly, the findings of this study suggest that most participants’ psychiatrists did not abide to directions based on the guideline. Thus, nurses have

the ethical obligation of non-maleficence to advocate on patients' behalf to ensure care recipients are aware of the side effects of the medications. They are obliged to help address care recipients' concerns, including those related to the side effects of the pharmacological treatment. Nurses should also challenge psychiatric polypharmacy, prescription of two or more psychiatric medications concurrently, and prescription of high dosages of medications. Nurses need to advocate for alternative approaches to mental health such as cognitive behavioural therapy and psychotherapy and for resources to address the needs and concerns of people with psychotic disorders for holistic and patient-centered care.

The findings of this study emphasize that nursing practices need to promote actions that consider a care recipient as a whole person with mental, physical, spiritual, social and emotional needs. The practice of nurses cannot rely on one epistemological position of post-positivism ("how much" and "how many") to answer complex practical problems. Nurse participants in this study cautioned that using quantitative measures leads healthcare providers to overlook or misunderstand patients' needs and concerns and therefore implement interventions that are "missing the point". To act with moral agency and provide effective, humane, and compassionate care, nurses need access to various types of knowledge and knowing in their practice (Tanlaka et al., 2019). Nurses will not be able to practice ethically only by assuming medical and technical techniques. Based on the findings of this study, I suggest that nurses integrate care recipients' experiences as a form of evidence to inform their day-to-day practices. This study suggests that nurses listen attentively to care recipients' experiences as the most powerful way of empowering patients and overcoming oppression in psychiatry (Brody, 2014).

Stigma and dismissive behaviours were reported to be the main barrier to addressing physical health concerns of people with psychotic disorders. Nurses need to practice reflexively

by shifting the focus inward and reflecting on personal and professional values, beliefs, attitudes and feelings about people with psychotic disorders and how these perspectives impact their nursing practice. Engaging with a mentor or using online tools can help identify personal biases and stigmatizing beliefs and attitudes towards people with mental illness (Shahwan et al., 2020). On an interpersonal level, nurses need to critically evaluate how they relate to care recipients and vice versa and can ask for feedback from care recipients or a trusted colleague (Horrill et al., 2021). To help establish trusting, collaborative, respectful relationships and provide a safe space where people with psychotic disorders can voice their concerns, nurses should use active listening, focus on care recipients' strength, engage in a non-judgmental way and share power by involving them in decision making related to all aspects of their care (Horrill et al., 2021). Nurses must also support efforts to identify racism and other types of discrimination and implement appropriate interventions to address stigma and discrimination at mental health organizations. At the structural level, nurses need to consider how the context is shaping the experiences of people with psychotic disorders. Nurses must engage with care recipients' life to identify and disrupt any structural inequities that silence or dismiss their experiences and voices. This includes forming a committee within the workplace, revisiting policies, participating in protests, and partnering with organizations outside the workplace (Horrill et al., 2021). In addition, the approach that was used in the UK to improve mental health services with digital storytelling shows promising results for practice and policy changes (Cahoon et al., 2018). Findings of this study confirmed the benefits of digital storytelling for bringing care recipients' voices of people with psychotic disorders forward and engaging the viewers in discussion and reflection. Therefore, to help disrupt oppressive and exclusionary ideologies, practices and policies in psychiatry, nurses are encouraged to advocate for similar approaches in Canadian

mental health institutions to help promote epistemic justice and design interventions around care recipients' perspectives, needs and preferences.

Education

Spivak raises several compelling issues surrounding the politics of who can speak and in what ways. The issues of whose experiences, perspective, and knowledge are privileged in light of unequal distribution of sociopolitical, economic and cultural power is important. According to Medina (2013), "In a situation of oppression, epistemic relations are screwed up" (p. 27). Empowered groups can challenge the constriction of knowledge, practice, policies and education. The aim is to highlight the possibilities and limitations of subaltern agency. In this study, nurses believed that changing the educational system for health professions (medicine in particular) to acknowledge and incorporate other ways of knowing was essential in deconstructing the system. Postcolonial scholars have critiqued Western knowledge production, mainly representing subjects under scrutiny to sustain hegemonic governance. Accordingly, Spivak (2004) has moved from the earlier notion of "unlearning of privilege" to "learning to learn from below", which more accurately speaks to the need to abandon "convictions of triumphalist superiority" (p. 551). Excluding marginalized experiences in academic knowledge production has also been critiqued by the Survivor movement, the Mad movement, the Recovery movement, the Antipsychiatry movement, as well as advocates who promote Indigenous, disability, feminist and queer perspectives. Crisis in representing people with psychotic disorders demands challenging approaches and means by which "knowledge" and "truth" are produced by authoritative voices (Voronka, 2016). One resolution to this crisis is to incorporate subjugated lived experiences of people with psychotic disorders to "pluralize authenticity, voice, and truth claims." (Voronka, 2016, p. 191). Knowledge production about marginalized persons should

come from those with lived experience of the topic under study, which requires a shift from *speaking for* to *speaking from* experience.

Changing health professionals' educational system to acknowledge and incorporate other ways of knowing was identified as an essential action in deconstructing the mental health system. The educational system needs to reinforce the subjective experiences of care recipients as a form of evidence. Nurses require complex knowledge to help them connect with care recipients and explore and address their concerns. I suggest incorporating digital stories in nursing undergraduate curricula as a form of evidence and teaching about digital stories in research courses. Digital stories can help students focus on what best reflects the perspectives, values, and mission of nursing. For example, digital stories can help shift the emphasis from natural sciences to human sciences, which considers human beings a complex whole. They can help students reflect on the meaning of life experiences and factors that shape those experiences, such as history, politics, social structures, gender, and culture. Digital stories can help students focus on providing high-quality and more holistic nursing care that preserves people's dignity and manifests empathy. Nurse educators can use digital stories to facilitate students' understanding of different circumstances of care recipients' lives and reflect on social determinants of health and unjust conditions that lead to health problems. Therefore, I suggest incorporating digital stories in students' assessment, treatment, and plans for recovery and challenging students to reflect on the content of stories in relation to the broader context of psychiatry. Engaging in reflective education and thinking can help students challenge existing policies and practices that cause inequity, dehumanization and silencing of people with psychotic disorders. To help raise students' awareness about harmful practices of psychiatry and encourage reflexivity, they need to learn about the history of psychiatry and various movements of

resistance such as the Mad movement and Antipsychiatry movement, in addition to the Recovery movement.

Nurses in this study distanced themselves from the process of change and advocacy. Nursing education and curriculums have failed to prepare nurses for a social-political role, especially in developing their roles as patient advocates (Turale & Kunaviktikul, 2019). Safari et al. (2020) argue that such a shortcoming exists because nursing curricula have failed to recognize the importance of health policy for a long time. Individuals' attitude is correlated to their involvement in politics. During their basic training, nurses need to be educated about the stereotypes, roots of oppression, and the historical effect on nursing's attitudes towards politics. This will emphasize nurse graduates' autonomy, decrease the negative image of politics and increase self-esteem to shape professionals who are able to uphold the integrity of the professional codes of nursing practice by becoming politically active (Safari et al., 2020; Turale & Kunaviktikul, 2019). Current and future nurses need to recognize their current abilities and strength and use their resources to bring change (Safari et al., 2020; Turale & Kunaviktikul, 2019). This can be done by empowering student nurses to realize the socio-political complexity of the health care system and learn to gain political skills and competencies to negotiate and positively influence the health care system (Safari et al., 2020; Turale & Kunaviktikul, 2019). Creating spaces that are emotionally safe and free of judgment is essential to help students nurses critically reflect on their own beliefs and behaviours as well as structural barriers, including socio-economic, political and institutional (Horrill et al., 2021). Other knowledge that nurses need to acquire to effectively engage and influence the political decisions that affect health care is regarding the financing of the healthcare services (Myrick, 2005). Turale and Kunaviktikul (2019) suggest that policy courses that identify and address these goals be implemented at the

baccalaureate level to prepare nursing students for careers in health policy and management and raise their awareness of political action processes. Some of the objectives that need to be addressed in these policy courses are the contemporary process of health policymaking along with broad political dynamics that have conditioned the country's past and present health policy. In addition, they should explore the institutional and economic complexity of the country's health care system and its mental health system and the interactions between stakeholders in health financing and other organizations. Students should be encouraged to analyze the current challenges and dilemmas that healthcare providers and policymakers face and look at the cultural and ideological underpinning of the modern concept of health (Fyffe, 2009). In addition to learning about political actions, nursing students need to be mentored by political figures to gain expertise because experience can spark an interest in political actions and increase confidence and competency. Professional organizations need to raise awareness, provide the opportunity for learning about politics and facilitate mentoring to enable current nurses to be involved in political action (Safari et al., 2020; Turale & Kunaviktikul, 2019). Knowledge about political action in nursing can then be used to examine current issues affecting nursing to advocate for change of the existing political and legal structures.

Administration and Policy

Spivak's theory suggests focusing upstream on structures of subjugation and discursive hegemony that produce subalternity in the first place. When applied to excluding knowledge and voices of people with psychotic disorders in psychiatry, the first task is to turn an analytic lens on psychiatry itself and the possibilities of elevating the narratives of people with psychotic disorders (Karmen, 2020). Spivak argues that those with subaltern status have no voice or power in society because they are systematically denied the opportunity to represent themselves in

political systems or public debates. To overcome these limitations, patients' expertise should become the starting point for services and care. This is important when working with people vulnerable to stigmatization, oppression, and marginalization. By outlining healthcare professionals' roles and responsibilities, orientation of services and programs, direction of funding and research, the system is very powerful in setting the norms and expectations not just towards patients but also healthcare providers. This raises the question of what hopes patients can have in being heard, especially when they express realities and thoughts that do not fit psychiatry's dominant discourses.

Care practices in psychiatry were also described as being governed by methods that favour quantitative approaches in forms of standard tools and checklists that did not reflect the complexity of patients' embodied experiences. Collecting and communicating care through standardized tools, with marginal space for patients' stories was believed by nurse participants to have created a gap in communication and understanding at an interpersonal (patients and healthcare providers) and organizational level (quality measure and distribution of budget and other resources). Luchins (2012) warned about collecting and communicating care and quality through quantitative tools. According to Luchins (2012), quantitative tools for quality improvement were adopted in the healthcare system from industries that tried to improve their manufacturing. Using quantitative tools in healthcare risks conflating specific clinical outcomes with quality care and what is measured with what is valued. Many argue that establishing objective performance measures to improve health care systems contradicts the original purpose of providing quality care because improved clinical outcomes do not necessarily mean high-quality care and patient satisfaction (Angell, 2011; Luchins, 2012; Migone, 2017). According to Mazzotta (2016), policies that rely on and promote quantified approaches to care can be harmful

to healthcare providers, especially nurses, because it restricts their autonomy, creativity, critical reasoning, understanding, compassion, and ability to provide quality care. Preoccupation with technical interventions, medical directives and technical skills can diminish nursing interaction and connection with patients (Mazzotta, 2016). Eliminating subjective assessments and enforcing checklists and quantitative measures means patients are structurally and discursively relegated to the margins. By silencing and dismissing patients' experiences and perspectives (in this case, physical health concerns), the available evidence for developing practice, policy and research can be skewed. Therefore, those in power remain in control of representation and deciding on what is relevant and important for practice, policies, resources, and research (Potter, 2020, p. 6).

Digital stories are powerful tools for change at the individual, community, and policy levels. By creating an opportunity for dialogue and exposing disadvantages encountered by people with mental illness as a result of systematic discrimination, digital stories can potentially help expose and challenge circumstances, services, practices, and policies that are not inclusive and empowering. Policy development strategies should include positioning patients' experiences, subjectivity, and sense of agency at every level of care. Digital stories create opportunities for engaging care recipients in knowledge creation and can be a powerful dissemination tool to inform policymakers about patients' needs and concerns. According to Hardy & Sumner (2014), digital stories can help "move away from an outdated system towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement" (p. 229). While this research was exploratory, I suggest conducting more research to investigate the impact of digital stories on changing practices and policies that exclude the voices of people with psychotic disorders related to their physical health or other concerns.

Limitations and Suggestions

Being the primary researcher, I led the data collection and analysis. I facilitated the sessions and helped story makers construct their stories (brainstorm their ideas, select the most concerning issue, write and record their narratives, and add audiovisuals). Being personally involved in all stages of research can be considered an ethical dilemma because researchers can influence the processes and findings of the research (Clancy, 2013; Doody & Noonan, 2013). I used “mindfulness” as a recommended method during data analysis to help deepen self-reflexivity and ensure ethical outcomes. According to Nagata (2003), the "quality of qualitative research is fundamentally determined by the quality of the consciousness of the researcher" (p.33). Since minds produce thoughts spontaneously, mindfulness requires relating differently to the thoughts and sensations that arise. With mindfulness, I redirected my attention to the present moment and observed automatic thoughts and emotions without engaging with them. Instead of explaining, solving, and dwelling on thoughts and emotions, I observed, identified, acknowledged, and allowed them to pass (Shapiro et al., 2005). In other words, being in a state of mindfulness helped me detach from thoughts and emotions that arose in my mind in the present moment to keep non-judgemental awareness (O’Leary et al., 2016). Reflective journaling throughout the study and discussions and debates with academic supervisors helped me recognize the ongoing engagement with my experiences as a mental health nurse. I was also honest and transparent with all the participants about my previous role as a mental health nurse and the evolution of my doctoral research, including my epistemological stance within the critical social paradigm.

One methodological decision that can constitute both a limitation and a strength was analyzing the story narratives. Initially, I had no intention to analyze the content of the stories

because the process of digital storytelling itself was of interest to this research. However, analysis of the narratives was undertaken when one theme (not being heard) became a common finding across all stories. Analysis of the narratives enabled me to present the content of the stories in this dissertation. This was important because limited literature exploring the perspectives of people with psychotic disorders inspired this research. Furthermore, ignoring the content of the stories symbolically perpetuated the problem of not paying attention to patients' voices. Analysis of the narratives allowed me to expose and critique power structures that marginalize voices of people with psychotic disorders not only in research but in practice and policy. However, providing an analysis of the stories instead of presenting the digital stories themselves takes away the powerful effects of the audiovisuals discussed in this dissertation. Since this was an exploratory study, I aimed to provide as much privacy and confidentiality as possible; however, my plan for future research is to ask for permission to publish digital stories as part of my findings.

Another decision that may constitute a limitation is that physical health concerns were the topic of interest in this study. Therefore, voices of those who had concerns about other aspects of their life were not captured in this research. The reason for selecting this topic was discussed in more detail in the background chapter. However, story makers in this research suggested providing opportunities for other topics such as social stigma, peer support and mental health and well-being. People with psychotic disorders readily engaged in the processes of digital storytelling in this research; therefore, I recommend providing more opportunities for people with psychotic disorders to bring their voices (experiences, knowledge, concerns, and needs) forward, regardless of the topic. Finally, all digital story viewers were nurses. Having psychiatrists and other healthcare professionals reflect on the stories could have provided more

information about the differences between nurses' political agency compared to other healthcare professionals and differences between how they perceive the impact of digital stories in disrupting ideologies, practices and policies that subjugate voices of people with psychotic disorders.

There are a few factors to take into consideration when using digital storytelling as a research methodology to bring voices of people with psychotic disorders forward into research processes. Not all individuals, particularly those from marginalized groups, are able to readily engage because of systemic and societal barriers such as stigma and discrimination that condition participants to exclusion, compliance and invisibility, and therefore prevent authentic participation (Beltrán & Begun, 2014). People with psychotic disorders often feel vulnerable to criticism, judgment, degrading responses, and negative consequences for disclosing and sharing personal experiences and opinions. For example, one of the participants in this research explained that she was mistreated by law enforcement personnel for reporting suicidal ideation. Digital storytelling requires a commitment to attending several sessions, which can be a drawback for participation. Researchers must address the unique trust, safety, comfort, and confidentiality concerns of people with psychotic disorders when engaging them in research. In this research, the sessions were conducted at a location that they found to be convenient and comfortable. As a researcher, I had no direct or indirect power over their medical treatment. Story makers had the opportunity to stay anonymous and take the time they needed to prepare and deliver their messages through a relatively safe medium, all of which helped decrease their fear and anxieties related to the project. Story makers in this study emphasized the importance of recruiting participants who are in the process of recovery since active symptoms create a barrier to participation. Weekly sessions were considered appropriate as one participant considered

longer or consecutive sessions a risk for relapse or withdrawal from the project. Should recruitment be facilitated by another person (e.g., research assistant or coordinator), storytelling can be easily confused with videotaping, which can feel especially threatening to participants. Introducing the project through safe channels (social workers, in groups) could create a sense of trust and increase recruitment. Conducting this research, I realized that I had to be more proactive in my recruitment strategy (presenting the study at different organizations). Story makers explained that the symptoms of their mental illness and the side effects of the medication could sometimes create a barrier to participation. Therefore, adapting to participants' realities is an indispensable step to redress injustice and convey meaningful engagement. It is essential to acknowledge that as a researcher from an academic setting, you are also part of systems that create/sustain epistemic injustices and cannot escape the power dynamics with care recipients/participants. It is critical for researchers to reflect and act on those power dynamics and their role in sustaining and benefiting from them.

Concluding Remarks

Spivak's theory of subalternity provides a critical and theoretical approach to understanding legacies of colonizing strategies that go beyond land usurpation and imposition of laws and policies on the colonized. In common understanding, colonizers dominated and subjugated people's bodies, minds, language, social norms, religious practices, and identity. Since psychiatry has the potential to "facilitates subjugation and exploitation" (Porter, 2015, p. 1), Spivak's postcolonial theory was helpful to understand, analyze, and interrogate discourses, representations, and knowledge production that continue to colonize ways of knowing, thinking, positioning, and dominating the inferior Others (Spivak, 1988). Using Spivak's theory in this thesis, I interrogated the subjugation of ontologies, epistemes, subjectivity, agency, power, and

knowledge of people with psychotic disorders. According to Kamens (2020), postcolonial theories are relevant to the study of the way patients' experiences are silenced because they "have emerged precisely in response to legacies of violence and appropriation, and they constitute explicit attempts to level these histories by recovering and elevating the voices of the oppressed" (p. 253).

Limited literature exploring the physical health needs of people with psychotic disorders inspired this research. I strove to explore the process of digital storytelling with this population as a means of recognizing and amplifying their voice and understand how nurses and healthcare leaders engage with the digital stories. The content of the stories revealed participants' struggles regarding current approaches to care to manage their mental illness. Participants revealed their physical health concerns and their negative effect on self and their relationships with society more broadly. Discussions with story makers revealed that the behaviours and approaches of healthcare providers in psychiatry were more concerning because they contributed to further physical, psychological, social, and personal harm. While participants had to make critical decisions about the anonymity and content of their stories, having the opportunity to voice their emotions and concerns, reconnect with self, and reflect on their problem provided them with feelings of accomplishment, well-being and fulfillment. Digital stories provided an opportunity for reflection on the content and format of the stories for the viewers.

I strongly suggest that digital storytelling is a powerful multisensory approach to allow people with psychotic disorders to represent themselves and poignantly communicate their experiences, knowledge and needs into inclusive and meaningful research processes. Having successfully used the approach of digital storytelling in this research, I speak from a place of experience to the various advantages of this collaborative approach. Findings from my research

can assist researchers and practitioners in considering the power of digital storytelling as a process and digital stories as an end product in facilitating understanding, navigating experiences, and uncovering issues that would otherwise remain buried. Identifying solutions that represent the context of people's lives and disseminating research findings in creative and inclusive ways can make a powerful contribution to knowledge and support the successful implementation and sustainability of the findings.

Postcolonial theory in general and Spivak's theory more specifically drew the parallel between systems of power (colonization and patriarchal system) that silence the subaltern in the context of colonization and people with mental illness in the context of psychiatry. Retracing the historical roots of the psychiatric system suggested similar processes of subjugation and oppression, which are embedded in the dogma of supremacy and justification of domination (rescue and spread of civilization). In this research, Spivak's theory exposed how a system that is built around those whose mental illness subverts their thinking, logic, credibility, continues to operate around discredited identities of patients and the paradoxical place of their body that is valued in some respects (disturbed brain biochemicals) and dismiss another respect (disturbed biochemical in other organs as a result of medical intervention). Spivak's theory of subalternity provided the theoretical basis for a critical analysis of the experiences of the story makers in relation to their physical health concerns and needs and exposed and challenging factors that result in marginalization, discrimination and oppression of people with psychotic disorders in clinical encounter and broader mental health work. The theory also helped address the voicelessness and silencing of people with psychiatric disorders in psychiatric discourses, practices, and policies. In addition, Spivak's theory helped highlight the thematic centrality of

epistemic violence and the role of the digital stories in overcoming epistemic injustice and opening a line of communication with those in the position of power in psychiatry.

References

- Abbey, S., Charbonneau, M., Tranulis, C., Moss, P., Baici, W., Dabby, L., . . . Paré, M. (2011). Stigma and discrimination. *Canadian Journal of Psychiatry*, 56(10), 1-9.
- Abbinnett, R. (2003). *Culture and identity: critical theories*. Sage.
- Abed, H. (2010). What factors affect the lifestyle choices of people with schizophrenia? *Mental Health Review Journal*, 15(2), 21-27.
- Abu El-Haj, N. (2005). Edward Said and the political present. *American Ethnologist*, 32(4), 538-555.
- Adams, V., & Nelson, J. A. (2009). The economics of nursing: Articulating care. *Feminist Economics*, 15(4), 3-29.
- Aho, K. (2008). Medicalizing mental health: A phenomenological alternative. *Journal of Medical Humanities*, 29, 243–259. doi:10. 1007/s10912-008-9065-1
- Albee, G. W. (2002). *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill* Whitaker, R (2002) Perseus Publishing, Cambridge, In: Wiley Online Library.
- Allen, J., Balfour, R., Bell, R., & Marmot, M. (2014). Social determinants of mental health. *International Review of Psychiatry*, 26(4), 392-407.
- Allison, D. B., & Casey, D. E. (2001). Antipsychotic-induced weight gain: a review of the literature. *The Journal of clinical psychiatry*.
- Alvesson, M., & Deetz, S. (2000). *Doing critical management research*. London: Sage Publications.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders (4th ed.)*: American Psychiatric Publishing, Inc.

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*: American Psychiatric Pub
- Anderson, J., Perry, J., Blue, C., Browne, A., Henderson, A., Khan, K. B., . . . Smye, V. (2003). “Rewriting” cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science*, 26(3), 196-214.
- Anderson, K., & Wallace, B. (2015). Digital storytelling as a trauma narrative intervention for children exposed to domestic violence. *Film and video-based therapy*, 95-107.
- Angell, M. (2011). The epidemic of mental illness: Why. *The New York Review of Books*, 58(11), 20-22.
- Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica*, 108(4), 304-309.
- Annamalai, A., Kosir, U., & Tek, C. (2017). Prevalence of obesity and diabetes in care recipients with schizophrenia. *World J Diabetes*, 8(8), 390-396. doi:10.4239/wjd.v8.i8.390
- Anthony, W., Rogers, E. S., & Farkas, M. (2003). Research on evidence-based practices: Future directions in an era of recovery. *Community mental health journal*, 39(2), 101-114.
- Antonio, R. J. (1981). Immanent critique as the core of critical theory: Its origins and developments in Hegel, Marx and contemporary thought. *British Journal of Sociology*, 330-345.
- Arboleda-Flórez, J., & Stuart, H. (2012). From sin to science: fighting the stigmatization of mental illnesses. *The Canadian Journal of Psychiatry*, 57(8), 457-463.
- Ashcroft, B., & Ahluwalia, P. (2008). *Edward said*: Routledge.

- Ashcroft, B., Griffiths, G., & Tiffin, H. (1998). *Key concepts in post-colonial studies*: Psychology Press.
- Ashcroft, B., Griffiths, G., & Tiffin, H. (2013). *Post-colonial studies: The key concepts*: routledge.
- Ashworth, M., Schofield, P., & Das-Munshi, J. (2017). Physical health in severe mental illness. *British Journal of General Practice*, 67(663), 436-437. doi:10.3399/bjgp17X692621
- Astier, I. (2007). *Les nouvelles règles du social*. Paris: PUF.
- Aukst-Margetic, B., Jaksic, N., Boricevic Marsanic, V., & Jakovljevic, M. (2014). Harm avoidance moderates the relationship between internalized stigma and depressive symptoms in patients with schizophrenia. *Psychiatry Research*, 219(1), 92-94.
- Baden, M. S., & Wimpenny, K. (2014). *A practical guide to arts-related research*: Springer.
- Banks, M., & Zeitlyn, D. (2015). *Visual methods in social research*: Sage.
- Barker, C. (2000). *Cultural studies: Theory and practice*. Londone, England: Sage.
- Barone, T., & Eisner, E.W. (2012). *Arts-based research*. London: Sage.
- Barker, F., Hulme, P. & Iversen, M. (1996). *Colonial discourse/postcolonial theory*. New York: Manchester University Press.
- Barney, K. (1994). Limitations of the critique of the medical model. *The Journal of mind and behavior*, 19-34.
- Bass, A. (2008). *Side effects: A prosecutor, a whistleblower, and a bestselling antidepressant on trial*: Algonquin Books.
- Bauer-Staeb, C., Jörgensen, L., Lewis, G., Dalman, C., Osborn, D. P., & Hayes, J. F. (2017). Prevalence and risk factors for HIV, hepatitis B, and hepatitis C in people with severe mental illness: a total population study of Sweden. *The Lancet Psychiatry*, 4(9), 685-693.

- Becker, T., & Hux, J. (2011). Risk of acute complications of diabetes among people with schizophrenia in Ontario, Canada. *Diabetes care*, 34(2), 398-402.
- Beebe, L. H., & Harris, R. F. (2013). Description of physical activity in outcare recipients with schizophrenia spectrum disorders. *Int J Ment Health Nurs*, 22(5), 430-436.
doi:10.1111/inm.12008
- Behmer, S. (2005). *Literature review digital storytelling: Examining the process with middle school students*. Paper presented at the Society for Information Technology & teacher education international conference.
- Beltrán, R., & Begun, S. (2014). 'It is Medicine' Narratives of Healing from the Aotearoa Digital Storytelling as Indigenous Media Project (ADSIMP). *Psychology and Developing Societies*, 26(2), 155-179.
- Benmayor, R. (2008). Digital storytelling as a signature pedagogy for the new humanities. *Arts and Humanities in Higher Education*, 7(2), 188-204.
- Bent, K. N. (1993). Perspectives on critical and feminist theory in developing nursing praxis. *Journal of Professional nursing*, 9(5), 296-303.
- Ben-Moshe, N. (2019). The internal morality of medicine: a constructivist approach. *Synthese*, 196(11), 4449-4467.
- Bernheim, E. (2016). The 'rhetoric of rights' in mental health: Between equality, responsibility and solidarity. *Power and the Psychiatric Apparatus: Repression, Transformation and Assistance*, Abingdon, Oxon: Routledge, 47-60.
- Bergqvist, A. (2020). Narrative understanding, value, and diagnosis: A particularist account of clinical formulations and shared decision-making in mental health. *Philosophy, Psychiatry, & Psychology*, 27(2), 149-167.

- Beverley, J. (1999). *Subalternity and representation: Arguments in cultural theory*. London: Duke University Press.
- Bickford, D. (2014). Postcolonial theory, nursing knowledge, and the development of emancipatory knowing. *ANS Adv Nurs Sci*, 37(3), 213-223.
doi:10.1097/ANS.0000000000000033
- Blackford, J. (2003). Cultural frameworks of nursing practice: exposing an exclusionary healthcare culture. *Nursing Inquiry*, 10(4), 236-244.
- Bland, R. C., & Parker, J. H. (1978). Prognosis in schizophrenia: prognostic predictors and outcome. *Archives of General Psychiatry*, 35(1), 72-77.
- Bhabha, H. (1994). The postcolonial and the postmodern. *The location of culture*, 171-197.
- Boydell, K. M., Solimine, C., & Siona, S. (2015). Visual embodiment of psychosis: ethical concerns in performing difficult experiences. *Visual Methodologies*, 3(2), 43-52.
- Booth, T., & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society*, 11(1), 55-70.
- Breggin, P. R. (2012). *Psychiatric drug withdrawal: A guide for prescribers, therapists, patients and their families*. Springer Publishing Company.
- Bracken, P., Thomas, P., Timimi, S., Asen, E., Behr, G., Beuster, C., Bhunnoo, S., Browne, I., Chhina, N., & Double, D. (2012). Psychiatry beyond the current paradigm. *The British journal of psychiatry*, 201(6), 430-434.
- Brody, H. (2014). Stories and the biopsychosocial model. *Philosophy, Psychiatry, & Psychology*, 21(3), 191-193.
- Brown, S., Birtwistle, J., Roe, L., & Thompson, C. (1999). The unhealthy lifestyle of people with schizophrenia. *Psychological medicine*, 29(3), 697-701.

- Browne, A. J. (2001). The influence of liberal political ideology on nursing science. *Nursing Inquiry*, 8(2), 118-129.
- Browne, A. J., Smye, V. L., & Varcoe, C. (2005). The relevance of postcolonial theoretical perspectives to research in Aboriginal health. *Canadian Journal of Nursing Research Archive*, 37(4).
- Brummans, B. H. (2014). Pathways to mindful qualitative organizational communication research. *Management Communication Quarterly*, 28(3), 440-447.
- Brushwood Rose, C., & Granger, C. A. (2013). Unexpected self-expression and the limits of narrative inquiry: exploring unconscious dynamics in a community-based digital storytelling workshop. *International Journal of Qualitative Studies in Education*, 26(2), 216-237. doi:10.1080/09518398.2012.666286
- Bowden, P., & Mummery, J. (2014). *Understanding feminism*. Routledge.
- Buchowski, M. (2006). The specter of orientalism in Europe: From exotic other to stigmatized brother. *Anthropological Quarterly*, 79(3), 463-482.
- Burgess, J., Klaebe, H., & McWilliam, K. (2010). Mediatisation and Institutions of Public Memory: Digital Storytelling and the Apology. *Australian Historical Studies*, 41(2), 149-165. doi:10.1080/10314611003716861
- Byskov, M. F. (2020). What Makes Epistemic Injustice an “Injustice”? *Journal of Social Philosophy*.
- Cahoon, P., Haigh, C., & Sumner, T. (2018). Working with Dignity and Respect: Improving Mental Health Services with Digital Stories *Cultivating Compassion* (pp. 127-139): Springer.

- Calton, T., Ferriter, M., Huband, N., & Spandler, H. (2008). A systematic review of the Soteria paradigm for the treatment of people diagnosed with schizophrenia. *Schizophrenia Bulletin*, 34(1), 181-192.
- Campbell, J. C., & Bunting, S. (1991). Voices and paradigms: perspectives on critical and feminist theory in nursing. *Advances in Nursing Science*, 13(3), 1-15.
- Canadian Federation of Mental Health Nursing. (2014). *Canadian Standards for Psychiatric-Mental Health Nursing*. <https://live-cfmhn.pantheonsite.io/wp-content/uploads/2019/05/2014-Standards-of-Practice-Final.pdf>
- Canadian Institute for Health Information (2017). *Regulated Nurses, 2016*. https://secure.cihi.ca/free_products/regulated-nurses-2016-report-en-web.pdf
- Canadian Mental Health Association. (2020a). Stigma and Discrimination. <https://ontario.cmha.ca/documents/stigma-and-discrimination/>
- Canadian Mental health Association. (2007). *Poverty and mental illness*. https://ontario.cmha.ca/wp-content/uploads/2007/11/cmha_ont_poverty_backgrounder_112007.pdf
- Canadian Mental Health Association. (2020b). *Unemployment, mental health and substance use*. <https://cmha.bc.ca/documents/unemployment-mental-health-and-substance-use/>
- Canadian Mental Health Association. (2020c). *Poverty and Mental*
- Canadian Nurses Association (2018). Policy and Advocacy. <https://www.cna-aiic.ca/en/policy-advocacy>
- Canadian Nurses Association. (2021). Statement Position: Nursing Leadership. https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/nursing-leadership_position-statement.pdf

- Canadian Psychiatric Association (CPA). (2005). *Clinical Practice Guidelines: Treatment of Schizophrenia; III. Pharmacotherapy*. http://www1.cpa-apc.org/French_Site/Publications/Clinical_Guidelines/schizophrenia/november2005/cjp-cpg-suppl1-05-pharmacotherapy.pdf).
- Canadian Psychiatric Association (2017). Guidelines for the Pharmacotherapy of Schizophrenia in Adults. *Can J Psychiatry*, 62(9), 604-616. doi:10.1177/0706743717720448
- Canales, M.K. (2000). Othering: Toward an understanding of difference. *Advances in Nursing Science*, 22(4), 16–31.
- Caplan, P. J. (2014). When you try to speak truth to power: What happens if the powerful turn off their hearing aids. *Power and the psychiatric apparatus: Repression, transformation and assistance*, 165-181.
- Carl, J. J. C. (2006). Disrupting Preconceptions: Postcolonialism and Education.
- Carney, C. P., Jones, L., & Woolson, R. F. (2006). Medical comorbidity in women and men with schizophrenia: a population-based controlled study. *Journal of general internal medicine*, 21(11), 1133-1137.
- Carey, M. A. (1994). The group effect in focus groups: Planning, implementing, and interpreting focus group research. *Critical issues in qualitative research methods*, 225, 41.
- Carolan, M. (2003). Reflexivity: a personal journey during data collection. *Nurse Researcher*, 10(3), 7.
- Cartwright, C., Gibson, K., Read, J., Cowan, O., & Dehar, T. (2016). Long-term antidepressant use: patient perspectives of benefits and adverse effects. *Patient preference and adherence*, 10, 1401.

- Cashmore, E. (1996). (3rd ed.). *Dictionary of race and ethnic relations*. London, England: Routledge
- Castleden, H., Daley, K., Sloan Morgan, V., & Sylvestre, P. (2013). Settlers unsettled: Using field schools and digital stories to transform geographies of ignorance about Indigenous peoples in Canada. *Journal of Geography in Higher Education*, 37(4), 487-499.
- Caxaj, C. S. (2015). Indigenous Storytelling and Participatory Action Research: Allies Toward Decolonization? Reflections From the Peoples' International Health Tribunal. *Glob Qual Nurs Res*, 2, 2333393615580764. doi:10.1177/2333393615580764
- Chadwick, A., Street, C., McAndrew, S., & Deacon, M. (2012). Minding our own bodies: Reviewing the literature regarding the perceptions of service users diagnosed with serious mental illness on barriers to accessing physical health care. *International Journal of Mental Health Nursing*, 21(3), 211-219.
- Chiesa, A., & Serretti, A. (2009). Mindfulness-based stress reduction for stress management in healthy people: a review and meta-analysis. *The journal of alternative and complementary medicine*, 15(5), 593-600.
- Chien, W. T., Leung, S. F., Yeung, F. K., & Wong, W. K. (2013). Current approaches to treatments for schizophrenia spectrum disorders, part II: psychosocial interventions and patient-focused perspectives in psychiatric care. *Neuropsychiatr Dis Treat*, 9, 1463-1481. doi:10.2147/ndt.s49263
- Chulach, T., & Gagnon, M. (2016). Working in a 'third space': a closer look at the hybridity, identity and agency of nurse practitioners. *Nursing Inquiry*, 23(1), 52-63. doi:10.1111/nin.12105

- Church, K. (1997). Business (not quite) as usual: Psychiatric survivors and community economic development in Ontario. *Community economic development: In search of empowerment*, 254, 48.
- Chwastiak, L. A., Rosenheck, R. A., McEvoy, J. P., Stroup, T. S., Swartz, M. S., Davis, S. M., & Lieberman, J. A. (2009). The impact of obesity on health care costs among persons with schizophrenia. *General hospital psychiatry*, 31(1), 1-7.
- Clancy, M. (2013). Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse researcher*, 20(6).
- Clarke, D. E., Dusome, D., & Hughes, L. (2007). Emergency department from the mental health client's perspective. *Int J Ment Health Nurs*, 16(2), 126-131. doi:10.1111/j.1447-0349.2007.00455.x
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., . . . Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychol Med*, 45(1), 11-27. doi:10.1017/s0033291714000129
- Corrigan, P. W., Edwards, A. B., Green, A., Diwan, S. L., & Penn, D. L. (2001). Prejudice, social distance, and familiarity with mental illness. *Schizophr Bull*, 27(2), 219-225.
- Corrigan, P. W., & Watson, A. C. (2007). The stigma of psychiatric disorders and the gender, ethnicity, and education of the perceiver. *Community Mental Health Journal*, 43(5), 439-458.
- Cohen, M., Kahn, D., & Steeves, R. (2000). Phenomenological research: A practical guide for nurse researchers. In: Thousand Oaks, CA: Sage Publications, Inc.

- Cohen, L., Manion, L., & Morrison, K. (2007). *Research methods in education (6th ed.)*. London: Routledge.
- Cooper, S. J., Reynolds, G. P., ;, W. e. c.-a., Barnes, T., England, E., Haddad, P., . . . Osborn, D. (2016). BAP guidelines on the management of weight gain, metabolic disturbances and cardiovascular risk associated with psychosis and antipsychotic drug treatment. *Journal of psychopharmacology*, 30(8), 717-748.
- Cope, D. G. (2014). *Methods and meanings: credibility and trustworthiness of qualitative research*. Paper presented at the Oncology nursing forum.
- Correll, C. U., Solmi, M., Veronese, N., Bortolato, B., Rosson, S., Santonastaso, P., . . . Collantoni, E. (2017). Prevalence, incidence and mortality from cardiovascular disease in care recipients with pooled and specific severe mental illness: a large-scale meta-analysis of 3,211,768 care recipients and 113,383,368 controls. *World Psychiatry*, 16(2), 163-180.
- Cox, S. Drew, S. Guillemin, M. Howell, C. Warr, D. and Waycott, J. (2014) Guidelines for Ethical Visual Research Methods. Retrieved from http://artshealthnetwork.ca/ahnc/ethical_visual_research_methods-web.pdf
- Collins, E., Tranter, S., & Irvine, F. (2012). The physical health of the seriously mentally ill: an overview of the literature. *Journal of Psychiatric and Mental Health Nursing*, 19(7), 638-646. doi:10.1111/j.1365-2850.2011.01831.x
- Conrad, D., & Sinner, A. (2015). *Creating together: Participatory, community-based, and collaborative arts practices and scholarship across Canada*: Wilfrid Laurier Univ. Press.
- Correll, C. U., Druss, B. G., Lombardo, I., O'Gorman, C., Harnett, J. P., Sanders, K. N., Alvir, J. M., & Cuffel, B. J. (2010). Findings of a US national cardiometabolic screening program among 10,084 psychiatric outpatients. *Psychiatric Services*, 61(9), 892-898.

- Cohen, J. L., Johnson, J. L., & Orr, P. (2015). *Video and filmmaking as psychotherapy: Research and practice*. Routledge.
- Coleman, L., Ramm, J., & Cooke, R. (2010). The effectiveness of an innovative intervention aimed at reducing binge drinking among young people: results from a pilot study. *Drugs: Education, Prevention and Policy*, 17(4), 413-430.
- Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research*, 15(1), 129-138.
- Cowan, F., Willis, N., Miller, A., Mavhu, W., & Frewin, L. (2013). " My Story"-HIV positive adolescents tell their story through film. *Children and Youth Services Review*, 45, 129-136.
- Crehan K. (2002). *Gramsci, culture and anthropology*. Berkeley, Los Angeles: University of California Press.
- Crowe, M. (2000). Constructing normality: a discourse analysis of the DSM-IV. *J Psychiatr Ment Health Nursing*, 7(1), 69-77.
- Crowe, M. (2006). Psychiatric diagnosis: Some implications for mental health nursing care. *Journal of Advanced Nursing*, 53, 125–131. doi:10.1111/j.1365-2648.2006.03691.x
- Cueva, M., Kuhnley, R., Revels, L. J., Cueva, K., Dignan, M., & Lanier, A. P. (2013). Bridging storytelling traditions with digital technology. *International Journal of Circumpolar Health*, 72(1), 20717.
- Cueva, M., Kuhnley, R., Lanier, A., Dignan, M., Revels, L., Schoenberg, N. E., & Cueva, K. (2016). Promoting culturally respectful cancer education through digital storytelling. *International journal of indigenous health*, 11(1), 34.

- Cunsolo Willox, A., Harper, S. L., Edge, V. L., Storytelling, M. W., Lab, D. M., & Government, R. I. C. (2013). Storytelling in a digital age: digital storytelling as an emerging narrative method for preserving and promoting indigenous oral wisdom. *Qualitative Research*, 13(2), 127-147.
- Cutcliffe, J. R., & Riahi, S. (2014). Twenty-First-Century" Snake Oil" Salesmanship: Contemporary Care of the Suicidal Person in Formal Mental Health Care.
- Czernichow, S., Mennen, L., Bertrais, S., Preziosi, P., Hercberg, S., & Oppert, J. (2002). Relationships between changes in weight and changes in cardiovascular risk factors in middle-aged French subjects: effect of dieting. *International journal of obesity*, 26(8), 1138.
- Czyzewski, K. (2011). Colonialism as a broader social determinant of health. *International Indigenous Policy Journal*, 2(1).
- Davidson, L., Drake, R. E., Schmutte, T., Dinzeo, T., & Andres-Hyman, R. (2009). Oil and water or oil and vinegar? Evidence-based medicine meets recovery. *Community mental health journal*, 45(5), 323-332.
- De Hert, M., Falissard, B., Mauri, M., Shaw, K., & Wetterling, T. (2008). P. 3. c. 071 Epidemiological study for the evaluation of metabolic disorders in care recipients with schizophrenia: The METEOR Study. *European Neuropsychopharmacology*, 18, S444-S445.
- De Hert, M., Correll, C. U., Bobes, J., Cetkovich-Bakmas, M., Cohen, D., Asai, I., . . . Leucht, S. (2011a). Physical illness in care recipients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. *World Psychiatry*, 10(1), 52-77.

- De Hert, M., Hudyana, H., Dockx, L., Bernagie, C., Sweers, K., Tack, J., . . . Peuskens, J. (2011b). Second-generation antipsychotics and constipation: a review of the literature. *European Psychiatry*, 26(1), 34-44.
- de Jager, A., Fogarty, A., Tewson, A., Lenette, C., & Boydell, K. M. (2017). Digital storytelling in research: A systematic review. *The Qualitative Report*, 22(10), 2548-2582.
- De Kock, L. (1992). An Interview with Gayatri Chakravorty Spivak. *Ariel: A review of international English literature*, 23(3).
- De Leeuw, S., Greenwood, M. & Cameron, E. (2009). Deviant constructions: How governments preserve colonial narratives of addiction and poor mental health to intervene into the lives of Indigenous children and families in Canada. *International Journal of Mental Health and Addiction*, 8 (1), 282-295.
- De Vecchi, N., Kenny, A., Dickson-Swift, V., & Kidd, S. (2017). Exploring the Process of Digital Storytelling in Mental Health Research: A Process Evaluation of Consumer and Clinician Experiences. *International Journal of Qualitative Methods*, 16(1), 1609406917729291.
- De Vecchi, N., Kenny, A., Dickson-Swift, V., & Kidd, S. (2016). How digital storytelling is used in mental health: A scoping review. *International Journal of Mental Health Nursing*, 25(3), 183-193.
- Denzin, N. K. (1989). Interpretive interactionism. California: Sage Publications
- Des Jardin, K. (2001). Political involvement in nursing-politics, ethics, and strategic action. *Association of Perioperative Registered Nurse journal*, 74(5), 613-622.

- Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical psychology review, 33*(7), 846-861.
- Doherty, A. M., & Gaughran, F. (2014). The interface of physical and mental health. *Social psychiatry and psychiatric epidemiology, 49*(5), 673-682.
- Doody, O., & Noonan, M. (2013). Preparing and conducting interviews to collect data. *Nurse researcher, 20*(5).
- Drake, R. E., Goldman, H. H., Leff, H. S., Lehman, A. F., Dixon, L., Mueser, K. T., & Torrey, W. C. (2001). Implementing evidence-based practices in routine mental health service settings. *Psychiatric Services, 52*(2), 179-182.
- Duggan, P. S., Geller, G., Cooper, L. A., & Beach, M. C. (2006). The moral nature of patient-centeredness: is it “just the right thing to do”? *Patient education and counseling, 62*(2), 271-276.
- Eagleton, T. (1999). In the gaudy supermarket. *London review of books, 21*(10), 3.
- Eakin, J. M., & Gladstone, B. (2020). “Value-adding” Analysis: Doing More With Qualitative Data. *International Journal of Qualitative Methods, 19*, 1609406920949333.
- Ehrlich, C., Chester, P., Kisely, S., Crompton, D., & Kendall, E. (2017). Making sense of self-care practices at the intersection of severe mental illness and physical health—An Australian study. *Health & social care in the community.*
- Ekuma, K. (2019). Postcolonialism and national HRD: understanding contemporary challenges to skills development in sub-Saharan Africa. *Human Resource Development International, 22*(4), 321-342.

- Ellem, K., Wilson, J., Chui, W. H., & Knox, M. (2008). Ethical challenges of life story research with ex-prisoners with intellectual disability. *Disability & Society*, 23(5), 497-509.
- Emmison, M., & Smith, P. (2000). Researching the Visual: Images, Objects. *Contexts*.
- England, P. H. (2014). Adult obesity and type 2 diabetes.
(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/338934/Adult_obesity_and_type_2_diabetes_.pdf).
- Esposito, K., Chiodini, P., Colao, A., Lenzi, A., & Giugliano, D. (2012). Metabolic syndrome and risk of cancer. *Diabetes care*, 35(11), 2402-2411.
- Etherington, N., Rodrigues, I. B., Giangregorio, L., Graham, I. D., Hoens, A. M., Kasperavicius, D., Kelly, C., Moore, J. E., Ponzano, M., & Pesseau, J. (2020). Applying an intersectionality lens to the theoretical domains framework: a tool for thinking about how intersecting social identities and structures of power influence behaviour. *BMC Medical Research Methodology*, 20(1), 1-13.
- Evans, M. (2000). The significance of ethical sophistication. *Journal of Psychosocial Nursing and Mental Health Services*, 38(4), 8–13.
- Fan, Z., Wu, Y., Shen, J., Ji, T., & Zhan, R. (2013). Schizophrenia and the risk of cardiovascular diseases: a meta-analysis of thirteen cohort studies. *Journal of psychiatric research*, 47(11), 1549-1556.
- Farmer, T., Robinson, K., Elliott, S. J., & Eyles, J. (2006). Developing and implementing a triangulation protocol for qualitative health research. *Qualitative Health Research*, 16(3), 377-394.

- Faulkner, G., Cohn, T., & Remington, G. (2006). Validation of a physical activity assessment tool for individuals with schizophrenia. *Schizophrenia research*, 82(2), 225-231.
- Federman, C. 2012. The mentally ill and civil commitment: Assessing dangerousness in law and psychiatry. In D. Holmes et al. (Eds). (Re)thinking violence in health care settings: A critical approach. Surrey: Ashgate, 297–314
- Ferrari, M., Rice, C., & McKenzie, K. (2015). ACE Pathways Project: Therapeutic catharsis in digital storytelling. *Psychiatric Services*, 66(5), 556-556.
- Fielden, K. (2012). Re-conceptualising research: A mindful process for qualitative research in information systems. In *Societal impacts on information systems development and applications* (pp. 130-141): IGI Global.
- Finkelman, A. (2017). *Professional Nursing Concepts: Competencies for Quality Leadership: Competencies for Quality Leadership*: Jones & Bartlett Learning.
- Frances, A. (2013). The past, present and future of psychiatric diagnosis. *World Psychiatry*, 12(2), 111.
- Friesacher, H. (2017). Chapter Four: Nursing and Critique: Elements for a Theory in Nursing. *Pflegewissenschaft und Pflegebildung*, 91.
- Ford, E. S., Giles, W. H., & Dietz, W. H. (2002). Prevalence of the metabolic syndrome among US adults: findings from the third National Health and Nutrition Examination Survey. *Jama*, 287(3), 356-359.
- Foth, T. (2013). Shock Therapies as Intensification of the War against Madness in Hamburg, Germany: 1930–1943. *Canadian Bulletin of Medical History*, 30(2), 161-184.
- Foucault, M. (1965). *Madness and civilization: A history of insanity in the age of reason*. New York, Random House.

- Foucault, M. (1980). *Power/Knowledge*. New York. Pantheon.
- Foucault, M. (2003). *Madness and civilization*: Routledge.
- Fyffe, T. (2009). Nursing shaping and influencing health and social care policy. *Journal of Nursing Management*, 17(6), 698-706.
- Frese III, F. J., Stanley, J., Kress, K., & Vogel-Scibilia, S. (2001). Integrating evidence-based practices and the recovery model. *Psychiatric Services*, 52(11), 1462-1468.
- Fricke, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.
- Fromm, E., & Anderson, L. A. (2017). *The sane society*: Routledge.
- Frosh, S. (2004). Knowing more than we can say. In D. A. Pare & G. Learner (Eds.), *Collaborative practice in psychology and therapy* (pp. 55-68). New York: Haworth Press.
- Gachago, D., Cronje, F., Ivala, E., Condy, J., & Chigona, A. (2013). *Stories of Resistance: Digital Counterstories Among South African Pre-Service Student Educators*. Paper presented at the ICEL2013-Proceedings of the 8th International Conference on e-Learning: ICEL 2013.
- Ganguly, P., Soliman, A., & Moustafa, A. A. (2018). Holistic Management of Schizophrenia Symptoms Using Pharmacological and Non-pharmacological Treatment. *Front Public Health*, 6, 166. doi:10.3389/fpubh.2018.00166
- Garden, R. (2010). Telling stories about illness and disability: the limits and lessons of narrative. *Perspectives in Biology and Medicine*, 53(1), 121-135.

- Gatov, E., Rosella, L., Chiu, M., & Kurdyak, P. A. (2017). Trends in standardized mortality among individuals with schizophrenia, 1993–2012: a population-based, repeated cross-sectional study. *Canadian Medical Association Journal*, 189(37), E1177-E1187.
- Gautam, S., & Meena, P. S. (2011). Drug-emergent metabolic syndrome in care recipients with schizophrenia receiving atypical (second-generation) antipsychotics. *Indian J Psychiatry*, 53(2), 128-133. doi:10.4103/0019-5545.82537
- Gazarian, P. K., Fernberg, L. M., & Sheehan, K. D. (2016, Mar). Effectiveness of narrative pedagogy in developing student nurses' advocacy role. *Nurs Ethics*, 23(2), 132-141. <https://doi.org/10.1177/0969733014557718>
- Gergen, K. J. (2007). The self: Colonization in psychology and society. *Psychology's territories: Historical and contemporary perspectives from different disciplines*, 149-168.
- Gilliam, M., Orzalli, S., Heathcock, S., Sutherland, E., Jagoda, P., Menendez, A., & Ojengbede, O. (2012). From intervention to invitation: reshaping adolescent sexual health through story telling and games. *African journal of reproductive health*, 16(2), 189-196.
- Gilman, S. L. (2014). Madness as disability. *History of Psychiatry*, 25(4), 441-449.
- Goodman, R., & Newman, D. (2014). Testing a digital storytelling intervention to reduce stress in adolescent females. *Storytelling, Self, Society*, 10(2), 177-193.
- Gorman, R. (2013). Mad nation? Thinking through race, class, and mad identity politics. *Mad matters: A critical reader in Canadian mad studies*, 269-280.
- Gøtzsche, P. C. (2015). *Deadly psychiatry and organised denial*. Art People.
- Gillian, R. (2016). *Visual methodologies: An introduction to researching with visual materials* (4th ed.). United Kingdom: Sage.

- Gilmour, J. A., & Brannelly, T. (2010). Representations of people with dementia - subaltern, person, citizen. *Nuring Inquiry*, 17(3), 240-247. doi:10.1111/j.1440-1800.2009.00475.x
- Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., Dai, S., Ford, E. S., Fox, C. S., Franco, S., Fullerton, H. J., Gillespie, C., Hailpern, S. M., Heit, J. A., Howard, V. J., Huffman, M. D., Judd, S. E., Kissela, B. M., Kittner, S. J., Lackland, D. T., ... American Heart Association Statistics Committee and Stroke Statistics Subcommittee (2014). Heart disease and stroke statistics--2014 update: a report from the American Heart Association. *Circulation*, 129(3), e28–e292.
<https://doi.org/10.1161/01.cir.0000441139.02102.80>
- Goffman, E. (1963). *Stigma: Note on the management of spoiled identity*. Englewood cliffs, NJ: Prentice-Hall
- Gonzales, P. (2012). *Red medicine: Traditional indigenous rites of birthing and healing*: University of Arizona Press.
- Government of Canada. (2013). *What makes Canadians healthy or unhealthy?*
<https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health/what-makes-canadians-healthy-unhealthy.html>
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map? *Journal of continuing education in the health professions*, 26(1), 13-24.
- Graham, I. D., Tetroe, J., & Pearson, A. (2014). *Turning knowledge into action: practical guidance on how to do integrated knowledge translation research*: Lippincott Williams & Wilkins.
- Griffiths, G., & Ashcroft, F. M. (1995). *The post-colonial studies reader*: Psychology Press.

- Grob, G. N. (2011). The attack of psychiatric legitimacy in the 1960s: rhetoric and reality. *Journal of the History of the Behavioral Sciences*, 47(4), 398-416.
- Gronholm, P. C., Onagbesan, O., & Gardner-Sood, P. (2017). Care coordinator views and experiences of physical health monitoring in clients with severe mental illness: A qualitative study. *International Journal of Social Psychiatry*, 63(7), 580-588.
- Gubrium, A. (2009). Digital storytelling: an emergent method for health promotion research and practice. *Health Promot Pract*, 10(2), 186-191. doi:10.1177/1524839909332600
- Gubrium, A. C., Krause, E. L., & Jernigan, K. (2014). Strategic Authenticity and Voice: New Ways of Seeing and Being Seen as Young Mothers through Digital Storytelling. *Sex Res Social Policy*, 11(4), 337-347. doi:10.1007/s13178-014-0161-x
- Guest, G., MacQueen, K. M., & Namey, E. E. (2012). Introduction to applied thematic analysis. *Applied thematic analysis*, 3(20), 1-21.
- Guha, R. (1988). Preface. In R. Guha & G. C. Spivak (Eds.), *Selected subaltern studies*. New York: Oxford University Press
- Hancox, D. (2012). The process of remembering with the Forgotten Australians: Digital storytelling and marginalized groups. *Human Technology: An Interdisciplinary Journal on Humans in ICT Environments*.
- Handerer, F., Kinderman, P., Timmermann, C., & Tai, S. J. (2021). How did mental health become so biomedical? The progressive erosion of social determinants in historical psychiatric admission registers. *History of Psychiatry*, 32(1), 37-51.
- Harding, S. (1993). Rethinking standpoint epistemology: what is “strong objectivity?” in L. Alcoff and E. Potter (eds) *Feminist Epistemologies*, London: Routledge.

- Hall, W. (2019). Psychiatric medication withdrawal: Survivor perspectives and clinical practice. *Journal of Humanistic Psychology*, 59(5), 720-729.
- Halter, M. J., & Varcarolis, E. M. (2013). *Varcarolis' Foundations of Psychiatric Mental Health Nursing*: Elsevier Health Sciences.
- Hamilton, S., Pinfold, V., Cotney, J., Couperthwaite, L., Matthews, J., Barret, K., . . . Henderson, C. (2016). Qualitative analysis of mental health service users' reported experiences of discrimination. *Acta Psychiatr Scand*, 134 Suppl 446(Suppl Suppl 446), 14-22.
doi:10.1111/acps.12611
- Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health*, 18(3), 271-283.
- Happell, B., Ewart, S. B., Platania-Phung, C., Bocking, J., Griffiths, K., Scholz, B., & Stanton, R. (2016). Embedding a physical health nurse consultant within mental health services: Consumers' perspectives. *International Journal of Mental Health Nursing*, 25(4), 377-384.
- Hardy, P., & Sumner, T. (2014). *Cultivating compassion: how digital storytelling is transforming healthcare*: Kingsham Press.
- Hardy, P., & Sumner, T. (2018). *Cultivating compassion: How digital storytelling is transforming healthcare*: Springer.
- Hardy, P., & Sumner, T. (2017). Digital Storytelling with Users and Survivors of the UK Mental Health System. In M. Dunford & T. Jenkins (Eds.), *Digital Storytelling : Form and Content* (pp. 57-69). London: Palgrave Macmillan UK.

- Hartel, J., & Thomson, L. (2011). Visual approaches and photography for the study of immediate information space. *Journal of the American Society for Information Science and Technology*, 62(11), 2214-2224. doi:10.1002/asi.21618
- Hardy, P. (2007). An investigation into the application of the Patient Voices digital stories in healthcare education: quality of learning, policy impact and practice-based value. *Faculty of Social Sciences, School of Education*.
- Hardy, P. (2017). Physician, know thyself: Using digital storytelling to promote reflection in medical education *Digital Storytelling in Higher Education* (pp. 37-54): Springer.
- Hartl, K. (1992). A-Way Express: A way to empowerment through competitive employment. *Canadian Journal of Community Mental Health*.
- Hartley, J., & McWilliam, K. (2009). *Story circle: Digital storytelling around the world*: John Wiley & Sons.
- Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17(1), 13-26.
- Harper, M., & Cole, P. (2012). Member checking: Can benefits be gained similar to group therapy. *The qualitative report*, 17(2), 510-517.
- Harrow, M., & Jobe, T. H. (2018). Long-term antipsychotic treatment of schizophrenia: does it help or hurt over a 20-year period? *World Psychiatry*, 17(2), 162.
- Harrow, M., Jobe, T. H., Faull, R. N., & Yang, J. (2017). A 20-year multi-followup longitudinal study assessing whether antipsychotic medications contribute to work functioning in schizophrenia. *Psychiatry research*, 256, 267-274.

- Harrison, B. (2002). Seeing health and illness worlds-Using visual methodologies in a sociology of health and illness: A methodological review. *Sociology of Health & Illness*, 24(6), 856–872. doi: 10.1111/1467-9566.00322
- Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Wanderling, J., Dube, K., Ganey, K., Giel, R., & Der Heiden, W. A. (2001). Recovery from psychotic illness: a 15-and 25-year international follow-up study. *The British journal of psychiatry*, 178(6), 506-517.
- Heald, A., Pendlebury, J., Anderson, S., Narayan, V., Guy, M., Gibson, M., . . . Livingston, M. (2017). Lifestyle factors and the metabolic syndrome in Schizophrenia: a cross-sectional study. *Ann Gen Psychiatry*, 16, 12. doi:10.1186/s12991-017-0134-6
- Henderson, D. C., Borba, C. P., Daley, T. B., Boxill, R., Nguyen, D. D., Culhane, M. A., . . . Freudenreich, O. (2006). Dietary intake profile of care recipients with schizophrenia. *Annals of Clinical Psychiatry*, 18(2), 99-105.
- Henderson, C., Noblett, J., Parke, H., Clement, S., Caffrey, A., Gale-Grant, O., Schulze, B., Druss, B., & Thornicroft, G. (2014). Mental health-related stigma in health care and mental health-care settings. *The Lancet Psychiatry*, 1(6), 467-482.
- Hennink, M. M. (2007). *International focus group research: A handbook for the health and social sciences*: Cambridge University Press.
- Higgs, J., & Titchen, A. (1998). Research and knowledge. *Physiotherapy*, 84(2), 72-80.
- Retrieved from
<http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=1998049745&site=ehost-live>
- Hill, A. (2010). Digital storytelling for gender justice: Exploring the challenges of participation and the limits of polyvocality. In D. Berghoffen, P. Gilbert, T. Harvey, & C. McNeely

- (Eds.), *Confronting global gender justice: Women's lives, human rights*. Oxford: Routledge.
- Hirsch, L., Yang, J., Bresee, L., Jette, N., Patten, S., & Pringsheim, T. (2017). Second-Generation Antipsychotics and Metabolic Side Effects: A Systematic Review of Population-Based Studies. *Drug Saf*, 40(9), 771-781. doi:10.1007/s40264-017-0543-0
- Hjorthøj, C., Stürup, A. E., McGrath, J. J., & Nordentoft, M. (2017). Years of potential life lost and life expectancy in schizophrenia: a systematic review and meta-analysis. *The Lancet Psychiatry*, 4(4), 295-301.
- Ho, B.-C., Andreasen, N. C., Ziebell, S., Pierson, R., & Magnotta, V. (2011). Long-term antipsychotic treatment and brain volumes: a longitudinal study of first-episode schizophrenia. *Arch Gen Psychiatry*, 68(2), 128-137.
- Hoftman, G. D. (2017). The burden of mental illness beyond clinical symptoms: impact of stigma on the onset and course of schizophrenia spectrum disorders. *American Journal of Psychiatry Residents' Journal*.
- Holmes, D., & Federman, D. (2003). Constructing monsters: Correctional discourse and nursing practice. *International Journal of Psychiatric Nursing*, 8(1), 942-962.
- Holmes, D., & Murray, S. J. (2014). Censoring violence: Censorship and critical research in forensic psychiatry.
- Holmes, D., Murray, S. J., Perron, A., & McCabe, J. (2008b). Nursing Best Practice Guidelines: reflecting on the obscene rise of the void. *J Nurs Manag*, 16(4), 394-403. doi:10.1111/j.1365-2834.2008.00858.x

- Holmes, D., Roy, B., & Perron, A. (2008a). The use of postcolonialism in the nursing domain: colonial patronage, conversion, and resistance. *ANS Adv Nurs Sci*, 31(1), 42-51.
doi:10.1097/01.ans.0000311528.73564.83
- Ibrahim, M., & Morrow, M. (2015). Weaning off colonial psychiatry in Kenya. *Journal of Ethics in Mental Health*, 1, 1-6.
- Insel, T. R. (2007). Neuroscience: Shining light on depression. *Science*, 317, 757–758.
- Insel, T. R. (2010). Faulty circuits. *Scientific American*, 302, 44–51.
- Inden, R. (1986). Orientalist constructions of India. *Modern Asian Studies*, 20(3), 401-446.
- Ingram, D. (2017). Critical Theory and the Struggle for Recognition. *Berlin Journal of Critical Theory*, 1(1).
- Jacob, K. (2015). Recovery model of mental illness: A complementary approach to psychiatric care. *Indian journal of psychological medicine*, 37(2), 117.
- Jacob, J. D., Perron, A., & Holmes, D. (2014). Unmasking the Psychiatric Apparatus. *Power and the psychiatric apparatus: Repression, transformation and assistance*, 1-22.
- Jacobs, D. H. (2016). American medical psychiatry: A contemporary case of Lysenkoism. *Power and the psychiatric apparatus: Repression, Transformation and Assistance*, Burlington, VT: Ashgate Publishing Company, 287-296.
- Jacob, J. D., Perron, A., & Corneau, P. (2016). Structural othering: Towards an understanding of place in the construction of disruptive subjectivities. *Power and the psychiatric apparatus: Repression, transformation and assistance*, 2014.2149-2163.
- Jibson, M. D., Marder, S., & Hermann, R. (2014). First-generation antipsychotic medications: Pharmacology, administration, and comparative side effects. *UptoDate Waltham, MA* (Accessed June 17, 2014).

- Joseph, A. J. (2016). *Deportation and the confluence of violence within forensic mental health and immigration systems*. Springer.
- Kamens, S. R. (2020). Postcolonialism and (anti) psychiatry: On hearing voices and ghostwriting. *Philosophy, Psychiatry, & Psychology*, 27(3), 253-265.
- Kato, T. (2011). A renovation of psychiatry is needed. *World Psychiatry*, 10(3), 198-199.
<https://doi.org/10.1002/j.2051-5545.2011.tb00056.x>
- Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: past, present, and future. *Clinical psychology: Science and practice*, 10(2), 144-156.
- Kendall, E., Ehrlich, C., Sunderland, N., Muenchberger, H., & Rushton, C. (2011). Self-managing versus self-management: reinvigorating the socio-political dimensions of self-management. *Chronic Illness*, 7(1), 87-98.
- Kent, G. (2016). Shattering the silence: The power of purposeful storytelling in challenging social security policy discourses of 'blame and shame' in Northern Ireland. *Critical Social Policy*, 36(1), 124-141.
- Kirby, M., & Keon, M. (2006). Out of the Shadows at Last: Transforming Mental Health, Mental Illness, and Addictions in Canada. *Ottawa, ON: The Standing Senate Committee on Social Affairs, Science, and Technology*. Retrieved March, 1, 2011.
- Kirk, S. A., Gomory, T., & Cohen, D. (2017). *Mad science: Psychiatric coercion, diagnosis, and drugs*. Routledge.
- Kirkham, S. R., & Anderson, J. M. (2002). Postcolonial nursing scholarship: From epistemology to method. *Advances in nursing science*, 25(1), 1-17.
- Kirkham, S. R., & Browne, A. J. (2006). Toward a critical theoretical interpretation of social justice discourses in nursing. *Advances in Nursing Science*, 29(4), 324-339.

- Kisely, S., Smith, M., Lawrence, D., Cox, M., Campbell, L. A., & Maaten, S. (2007). Inequitable access for mentally ill care recipients to some medically necessary procedures. *Canadian Medical Association Journal*, 176(6), 779-784.
- Kleinman, A. (2008). *Rethinking psychiatry*. Simon and Schuster.
- Knaak, S., Mantler, E., & Szeto, A. (2017). Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. Healthcare management forum Lambert, J. (2012). *Digital storytelling: Capturing lives, creating community* (4th ed.). New York, London: Routledge
- Knaak, S., & Patten, S. (2016). A grounded theory model for reducing stigma in health professionals in Canada. *Acta Psychiatr Scand*, 134 Suppl 446, 53-62.
doi:10.1111/acps.12612
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of advanced nursing*, 28(4), 882-890.
- Kotov, R., Fochtmann, L., Li, K., Tanenberg-Karant, M., Constantino, E. A., Rubinstein, J., Perlman, G., Velthorst, E., Fett, A.-K. J., & Carlson, G. (2017). Declining clinical course of psychotic disorders over the two decades following first hospitalization: evidence from the Suffolk County Mental Health Project. *American Journal of Psychiatry*, 174(11), 1064-1074.
- Krupa, T., Kirsh, B., Cockburn, L., & Gewurtz, R. (2009). Understanding the stigma of mental illness in employment. *Work*, 33(4), 413-425.
- Kuhn, T. S. (1962). Historical structure of scientific discovery. *Science*, 136(3518), 760-764.

- LaMarre, A., & Rice, C. (2016). *Embodying Critical and Corporeal Methodology: Digital Storytelling With Young Women in Eating Disorder Recovery*. Paper presented at the Forum: Qualitative Social Research.
- Lambert, J. (2009). *Where it all started: The center for digital storytelling in California*: na.
- Lambert, J. (2010). Digital storytelling cookbook. Berkeley. In: CA: Digital Diner Press.
- Laursen, T. M., Munk-Olsen, T., & Vestergaard, M. (2012). Life expectancy and cardiovascular mortality in persons with schizophrenia. *Current opinion in psychiatry*, 25(2), 83-88.
- Leavy, P. (2015). *Method meets art: Arts-based research practice*: Guilford Publications.
- Lee, L. T., Chen, K. C., Chang, W. H., Chen, P. S., Lee, I. H., & Yang, Y. K. (2015). Holistic Consideration of Care recipients with Schizophrenia to Improve Medication Adherence and Outcomes. *Clin Psychopharmacol Neurosci*, 13(2), 138-143.
doi:10.9758/cpn.2015.13.2.138
- Leitch, R. (2006). Limitations of language: Developing arts-based creative narrative in stories of teachers' identities. *Teachers and teaching: Theory and practice* 12(5), 549–569.
- Lemon, L. (2017). Applying a mindfulness practice to qualitative data collection. *The Qualitative Report*, 22(12), 3305.
- Lenette, C., Cox, L., & Brough, M. (2013). Digital Storytelling as a Social Work Tool: Learning from Ethnographic Research with Women from Refugee Backgrounds. *British Journal of Social Work*, 45(3), 988-1005. doi:10.1093/bjsw/bct184
- Lenette, C., & Boddy, J. (2013). Visual ethnography and refugee women: nuanced understandings of lived experiences. *Qualitative Research Journal*, 13(1), 72-89.

- Leung, F.-H., & Savithiri, R. (2009). Spotlight on focus groups. *Canadian Family Physician*, 55(2), 218-219.
- Leucht, S., Burkard, T., Henderson, J., Maj, M., & Sartorius, N. (2007). Physical illness and schizophrenia: a review of the literature. *Acta Psychiatrica Scandinavica*, 116(5), 317-333.
- Lewis, B. (2011). *Narrative psychiatry: How stories can shape clinical practice*. JHU Press.
- Li, M., Fan, Y.-L., Tang, Z.-Y., & Cheng, X.-S. (2014). Schizophrenia and risk of stroke: a meta-analysis of cohort studies. *International journal of cardiology*, 173(3), 588-590.
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newberry Park. In: CA: Sage.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology*, 27, 363-385.
- Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social science & medicine*, 71(12), 2150-2161.
- Lo, Y.-T., Chang, Y.-H., Lee, M.-S., & Wahlqvist, M. L. (2009). Health and nutrition economics: diet costs are associated with diet quality. *Asia Pacific journal of clinical nutrition*, 18(4), 598-604.
- Löffler, W., Kilian, R., Toumi, M., & Angermeyer, M. (2003). Schizophrenic care recipients' subjective reasons for compliance and noncompliance with neuroleptic treatment. *Pharmacopsychiatry*, 36(03), 105-112.
- Loftis, J. M., Matthews, A. M., & Hauser, P. (2006). Psychiatric and substance use disorders in individuals with hepatitis C. *Drugs*, 66(2), 155-174.

- Loh, A., Leonhart, R., Wills, C. E., Simon, D., & Härter, M. (2007). The impact of care recipient participation on adherence and clinical outcome in primary care of depression. *Care recipient education and counseling*, 65(1), 69-78.
- Lorenz, L. S., & Kolb, B. (2009). Involving the public through participatory visual research methods. *Health expectations*, 12(3), 262-274.
- Loomba, A. (1993). Dead Women Tell No Tales: Issues of Female Subjectivity. *Subaltern Agency*.
- Loomba, A. (1998). 1998: Colonialism/postcolonialism. London: Routledge.
- Lopez, V., & Whitehead, D. (2013). Sampling data and data collection in qualitative research. *Nursing & midwifery research: Methods and appraisal for evidence-based practice*, 123-140.
- Luchins D. (2012). Two approaches to improving mental health care: positivist/quantitative versus skill-based/qualitative. *Perspectives in biology and medicine*, 55(3), 409–434.
<https://doi.org/10.1353/pbm.2012.0024>
- Luchs, M., & Miller, E. (2016). Not so far away: A collaborative model of engaging refugee youth in the outreach of their digital stories. *Area*, 48(4), 442-448.
- Lugones, M. (2012). Methodological notes toward a decolonial feminism. *Decolonizing epistemologies: Latina/o theology and philosophy*, 68-86.
- Lundby, K. (2008). *Digital storytelling, mediatized stories: Self-representations in new media*: Peter Lang.
- Lyotard, J. F. (1984). *The postmodern condition: A report on knowledge*. Manchester: University of Manchester Press Higgs.

- Masters, J., Rudge, T., & West, S. (2016). Mainstreaming the Mentally Ill. *Power and the psychiatric apparatus: Repression, transformation and assistance*, 183.
- Mazzotta, C. P. (2016). Biomedical approaches to care and their influence on point of care nurses: a scoping review. *Journal of Nursing Education and Practice*, 6(8), 93-101.
- Mandair, A. (2016). Chapter Summary. *The Oxford Handbook of the Study of Religion*, 177.
- Manias, E., & Street, A. (2000). Possibilities for critical social theory and Foucault's work: a toolbox approach. *Nursing Inquiry*, 7(1), 50-60. doi: 10.1046/j.1440-1800.2000.00048.x
- Manu, P., Dima, L., Shulman, M., Vancampfort, D., De Hert, M., & Correll, C. U. (2015). Weight gain and obesity in schizophrenia: epidemiology, pathobiology, and management. *Acta Psychiatr Scand*, 132(2), 97-108. doi:10.1111/acps.12445
- Medina, J. (2013). *The epistemology of resistance: Gender and racial oppression, epistemic injustice, and the social imagination*. Oxford University Press.
- Melamed, O. C., Fernando, I., Soklaridis, S., Hahn, M. K., LeMessurier, K. W., & Taylor, V. H. (2019). Understanding engagement with a physical health service: a qualitative study of patients with severe mental illness. *The Canadian Journal of Psychiatry*, 64(12), 872-880.
- Mental Health Commission of Canada. (2009). Toward recovery & well-being: A framework for a mental health strategy for Canada.
https://www.mentalhealthcommission.ca/sites/default/files/FNIM_Toward_Recovery_and_Well_Being_ENG_0_1.pdf
- Mental Health Commission of Canada. (2012). Changing directions changing lives: The mental health strategy for Canada.

https://www.mentalhealthcommission.ca/sites/default/files/MHStrategy_Strategy_ENG.pdf

- Migone, P. (2017). The influence of pharmaceutical companies. *Research in Psychotherapy: Psychopathology, Process, and Outcome*, 20(2).
- Moreau, K. A., Eady, K., Sikora, L., & Horsley, T. (2018). Digital storytelling in health professions education: a systematic review. *BMC Medical Education*, 18(1), 1-9.
- Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25(9), 1212-1222.
- McConaghy, C. (2000). *Rethinking indigenous education: Culturalism, colonialism and the politics of knowing*. Flaxton, Australia: Post Pressed.
- McCreadie, R., Stevens, H., Henderson, J., Hall, D., McCaul, R., Filik, R., . . . Perrington, S. (2004). The dental health of people with schizophrenia. *Acta Psychiatrica Scandinavica*, 110(4), 306-310.
- McIntyre, R. S., Mancini, D. A., & Basile, V. S. (2001). Mechanisms of antipsychotic-induced weight gain. *The Journal of clinical psychiatry*.
- McNiff, S. (2008). Art-based research. *Handbook of the arts in qualitative research*, 29-40.
- Middleton, H., & Moncrieff, J. (2019). Critical psychiatry: a brief overview. *BJPsych Advances*, 25(1), 47-54.
- Mihanović, M., Restek-Petrović, B., Bodor, D., Molnar, S., Orešković, A., & Presečki, P. (2010). Suicidality and side effects of antidepressants and antipsychotics. *Psychiatria Danubina*, 22(1), 79-84.
- Minds, O. (2011). Healthy Minds: Ontario's comprehensive mental health and addictions strategy. *Ottawa (ON): Government of Ontario*.

- Mitchell, A. J., Vancampfort, D., Sweers, K., van Winkel, R., Yu, W., & De Hert, M. (2011). Prevalence of metabolic syndrome and metabolic abnormalities in schizophrenia and related disorders—a systematic review and meta-analysis. *Schizophr Bull*, 39(2), 306-318.
- Moffat, T. (2010). The “childhood obesity epidemic”. *Medical anthropology quarterly*, 24(1), 1-21.
- Molloy, J. K. (2007). Photovoice as a Tool for Social Justice Workers. *Journal of Progressive Human Services*, 18(2), 39-55. doi:10.1300/J059v18n02_04
- Moore, S., Shiers, D., Daly, B., Mitchell, A., & Gaughran, F. (2015). Promoting physical health for people with schizophrenia by reducing disparities in medical and dental care. *Acta Psychiatrica Scandinavica*, 132(2), 109-121.
- Moncrieff, J. (2013). *The bitterest pills: The troubling story of antipsychotic drugs*. Springer.
- Morgan, C., Lappin, J., Heslin, M., Donoghue, K., Lomas, B., Reininghaus, U., Onyejiaka, A., Croudace, T., Jones, P. B., & Murray, R. M. (2014). Reappraising the long-term course and outcome of psychotic disorders: the AESOP-10 study. *Psychological medicine*, 44(13), 2713-2726.
- Morgan, V. S., & Castleden, H. (2014). Redefining the Cultural Landscape in British Columbia: Huu-ay-aht Youth Visions for a Post-Treaty Era in Nuu-chah-nulth Territory. *ACME: An International Journal for Critical Geographies*, 13(3), 551-580.
- Mosquera, D., & Ross, C. (2017). A psychotherapy approach to treating hostile voices. *Psychosis*, 9(2), 167-175.

- Mill, J. E., Allen, M. N., & Morrow, R. A. (2016). Critical theory: Critical methodology to disciplinary foundations in nursing. *Canadian Journal of Nursing Research Archive*, 33(2).
- Moilanen, J., Haapea, M., Miettunen, J., Jääskeläinen, E., Veijola, J., Isohanni, M., & Koponen, H. (2013). Characteristics of subjects with schizophrenia spectrum disorder with and without antipsychotic medication—a 10-year follow-up of the Northern Finland 1966 Birth Cohort study. *European Psychiatry*, 28(1), 53-58.
- Mohammed, S. A. (2006). Moving beyond the 'exotic': applying postcolonial theory in health research. *Advances in Nursing Science*, 29(2), 98-109.
- Morrison, N. K. (1985). Shame in the treatment of schizophrenia: theoretical considerations with clinical illustrations. *Yale Journal of Biology and Medicine*, 58(3), 289-297.
- Morris, R. (2010). *Can the subaltern speak?: Reflections on the history of an idea*: Columbia University Press.
- Morton, S. (2003). *Gayatri Chakravorty Spivak*: Routledge.
- Morton, S. (2007). *Gayatri Spivak: ethics, subalternity and the critique of postcolonial reason*: Polity.
- Mercer, D. (2014). Sex offender therapy: Collusion, confession and game-playing. *Power and the psychiatric apparatus: Repression, transformation and assistance*, 251-266.
- McMillan, K. (2018). *A critical organizational analysis of frontline nurses' experience of rapid and continuous change in an acute health care organization*. Université d'Ottawa/University of Ottawa.
- McMillan, K., & Perron, A. (2020). Nurses' engagement with power, voice and politics amidst restructuring efforts. *Nursing inquiry*, 27(3), e12345.

- McMurray, R., Pullen, A., & Rhodes, C. (2010). Ethical subjectivity and politics in organizations: A case of health care tendering. *Organization*, 18(4), 541-561.
- Meadows, D. (2003). Digital storytelling: Research-based practice in new media. *Visual Communication*, 2(2), 189-193.
- Medical co-morbidity risk factors and barriers to care for people with schizophrenia. *Journal of psychiatric and mental health nursing*, 13(4), 447-452.
- Mill, J. E., Allen, M. N., & Morrow, R. A. (2001). Critical theory: critical methodology to disciplinary foundations in nursing. *Canadian Journal of Nursing Research*, 33(2), 109-127.
- Muench, J., & Hamer, A. M. (2010). Adverse effects of antipsychotic medications. *American family physician*, 81(5), 617-622.
- Muir-Cochrane, E., & Gerace, A. (2014). Containment practices in psychiatric care. *Power and the psychiatric apparatus: Repression, transformation and assistance*, 91-115.
- Munshi, T., Asmer, M. S., Penfold, S., Pikard, J., Mauer-Vakil, D., & Banwell, E. (2017). Physical exam in mental health: implementation of a form to guide medical assessment of acute psychiatric inpatient recipients. *Clinical Audit*, 9, 1.
- Muir-Cochrane, E. (2006). Educating nurses for the knowledge economy. *International Journal of Nursing Education Scholarship*, 2(1), 1-7.
- Nagata, A. L. (2003). Mindful inquiry: A learner-centered approach to qualitative research. *Journal of Intercultural Communication*, 6, 23-36.
- Nash, M., & McDermott, J. (2011). Mental health and long-term conditions. 1: Physical health. *Nursing times*, 107(25), 12-14.

- Nash, A., Kingstone, T., Farooq, S., Tunmore, J., & Chew-Graham, C. A. (2021). Switching antipsychotics to support the physical health of people with severe mental illness: a qualitative study of healthcare professionals' perspectives. *BMJ open*, 11(2), e042497.
- Nasrallah, H. A. (2011). The antipsychiatry movement: Who and why. *Current Psychiatry*, 10(12), 4-53.
- Nordentoft, M., & Mortensen, P. B. (2011). Absolute risk of suicide after first hospital contact in mental disorder. *Archives of General Psychiatry*, 68(10), 1058-1064.
- Nordentoft, M., Wahlbeck, K., Hällgren, J., Westman, J., Ösby, U., Alinaghizadeh, H., . . . Laursen, T. M. (2013). Excess mortality, causes of death and life expectancy in 270,770 care recipients with recent onset of mental disorders in Denmark, Finland and Sweden. *PloS one*, 8(1), e55176.
- O'Leary, K., O'Neill, S., & Dockray, S. (2016). A systematic review of the effects of mindfulness interventions on cortisol. *Journal of health psychology*, 21(9), 2108-2121.
- O'Donnell, P., Lloyd, J., & Dreher, T. (2009). Listening, pathbuilding and continuations: A research agenda for the analysis of listening. *Continuum*, 23(4), 423-439.
- Oakes, J. M., & Rossi, P. H. (2003). The measurement of SES in health research: current practice and steps toward a new approach. *Social Science & Medicine*, 56(4), 769-784.
- Obesity Canada (2020). *Obesity in Canada*. <https://obesitycanada.ca/obesity-in-canada/>.
- Oexle, N., Müller, M., Kawohl, W., Xu, Z., Viering, S., Wyss, C., Vetter, S., & Rüsch, N. (2018). Self-stigma as a barrier to recovery: a longitudinal study. *European Archives of Psychiatry and Clinical Neuroscience*, 268(2), 209-212.
- O'Hagan, M., McKee, H., & Priest, R. (2009). Consumer survivor initiatives in Ontario: Building for an equitable future. *CSI Builder Project*, 104.

- Olfson, M., Uttaro, T., Carson, W. H., & Tafesse, E. (2005). Male sexual dysfunction and quality of life in schizophrenia. *The Journal of clinical psychiatry*, 66(3), 331-338.
- Oliveira, R. M. d., & Furegato, A. R. F. (2014). The opinion of care recipients with mental disorder about tobacco and its prohibition in psychiatric hospitalization. *Revista da Escola de Enfermagem da USP*, 48(3), 500-506.
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, 13(4), 695-705.
- Ostrow, L., Jessell, L., Hurd, M., Darrow, S. M., & Cohen, D. (2017). Discontinuing psychiatric medications: a survey of long-term users. *Psychiatric Services*, 68(12), 1232-1238.
- Owens, C., Farrand, P., Darvill, R., Emmens, T., Hewis, E., & Aitken, P. (2011). Involving service users in intervention design: a participatory approach to developing a text-messaging intervention to reduce repetition of self-harm. *Health Expect*, 14(3), 285-295. doi:10.1111/j.1369-7625.2010.00623.x
- Owen, M. J., Sawa, A., & Mortensen, P. B. (2016). Schizophrenia. *Lancet*, 388 North American Edition(10039), 86-97. doi:10.1016/S0140-6736(15)01121-6
- Owczarzak, J. (2009). Introduction: Postcolonial studies and postsocialism in Eastern Europe. *Focaal*, 2009(53), 3-19.
- Papadopoulos, C., Bowers, L., Quirk, A., & Khanom, H. (2012). Events preceding changes in conflict and containment rates on acute psychiatric wards. *Psychiatric Services*, 63(1), 40-47.
- Parry, B. (1987). Problems in current theories of colonial discourse. *Oxford literary review*, 9(1), 27-58.

- Partti, K., Vasankari, T., Kanervisto, M., Perälä, J., Saarni, S. I., Jousilahti, P., . . . Suvisaari, J. (2015). Lung function and respiratory diseases in people with psychosis: population-based study. *The British Journal of Psychiatry*, bjp. bp. 113.141937.
- Patel, P., Frederick, T., & Kidd, S. A. (2018). Physical health, community participation and schizophrenia. *Journal of health psychology*, 23(1), 79-83.
- Patient Voices Program. (2017). Care recipient Voices: Pip Hardy and Tony Sumner: co-founders of the Care recipient Voices Programme. (<http://www.carerecipientvoices.org.uk/who-we-are/who-are-we>).
- Perron, A. (2013). Nursing as ‘disobedient’ practice: Care of the nurse’s self, parrhesia, and the dismantling of a baseless paradox. *Nursing Philosophy*, 14, 154-167.
- Perron, A., Rudge, T., & Gagnon, M. (2014). Towards an “ethics of discomfort” in nursing: Parrhesia as fearless speech. In, P. N. Kagan, M.C Smith and P.L. Chinn (Eds.), *Philosophies and practices of emancipatory nursing: Social justice as praxis* (pp. 39-50). New York: Routledge.
- Perron, A., Rudge, T., & Holmes, D. (2010). Citizen minds, citizen bodies: the citizenship experience and the government of mentally ill persons. *Nurs Philos*, 11(2), 100-111. doi:10.1111/j.1466-769X.2010.00437.x
- Phelan, M., Stradins, L., & Morrison, S. (2001). Physical health of people with severe mental illness: can be improved if primary care and mental health professionals pay attention to it. *BMJ: British Medical Journal*, 322(7284), 443.
- Piat, M., & Sabetti, J. (2012). *Recovery in Canada: toward social equality*: Taylor & Francis.

- Pink, S. (2011). Sensory digital photography: re-thinking 'moving' and the image. *Visual Studies*, 26(1), 4-13. doi:10.1080/1472586X.2011.548484
- Pink, S. (2013). *Doing visual ethnography*: Sage.
- Polit, D. F., & Beck, C. T. (2012). Gender bias undermines evidence on gender and health. *Qualitative Health Research*, 22(9), 1298.
- Potter, N. N. (2020). The Haunting and Mourning of Subaltern Voices in Psychiatry. *Philosophy, Psychiatry, & Psychology*, 27(3), 273-276.
- Potter, N. N., & El-Mallakh, R. (2019). The interface of ethics and psychiatry: a philosophical case consultation on psychiatric ethics on the ground. *Philosophy, Psychiatry, & Psychology*, 26(3), 179-189.
- Potter, N. N. (2019a). Listening well to psychiatric service users: What does it mean to give uptake? *European Journal for Person Centered Healthcare*, 7 (3), 499–505.
- Potter, N. N. (2019b). Voice, silencing, and listening well: Socially located patients, oppressive structures, and an invitation to shift the epistemic terrain, In S. Tekin & R. Bluhm (Eds.), *Bloomsbury companion to philosophy of psychiatry* (pp. 305–324). London: Bloomsbury Press.
- Potter, N. N. (2015 a). Introduction, colonizing forces in psychiatry. *Journal of Ethics in Mental Health*. Available: https://jemh.ca/issues/v9/documents/JEMH_Open-Volume_Article_Theme_Colonization_Introduction_June2015.pdf. Accessed February 20, 2019.
- Potter, N. N. (2015 b). Reflections on Things We Don't Want to Think About: Intersections of Colonialism, Transgenerational Trauma, and Oppression Within Psychiatry.”. *Colonizing Forces in Psychiatry*, 1-7.

- Porter, D. (2015). Colonization by/in psychiatry: From over-medicalization to democratization. *Journal of Ethics in Mental Health Open Volume, 1*.
- Priebe, S. (2016, Dec). A social paradigm in psychiatry - themes and perspectives. *Epidemiol Psychiatr Sci, 25*(6), 521-527. <https://doi.org/10.1017/s2045796016000147>
- Price, D. M., Strodtman, L., Brough, E., Lonn, S., & Luo, A. (2015, Mar-Apr). Digital storytelling: an innovative technological approach to nursing education. *Nurse Educ, 40*(2), 66-70. <https://doi.org/10.1097/nne.0000000000000094>
- Prakash, G. (1992). Postcolonial criticism and Indian historiography. *Social Text*(31/32), 8-19.
- Prasad, A. N., & Sarkar, B. (2010). *Arundhati Roy: a critical elucidation*: Sarup Book Publishers.
- Prohl, I. (2018). *Meditation, Buddhism, and Science*, edited by David McMahan and Erik Braun, New York, Oxford University Press.
- Poland, B., Lehoux, P., Holmes, D., and Andrews, G. 2005. How place matters: Unpacking technology and power relations in health and social care. *Health and Social Care in the Community, 13*(2), 170–180.
- Radke, A. Q., Parks, J., & Ruter, T. J. (2010). A call for improved prevention and reduction of obesity among persons with serious mental illness. *Psychiatric Services, 61*(6), 617-619.
- Ramone, J. (2011). *Postcolonial theories*: Macmillan International Higher Education.
- Ray, W. A., Chung, C. P., Murray, K. T., Hall, K., & Stein, C. M. (2009). Atypical antipsychotic drugs and the risk of sudden cardiac death. *New England Journal of Medicine, 360*(3), 225-235.

- Read, J., Cartwright, C., & Gibson, K. (2018). How many of 1829 antidepressant users report withdrawal effects or addiction? *International Journal of Mental Health Nursing*, 27(6), 1805-1815.
- Reist, C., Mintz, J., Albers, L. J., Jamal, M. M., Szabo, S., & Ozdemir, V. (2007). Second-generation antipsychotic exposure and metabolic-related disorders in care recipients with schizophrenia: an observational pharmacoepidemiology study from 1988 to 2002. *Journal of Clinical Psychopharmacology*, 27(1), 46-51.
- Riach, G. K. (2017). *An analysis of Gayatri Chakravorty Spivak's can the subaltern speak?* Macat Library.
- Rice, C., Chandler, E., Harrison, E., Liddiard, K., & Ferrari, M. (2015). Project Re• Vision: Disability at the edges of representation. *Disability & Society*, 30(4), 513-527.
- Rimm, E. B., Stampfer, M. J., Giovannucci, E., Ascherio, A., Spiegelman, D., Colditz, G. A., & Willett, W. C. (1995). Body size and fat distribution as predictors of coronary heart disease among middle-aged and older US men. *American Journal of Epidemiology*, 141(12), 1117-1127.
- Rizvi, F., & Lingard, B. (2006). Edward Said and the cultural politics of education. *Discourse: Studies in the cultural politics of education*, 27(3), 293-308.
- Roberts, M. (2005). The production of the psychiatric subject: power, knowledge and Michel Foucault. *Nurs Philos*, 6(1), 33-42. doi:10.1111/j.1466-769X.2004.00196.x
- Roberts, L., Roalfe, A., Wilson, S., & Lester, H. (2006). Physical health care of care recipients with schizophrenia in primary care: a comparative study. *Family Practice*, 24(1), 34-40.

- Rocca, E., & Anjum, R. L. (2020). Complexity, Reductionism and the Biomedical Model. In *Rethinking Causality, Complexity and Evidence for the Unique Patient* (pp. 75-94). Springer.
- Rose, G. (2016). *Visual methodologies: An introduction to researching with visual materials*: Sage.
- Rose, R., Chakraborty, S., Mason-Lai, P., Brocke, W., Page, S. A., & Cawthorpe, D. (2016). The storied mind: A meta-narrative review exploring the capacity of stories to foster humanism in health care. *Journal of Hospital Administration*, 5(1), 52-61.
- Rosenberg, S. D., Goodman, L. A., Osher, F. C., Swartz, M. S., Essock, S. M., Butterfield, M. I., . . . Salyers, M. P. (2001). Prevalence of HIV, hepatitis B, and hepatitis C in people with severe mental illness. *American journal of public health*, 91(1), 31.
- Rosenhan, D. L. (1974). On being sane in insane places. *Clinical Social Work Journal*, 2(4), 237-256.
- Ross, C. A., & Goldner, E. M. (2009). Stigma, negative attitudes and discrimination towards mental illness within the nursing profession: a review of the literature. *Journal of psychiatric and mental health nursing*, 16(6), 558-567.
- Rössler, W., Salize, H. J., van Os, J., & Riecher-Rössler, A. (2005). Size of burden of schizophrenia and psychotic disorders. *European Neuropsychopharmacology*, 15(4), 399-409.
- Rössler, W. (2016). The stigma of mental disorders: A millennia-long history of social exclusion and prejudices. *EMBO reports*, 17(9), 1250-1253.
- Royal College of Psychiatrists. (2014). *Reports of the second round of the National Audit of Schizophrenia*. Retrieved from <https://www.rcpsych.ac.uk/docs/default->

[source/improving-care/ccqi/national-clinical-audits/ncap-library/national-audit-of-schizophrenia-document-library/nas-second-round-what-you-need-to-know.pdf?sfvrsn=d329c07_2](https://www.ncaap-library.org/national-audit-of-schizophrenia-document-library/nas-second-round-what-you-need-to-know.pdf?sfvrsn=d329c07_2)

- Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*, 20(8), 529-539.
- Said, E. (1978). *Orientalism: Western concepts of the Orient*. New York: Pantheon.
- Sawyer, C. B., & Willis, J. M. (2011). Introducing digital storytelling to influence the behavior of children and adolescents. *Journal of Creativity in Mental Health*, 6(4), 274-283.
- Safari, M. B., Bahadori, M., & Alimohammadzadeh, K. (2020). The Related Factors of Nurses' Participation and Perceived Benefits and Barriers in Health Policy Making. *Journal of Nursing Research*, 28(4), e103.
- Saunders, R. P., Evans, M. H., & Joshi, P. (2005). Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. *Health Promot Pract*, 6(2), 134-147.
- Savin-Baden, M., & Wimpenny, K. (2014). *A practical guide to arts-based research*. The Netherlands: Sense Publisher.
- Saxena, S., & Maj, M. (2017). Physical health of people with severe mental disorders: leave no one behind. *World Psychiatry*, 16(1), 1-2. doi:10.1002/wps.20403
- Selby, D. (1998). Bridging the gap?: a critical reading of Bhabha, Said and Spivak's postcolonial positions.
- Senn, T. E., & Carey, M. P. (2008). HIV, STD, and sexual risk reduction for individuals with a severe mental illness: review of the intervention literature. *Current psychiatry reviews*, 4(2), 87-100.

- Scarf, D., Zimmerman, H., Winter, T., Boden, H., Graham, S., Riordan, B. C., & Hunter, J. A. (2020). Association of Viewing the Films Joker or Terminator: Dark Fate With Prejudice Toward Individuals With Mental Illness. *JAMA Network Open*, 3(4), e203423-e203423.
- Shapiro, S. L., Astin, J. A., Bishop, S. R., & Cordova, M. (2005). Mindfulness-based stress reduction for health care professionals: results from a randomized trial. *International journal of stress management*, 12(2), 164.
- Schizophrenia Society of Canada. (2012). Learn about schizophrenia: Rays of hope. http://www.schizophrenia.ca/docs/Rays_of_Hope_4th_edition.pdf.
- Schizophrenia Society of Canada. (2020). *Learn more about schizophrenia*. https://www.schizophrenia.ca/learn_more_about_schizophrenia.php
- Schroeder, K., Kulage, K. M., & Lucero, R. (2015). Beyond positivism: Understanding and addressing childhood obesity disparities through a Critical Theory perspective. *Journals for Specialist in Pediatric Nursing*, 20(4), 259-270. doi:10.1111/jspn.12122
- Schomerus, G., Schwahn, C., Holzinger, A., Corrigan, P. W., Grabe, H. J., Carta, M. G., & Angermeyer, M. C. (2012). Evolution of public attitudes about mental illness: A systematic review and meta-analysis. *Acta Psychiatrica Scandinavica*, 125(6), 440-452.
- Schulze, B. (2007). Stigma and mental health professionals: a review of the evidence on an intricate relationship. *International review of psychiatry*, 19(2), 137-155.
- Schulte, P., & MacCabe, J. H. (2014). Clozapine: Gold Standard Treatment for Refractory Schizophrenia: Now or Never? *Treatment-Refractory Schizophrenia* (pp. 81-91): Springer.
- Schwanen, T. (2018). Towards decolonised knowledge about transport. *Palgrave Communications*, 4(1), 1-6.

- Schwarz, H. (2000). Mission impossible: Introducing postcolonial studies in the US academy. *A companion to postcolonial studies*, 1-20.
- Sharma, M. (2018). ‘Can the patient speak?’: postcolonialism and patient involvement in undergraduate and postgraduate medical education. *Medical education*, 52(5), 471-479.
- Shea, M. (2018). The Sheffield Carers’ Voices Project: Was It Therapeutic? *Cultivating Compassion* (pp. 213-227): Springer.
- Shedler, J. (2010). The efficacy of psychodynamic psychotherapy. *American psychologist*, 65(2), 98.
- Smith, D. J., Langan, J., McLean, G., Guthrie, B., & Mercer, S. W. (2013). Schizophrenia is associated with excess multiple physical-health comorbidities but low levels of recorded cardiovascular disease in primary care: cross-sectional study. *BMJ Open*, 3(4), e002808.
- Soundy, A., Wampers, M., Probst, M., De Hert, M., Stubbs, B., Vancampfort, D., . . . Ströhle, A. (2013). Physical activity and sedentary behaviour in outcare recipients with schizophrenia: A systematic review and meta-analysis. *International Journal of Therapy & Rehabilitation*, 20(12).
- Spector, R., Smojkis, M. & Chilton, L. (2011). Service-user involvement in a ward staff training project: Participants’ experiences of making digital stories. *Clinical Psychology Forum*, (220), 49–53.
- Spitzer, R. L., Lilienfeld, S. O., & Miller, M. B. (2005). Rosenhan Revisited: The Scientific Credibility of Lauren Slater's Pseudopatient Diagnosis Study¹. *The Journal of nervous and mental disease*, 193(11), 734-739.

- Stanley, S., & Laugharne, J. (2014). The impact of lifestyle factors on the physical health of people with a mental illness: a brief review. *International journal of behavioral medicine*, 21(2), 275-281.
- Staub, M. E. (2011). *Madness is civilization: When the diagnosis was social, 1948-1980*: University of Chicago Press.
- Stuart, H., Arboleda-Flórez, J., & Sartorius, N. (2012). *Paradigms lost: Fighting stigma and the lessons learned*. New York, NY, US: Oxford University Press.
- Stausberg, M., & Engler, S. (2016). *The Oxford handbook of the study of religion*: Oxford University Press.
- Sukhera, J., & Chahine, S. (2016). Reducing mental illness stigma through unconscious bias-informed education. *MedEdPublish*, 5.
- Steinberg, M. L., Williams, J. M., & Ziedonis, D. M. (2004). Financial implications of cigarette smoking among individuals with schizophrenia. *Tobacco Control*, 13(2), 206-206.
- Stenhouse, R., Tait, J., Hardy, P., & Sumner, T. (2013). Dangling conversations: reflections on the process of creating digital stories during a workshop with people with early-stage dementia. *Journal of psychiatric and mental health nursing*, 20(2), 134-141.
- Stokes, C., & Peet, M. (2004). Dietary sugar and polyunsaturated fatty acid consumption as predictors of severity of schizophrenia symptoms. *Nutritional neuroscience*, 7(4), 247-249.
- Stomski, N. J., & Morrison, P. (2017). Participation in mental healthcare: a qualitative meta-synthesis. *Int J Ment Health Syst*, 11, 67. doi:10.1186/s13033-017-0174-y
- StoryCenter. (2017a). Listen deeply, tell stories: About StoryCenter. (<https://www.storycenter.org/about/>).

StoryCenter. (2017b). Listen deeply, tell stories: Values & methods.

(<https://www.storycenter.org/about/>).

Strassnig, M., Brar, J. S., & Ganguli, R. (2003). Nutritional assessment of care recipients with schizophrenia: a preliminary study. *Schizophr Bull*, 29(2), 393-397.

Strongman, L. (2014). Postcolonialism and international development studies: a dialectical exchange? *Third World Quarterly*, 35(8), 1343-1354.

Szasz, T. (1961). *The myth of mental illness: Foundations of a theory of personal conduct* New York: Harper Perennial. *Original published*.

Szasz, T. S. (1962). *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*. Secker & Warburg.

Szasz, T. (1979). The myth of mental illness. In *Biomedical ethics and the law* (pp. 121-130): Springer.

Schneider, L. S., Dagerman, K. S., & Insel, P. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *Jama*, 294(15), 1934-1943.

Scott, J. W. (1991). The evidence of experience. *Critical inquiry*, 17(4), 773-797.

Shariff, N. (2014). Factors that act as facilitators and barriers to nurse leaders' participation in health policy development. *BMC nursing*, 13(1), 1-13.

Shorter, E. (2011). Still tilting at windmills: Commentary on... The myth of mental illness. *The Psychiatrist*, 35(5), 183-184.

Spivak, G. (1988). Can the subaltern speak? En. Nelson, C. & Grossberg, L.(Eds.), *Marxism and the interpretation of culture* (pp. 271-313). Urbana: University of Illinois Press.

Spivak, G. C. (1999). *A critique of postcolonial reason*: Harvard university press.

- Spivak, G. C., & Harasym, S. (2014). *The post-colonial critic: Interviews, strategies, dialogues*: Routledge.
- Spivak, G. C. (2004). Righting wrongs. *The South Atlantic Quarterly*, 103(2), 523-581.
- Spivak, G. C. (2005). Scattered speculations on the subaltern and the popular. *Postcolonial studies*, 8(4), 475-486.
- Srinivas, N. (2013). Could a subaltern manage? Identity work and habitus in a colonial workplace. *Organization Studies*, 34(11), 1655-1674.
- Summerfield, D. (2001). Does psychiatry stigmatize? *Journal of the Royal Society of Medicine*, 94(3), 148-149.
- Sutherland, A. (2017). Method and madness: de/colonising scholarship and theatre research with participants labelled mad. *Research in Drama Education: The Journal of Applied Theatre and Performance*, 22(3), 427-435.
- Taggart, H., & Bailey, S. (2015). Ending lethal discrimination against people with serious mental illness. *Br J Psychiatry*, 207(6), 469-470. doi:10.1192/bjp.bp.115.167759
- Taipale, H., Lähteenvuio, M., Tanskanen, A., Mittendorfer-Rutz, E., & Tiihonen, J. (2020). Comparative effectiveness of antipsychotics for risk of attempted or completed suicide among persons with schizophrenia. *Schizophr Bull.*
- Tanenbaum, S. J. (2006). The role of “evidence” in recovery from mental illness. *Health Care Analysis*, 14(4), 195-201.
- Thompson, D., Edelsberg, J., Colditz, G. A., Bird, A. P., & Oster, G. (1999). Lifetime health and economic consequences of obesity. *Archives of internal medicine*, 159(18), 2177-2183.

- Thompson, J. M., Buchbinder, S. B., & Shanks, N. H. (2012). An overview of healthcare management. *S, B Buchbinder and N, H Shanks (eds), Introduction to Health Care Management, 2.*
- Thornicroft, G., Rose, D., & Kassam, A. (2007). Discrimination in health care against people with mental illness. *International review of psychiatry, 19*(2), 113-122.
- Tiihonen, J., Lönnqvist, J., Wahlbeck, K., Klaukka, T., Niskanen, L., Tanskanen, A., & Haukka, J. (2009). 11-year follow-up of mortality in care recipients with schizophrenia: a population-based cohort study (FIN11 study). *The Lancet, 374*(9690), 620-627.
- Tikly, L. (1999). Postcolonialism and comparative education *Education, equity and transformation* (pp. 603-621): Springer.
- Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of advanced nursing, 48*(4), 388-396.
- Townley, B. (1993). Foucault, power/knowledge, and its relevance for human resource management. *Academy of Management Review, 18*(13), 518-545. doi: 10.5465/AMR.1993.9309035149
- Treffry-Goatley, A., Lessells, R., Sykes, P., Bärnighausen, T., de Oliveira, T., Moletsane, R., & Seeley, J. (2016). Understanding specific contexts of antiretroviral therapy adherence in rural South Africa: A thematic analysis of digital stories from a community with high HIV prevalence. *PloS one, 11*(2), e0148801.
- Tsai, K.-Y., Chung, T.-C., Lee, C.-C., Chou, Y.-M., Su, C.-Y., Shen, S.-P., . . . Chou, F. H.-C. (2014). Is low individual socioeconomic status (SES) in high-SES areas the same as low

- individual SES in low-SES areas: a 10-year follow-up schizophrenia study. *Social psychiatry and psychiatric epidemiology*, 49(1), 89-96.
- Turale, S., & Kunaviktikul, W. (2019). The contribution of nurses to health policy and advocacy requires leaders to provide training and mentorship. *International nursing review*, 66(3), 302-304.
- Turner, C. (2013). Deconstructing transitional justice. *Law and Critique*, 24(2), 193-209.
- Tuval-Maschlack, R., & Patton, B. (2015). Digital storytelling: Healing for the YouTube generation of veterans. J. Cohen., JL Johnson., & P. Orr.(Eds.), *Video and filmmaking as psychotherapy: Research and practice*, 146-162.
- Umberson, D., & Karas Montez, J. (2010). Social relationships and health: A flashpoint for health policy. *Journal of health and social behavior*, 51(1_suppl), S54-S66.
- Ungar, T., Knaak, S., & Szeto, A. C. (2016). Theoretical and practical considerations for combating mental illness stigma in health care. *Community Mental Health Journal*, 52(3), 262-271.
- van Bruinessen, I. R., van Weel-Baumgarten, E. M., Snippe, H. W., Gouw, H., Zijlstra, J. M., & van Dulmen, S. (2014). Active care recipient participation in the development of an online intervention. *JMIR Res Protoc*, 3(4).
- Van Herk, K. A., Smith, D., & Andrew, C. (2011). Examining our privileges and oppressions: incorporating an intersectionality paradigm into nursing. *Nursing inquiry*, 18(1), 29-39.
- Van Manen, M. (1997). Researching lived experience: Human science for an action sensitive pedagogy. Albany: SUNY Press.
- Vandenbergh, F., Gholam-Rezaee, M., Saigí-Morgui, N., Delacrétaz, A., Choong, E., Solida-Tozzi, A., . . . Hedjal, A. (2015). Importance of early weight changes to predict long-term

- weight gain during psychotropic drug treatment. *The Journal of clinical psychiatry*, 76(11), e1417-1423.
- Vanclay, F., Baines, J. T., & Taylor, C. N. (2013). Principles for ethical research involving humans: ethical professional practice in impact assessment Part I. *Impact Assessment and Project Appraisal*, 31(4), 243-253.
- Vandyk, A. D., & Baker, C. (2012). Qualitative descriptive study exploring schizophrenia and the everyday effect of medication-induced weight gain. *International Journal of Mental Health Nursing*, 21(4), 349-357.
- Victoria, H. (2016). *Telling tales: The development and impact of digital stories and digital storytelling in healthcare*. Manchester Metropolitan University.
- Vivienne, S., & Burgess, J. (2012). The digital storyteller's stage: Queer everyday activists negotiating privacy and publicness. *Journal of Broadcasting & Electronic Media*, 56(3), 362-377.
- Voronka, J. (2016). The politics of 'people with lived experience' Experiential authority and the risks of strategic essentialism. *Philosophy, Psychiatry, & Psychology*, 23(3), 189-201.
- Walsh, C. A., Rutherford, G. E., & Kuzmak, N. (2009). Characteristics of home: Perspectives of women who are homeless. *The Qualitative Report*, 14(2), 299-317.
- Walsh, J., Stevenson, C., Cutcliffe, J., & Zinck, K. (2008). Creating a space for recovery-focused psychiatric nursing care. *Nursing Inquiry*, 15, 251–259. doi:10.1111/j.1440-1800.2008.00422.x
- Walsh, C. A., Shier, M. L., Sitter, K. C., & Sieppert, J. D. (2010). Applied Methods of Teaching about Oppression and Diversity to Graduate Social Work Students: A Case Example of Digital Stories. *Canadian Journal for the Scholarship of Teaching and Learning*, 1(2), 3.

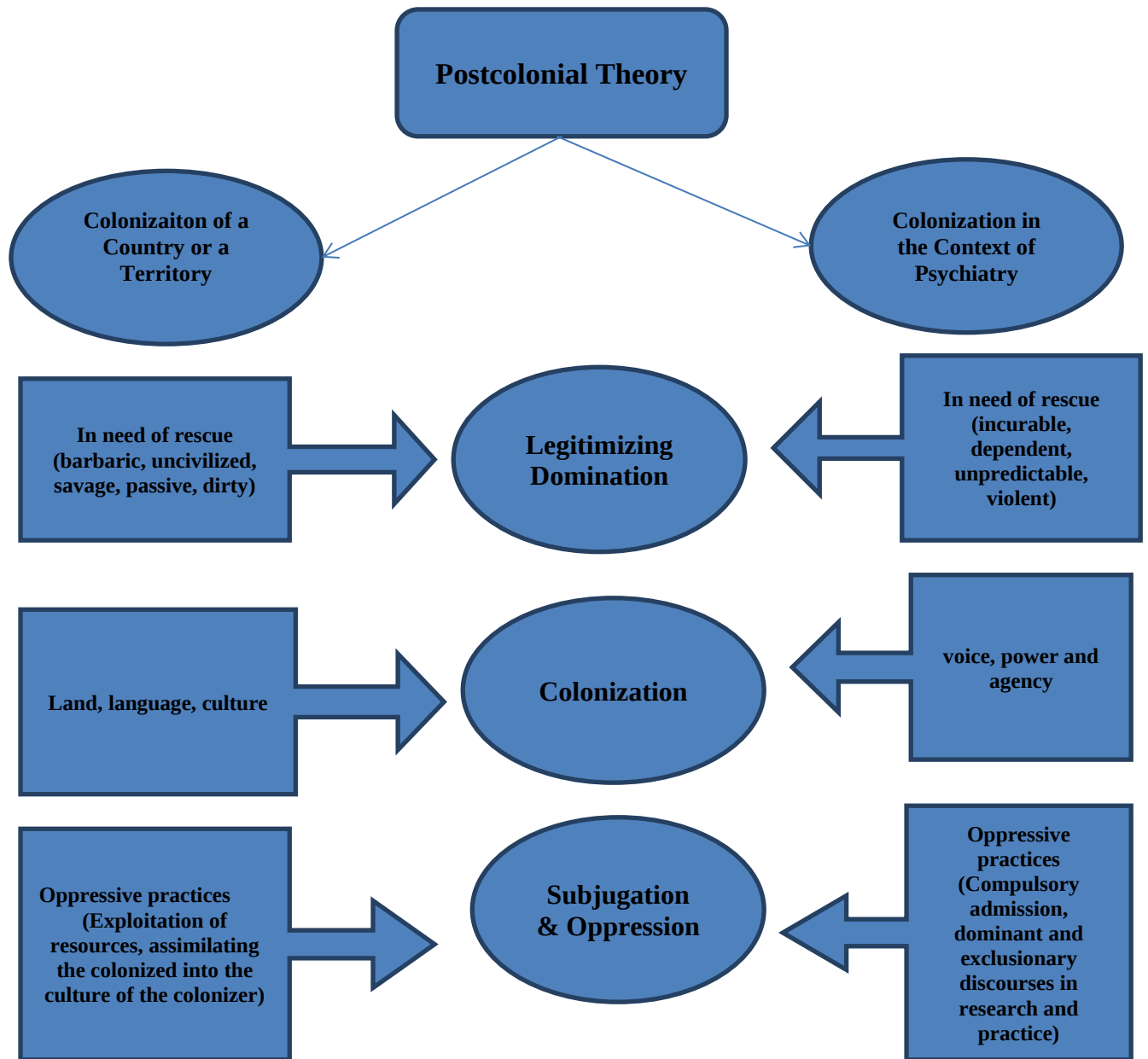
- Wand, T. (2019). Is it time to end our complicity with pharmacocentricity? *International Journal of Mental Health Nursing*, 28(1), 3-6. <https://doi.org/10.1111/inm.12554>
- Watts, G. (2012). More psychiatrists attack plans for DSM-5. In: British Medical Journal Publishing Group.
- Wacker, J. G. (1998). A definition of theory: research guidelines for different theory-building research methods in operations management. *Journal of operations management*, 16(4), 361-385.
- Wake, D. G. (2012). Exploring rural contexts with digital storytelling. *The Rural Educator*, 33(3).
- Walker, E. R., McGee, R. E., & Druss, B. G. (2015). Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. *JAMA Psychiatry*, 72(4), 334-341. doi:10.1001/jamapsychiatry.2014.2502
- Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: portraits of participation. *Health Educ Q*, 21(2), 171-186.
- Wang, C., & Burris, M. A. (1997). Photovoice: concept, methodology, and use for participatory needs assessment. *Health Educ Behav*, 24(3), 369-387.
- Watson, L. A., & Girard, F. M. (2004). Establishing integrity and avoiding methodological misunderstanding. *Qualitative health research*, 14(6), 875-881.
- Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of advanced nursing*, 53(4), 459-469.
- Wexler, L. (2011). Intergenerational dialogue exchange and action: Introducing a community-based participatory approach to connect youth, adults and elders in an Alaskan Native community. *International Journal of Qualitative Methods*, 10(3), 248-264.

- Wexler, L., Eglinton, K., & Gubrium, A. (2014). Using digital stories to understand the lives of Alaska Native young people. *Youth & Society*, 46(4), 478-504.
- Wexler, L., Gubrium, A., Griffin, M., & DiFulvio, G. (2013). Promoting positive youth development and highlighting reasons for living in Northwest Alaska through digital storytelling. *Health Promot Pract*, 14(4), 617-623. doi:10.1177/1524839912462390
- Wijnen, E., & Wildschut, M. (2015). Narrating goals: a case study on the contribution of Digital Storytelling to cross-cultural leadership development. *Sport in Society*, 18(8), 938-951. doi:10.1080/17430437.2014.997584
- Williams, P., & Chrisman, L. (1994). *Colonial discourse and post-colonial theory: A reader*: Columbia University Press.
- Willis, N., Frewin, L., Miller, A., Dziwa, C., Mavhu, W., & Cowan, F. (2014). “My story”—HIV positive adolescents tell their story through film. *Children and Youth Services Review*, 45, 129-136.
- Wils, R. S., Gotfredsen, D. R., Hjorthøj, C., Austin, S. F., Albert, N., Secher, R. G., Thorup, A. A. E., Mors, O., & Nordentoft, M. (2017). Antipsychotic medication and remission of psychotic symptoms 10 years after a first-episode psychosis. *Schizophrenia research*, 182, 42-48.
- Wilson, D. K., Hutson, S. P., & Wyatt, T. H. (2015). Exploring the role of digital storytelling in pediatric oncology care recipients’ perspectives regarding diagnosis: A literature review. *SAGE Open*, 5(1), 2158244015572099.
- Wirshing, D. A., Pierre, J. M., Erhart, S. M., & Boyd, J. A. (2003). Understanding the new and evolving profile of adverse drug effects in schizophrenia. *The Psychiatric Clinics of North America*, 26(1), 165-190.

- Wirshing, D. A., Pierre, J. M., Marder, S. R., Saunders, C. S., & Wirshing, W. C. (2002). Sexual side effects of novel antipsychotic medications. *Schizophrenia research*, 56(1), 25-30.
- Whitaker, R. (2001). *Mad in America: Bad science, bad medicine, and the enduring mistreatment of the mentally ill*. Basic Books.
- Whitaker, R. (2010). *Anatomy of an epidemic: Magic bullets, psychiatric drugs, and the astonishing rise of mental illness in America*. Random House Digital, Inc.
- Whitaker, R. (2016). The case against antipsychotics: A review of their long-term effects. *Mad in America Foundation*, 62(1), 5-13.
- Whitley, R. (2012). The antipsychiatry movement: dead, diminishing, or developing? *Psychiatric Services*, 63(10), 1039-1041.
- World Health Organization. (2013). Mental health action plan 2013-2020.
- World Health Organization. (2010). A conceptual framework for action on the social determinants of health.
https://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf
- World Health Organization. (2018). Management of physical health conditions in adults with severe mental disorder: WHO guidelines.
<https://apps.who.int/iris/bitstream/handle/10665/275718/9789241550383-eng.pdf?ua=1>
- World Health Organization. (2019). *Schizophrenia*. <https://www.who.int/news-room/fact-sheets/detail/schizophrenia>
- Wunderink, L., Nieboer, R. M., Wiersma, D., Sytema, S., & Nienhuis, F. J. (2013). Recovery in remitted first-episode psychosis at 7 years of follow-up of an early dose

- reduction/discontinuation or maintenance treatment strategy: long-term follow-up of a 2-year randomized clinical trial. *JAMA Psychiatry*, 70(9), 913-920.
- Young, R. J. C. (1999). Academic activism and knowledge formation in postcolonial critique. *Postcolonial Studies*, 2(1), 29–34.
- Young, R. J. (2009). What is the Postcolonial? *Ariel: A review of international English literature*, 40(1).
- Young, R. J. (2016). *Postcolonialism: An historical introduction*: John Wiley & Sons.
- Zhang, Q., & Wang, Y. (2004). Trends in the association between obesity and socioeconomic status in US adults: 1971 to 2000. *Obesity*, 12(10), 1622-1632.
- Zhang, J.-P. (2016). The benefits of antipsychotic drugs: symptom control and improved quality of life. In *Life-Threatening Effects of Antipsychotic Drugs* (pp. 295-309). Elsevier.

Appendix A: Relevance of Postcolonial Theory-Colonization in Psychiatry



Appendix B: Inclusion & Exclusion Criteria of Digital Storytelling Participants with Justification

Inclusion	Justification
-People with psychotic disorders (Schizophrenia/Schizoaffective disorder) -In stable condition	- People with schizophrenia, on average, die 20 years earlier than the general population due to poor physical health (WHO, 2018). Limited qualitative research has investigated the perspectives and challenges of physical health management for people with schizophrenia including barriers and facilitators to strategies that are feasible and acceptable. The contemporary construction of knowledge for people with psychotic disorders typically relies on patterns of inclusion and exclusion within healthcare settings. Under the biomedical model, perspectives, experiences of people with schizophrenia are subjugated as symptoms of the disease process, perpetuating dominant discourses that exclude patient's voice in research and practice. -Schizoaffective disorder is a condition in which a person experiences a combination of schizophrenia symptoms [hallucination or delusion] and mood disorder [mania or depression] (Topcu, Buchanan, Aubeeluck, & Garip, 2016). Both groups (people with schizophrenia & schizoaffective disorder) are at increased risk for poor physical health and development of chronic and life-threatening diseases.
-English speaking	- Sessions will be delivered in English
-Age 18 or older	- Six to eight people are required for this study. About 75% of people living with schizophrenia/schizoaffective disorder develop it between the ages of 16- 40. The following age range provides a reasonable sampling plan.
Living in the community & able to consent	-Community was selected as a setting for this study because at this stage, patients' mental symptoms such as hallucinations and delusions are more controlled and the chances of collaborating with the facilitator to make a digital story is higher -Participants showing signs of deterioration will be withdrawn from the study
Exclusion Criteria	Justification
-Diagnosis other than psychotic disorders	-The study is targeting people with psychotic disorders; therefore, patients who have another diagnosis will be excluded to ensure that the sample is representative of this population
-People who do not meet the inclusion criteria	- Those who meet the inclusion criteria are suitable for the design and the purpose of the study. Those who do not meet the inclusion criteria are excluded because they are not suitable for the purpose or the design of the study

Appendix C: Letter to Help with Recruitment Process

Purpose of the study- The purpose of my study is to explore the use of digital storytelling with people with psychotic disorders as a means of expressing their voice, and then to understand how nurses and healthcare managers perceive the digital stories. More specifically, I will 1) explore how people with psychotic disorders express their physical health needs, concerns and priorities through digital storytelling, 2) evaluate the process of making digital stories with people with psychotic disorders about their physical health, 3) explore how nurses and healthcare managers respond to the digital stories.

Just to provide you with some background- My concern with the physical health and more specifically obesity in people with psychotic disorders began when I worked as an agency staff nurse at the Royal Ottawa Hospital. While searching the literature, I found limited research has investigated the perspectives and challenges of physical health management for people with psychotic disorders. I had an interest to look at this problem from a critical perspective and help give voice to people with psychotic disorders.

The importance of this project- People with psychotic disorders are usually marginalized from mainstream society, community engagement, and political involvement. Creating knowledge to invoke meaningful change at practice or policy levels requires understanding the experiences and voice typically not heard. Uncovering voices of people with psychotic disorders requires methodologies that can authentically engage with participants in knowledge production.

About digital storytelling- Digital storytelling is an audio-visual vignette of approximately 2-5 minutes in length with a first-person narrative. It is an innovative methodology that can engage marginalized groups in participatory processes and raise awareness of subjugated knowledge from people who are not typically included in research. By presenting new possibilities for describing, reflecting, and sharing experiences, digital storytelling makes experiences and meanings tangible through audiovisual presentation. The 'digital' aspect takes advantage of technology through low-cost production. Digital stories produced with participants can engage with people to generate empathic bridges, raise awareness, promote compassion, and drive patient-centred change and innovation.

Inclusion criteria- For this study, I am looking for 6-8 participants with the following criteria: 1) primary diagnosis of schizophrenia/ schizoaffective disorder, 2) 18 years or older, 3), English speaking, 4) living in the community (in the region of Ottawa and well enough to provide consent). Those expressing interest will be subsequently scheduled for a pre-interview at a convenient location of their choice. In the pre-interview phase, I will explain the purpose of the study, describe the process of digital storytelling from conception to post-production, review examples of digital storytelling and obtain consent from participants.

The process of digital storytelling- Digital storytelling sessions will be held at a convenient location of participants' choice. The place needs to provide a quiet and private room to ensure confidentiality. Participants will be informed of options for location, including a conference or library meeting room at the University of Ottawa. Participants will be invited to meet individually with me to construct their story narrative. In these sessions, I will encourage them to

discuss their physical health needs, concerns, barriers, and facilitators to managing their physical health. I will help them construct their narratives to address not only their physiological health problems, but the factors that contribute to poor physical health such as socioeconomic context.

Participants will then receive one-on-one assistance from me to compose, edit, review and construct a personally meaningful digital story. In collaboration, participants will identify themes and craft scenes that are central to their digital story. Narratives from Phase-I will be used to guide the process. To contextualize the story and express emotional content, participants will be encouraged to select images or photographs that implicitly or explicitly relate to the situations described. In this collaborative process, I will navigate the software in order to help participants craft their stories. Participants will also be coached to record an audio for the digital story. Once audios are recorded and images/photos are assembled, I will guide participants through simple video-editing using a tutorial designed to help edit digital stories. Several one-on-one sessions may be needed to complete the digital stories based on participants' needs. The final product will be an audio-visual vignette of approximately two to five minutes in length which presents a first-person narrative in conjunction with visual material. Participants will receive a final version of their story in a playable DVD format and digital copy. I will supply the computer (personal laptop) and the software on which the digital stories will be developed. Following the completion of digital stories, an individual semi-structured interview will be conducted with each participant to evaluate the process of digital storytelling.

What happens to the Digital stories- Digital stories will be screened in a focus group with a convenience sample of nurses and healthcare managers, who will be recruited from graduate programs at the University of Ottawa. Presentation of stories will depend on participant's consent. Participants' rights are central to the study and my approach to consent is a multi-step process. Participants should not feel coerced into participating, and they can consent to making the digital stories but not to the interview, and/or the sharing with the focus group participants (nurses and managers). They determine the extent to which their digital story is shared with either just myself and my supervisors, or myself, supervisors and the nurses and healthcare managers will participate in the focus group. Consent for sharing can be revised once the story is completed.

Being a mental health nurse, I am aware that participants may feel anxious to create/produce something that I will find "satisfactory" (even though it's not my role/purpose as facilitator), they may feel pressure to "perform" a certain way. However, I am sensitive to this and I will guide them gently through the process to help alleviate their anxieties and they feel in control of the process. We would appreciate your support in disseminating this information to organizations and potential participants.



Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

Appendix D: Information Letter & Consent

Digital Storytelling-A Methodology for Engaging People with Schizophrenia in a Participatory Research Approach

RESEARCHERS

Principal Investigator

Liquaa Wazni, RN, PhD (c)
School of Nursing
Faculty of Health Sciences
University of Ottawa

Supervisors

Wendy Gifford, RN, PhD
Associate Professor
School of Nursing
Co-Director, Nursing Best Practice Research Center (NBPRC)
Faculty of Health Sciences
University of Ottawa
Phone (613) 562-5800 ext. 8975
wgifford@uottawa.ca

Amélie Perron, RN, PhD
Associate Professor
School of Nursing
Faculty of Health Sciences
University of Ottawa
Phone (613) 562-5800 ext. 8433
amelie.perron@uottawa.ca

613 562-5473
613 562-5443

451 Smyth
Ottawa ON K1H 8M5 Canada

www.uOttawa.ca

INVITATION TO PARTICIPATE:

You are invited to participate in a doctoral research that will be conducted by Liquaa Wazni, RN, PhD(c). The purpose of this study is two-fold: 1) to help people with schizophrenia express their physical health needs and concerns through a creative process known as digital storytelling, and 2) to determine how nurses and healthcare managers respond to these digital stories. Digital stories are an audio-visual vignette of approximately 2-5 minutes in length which present a first-person story in conjunction with audiovisual material (photos, images, soundtracks, etc.). The purpose of this research is to explore the process of digital storytelling with people diagnosed with schizophrenia as a means of expressing their voice. Your participation relates to the first aim of the study.

PARTICIPATION:

Participation in this study will require attending one-on-one sessions with the primary researcher (LW) to produce a digital story. Digital storytelling sessions will be held at a convenient location of your choice. The location must provide a quiet and private room to ensure confidentiality. Some options include a conference or library meeting room at the University of Ottawa but you are free to suggest other preferences. Several sessions might be required to complete the digital story based on your needs. Each session will take 60 to 90 minutes. The sessions will be scheduled and held at a time mutually agreed upon. This could include regular working hours or be outside of usual working hours (e.g. Saturday). Your participation will consist of two stages:

Stage 1-Developing a Digital Story

You will be invited to meet individually with the primary researcher (LW) to construct your story narrative. In these sessions, you will be encouraged to discuss your physical health needs and concerns. The primary researcher (LW) will help you construct your story to address not only your physiological health problems, but the factors underlying your health needs. You will then receive one-on-one assistance from the researcher (LW) to compose, edit, review and construct a personally meaningful digital story. In collaboration with the researcher, you will identify themes and draft scenes that are central to your digital story. To contextualize the story and express emotional content, you will be encouraged to select images or photographs that directly or indirectly relate to the situations described. In this collaborative process, the researcher (LW) will navigate the software in order to help you craft your story. You will also be coached to record an audio for the digital story. Once audios are recorded and images/photos are assembled, the researcher will guide you through simple video-editing using a tutorial. You will receive a final version of your story in a playable DVD format and digital copy. The researcher (LW) will supply the computer (personal laptop) and the software on which the digital stories will be developed.

Stage 2-Evaluation of the Digital Storytelling Process

Following the completion of your digital story, you will be invited to participate in **one** individual interview to evaluate the digital storytelling process. This interview will take approximately 30 to 40 minutes and will be scheduled and held at a time mutually agreed upon by you and the researcher. It will be digitally recorded and transcribed. The audio recording will then be deleted.

Part of the purpose of this study is to explore the potential impact of digital stories on healthcare practices. Several digital stories will be presented to 6 to 8 nurses and healthcare managers during a focus group session. If you agree, your digital story will be included in the viewing. Focus groups participants will view the stories and discuss the way these stories provide a meaningful source of information and evidence towards the advancement of healthcare practices and policies in the care of persons diagnosed with schizophrenia.

RISKS:

Participation in this study will entail that you share personal information which could reveal your identity. You may also feel anxious to create/produce something that the researcher (LW) will find "satisfactory". Every effort will be made to minimize these risks. Presentation of your story will depend on your consent. You will determine the extent to which your digital story is shared with 1) the primary researcher and supervisors, or 2) the primary researcher, supervisors and nurses and healthcare managers who will participate in the focus group. Consent for sharing can be revised once the story is completed. Being identified in the digital video will disclose your illness to the members of the focus group (nurses/healthcare leaders). Your participation is voluntary, and you can withdraw (stop taking part) at any time without any negative consequences. Over the course of the study, the primary researcher (LW) will check in with you to see if you still wish to continue participating.

CONFIDENTIALITY AND ANONYMITY:

Information in digital stories cannot be completely confidential. Given the nature of digital storytelling, you will use your voice and possibly images of your choosing which may reveal your identity. You have the option to remain anonymous or be identified within your story. If you elect to be anonymous, you will be provided with a pseudonym and your identifying information will be modified (e.g. photographs blurred). You also have the option to use your real name in connection with the story. You will determine the extent to which your digital story is shared: 1) only with the primary researcher and supervisors, or 2) only with the primary researcher, supervisors and nurses and healthcare managers who will participate in the focus group. Your story will not be shared with anyone else or in any other context. All information collected during the evaluation interview will be kept strictly **confidential** and only be used for the purposes of this study. Data collected from the individual interview will be protected and kept **anonymous** in the following ways:

- ♦ your name will not be associated in any way with the study;
- ♦ Your name will not appear on any information collected. A numerical identification code will be used on your interview transcription, and electronic copies of the data.
- ♦ Your name and corresponding identification code will be kept in a locked research office at the University of Ottawa, Nursing Best Practice Research Center.
- ♦ No names of individuals will be used in transcriptions or reporting of results – a numerical identification code will be used.
- ♦ Quotes used in reports or publications will not reveal your identity.

BENEFITS:

Participation in this study might give you a sense of creative accomplishment and empowerment. You will have the opportunity to produce a digital story which you are free to share with others. Your participation in this study will also give you an opportunity to express your physical health

needs and concerns, and, if you consent, share these with healthcare providers in an innovative way. Many people with schizophrenia report feeling unheard or misunderstood. Your participation in this study will help determine if digital storytelling can provide a means of expressing and sharing your voice with healthcare providers. Being identified in the digital storytelling may give you a sense of empowerment for owning your story.

CONSERVATION OF DATA:

The researcher (LW) will supply the computer (personal laptop) and the software on which the digital stories will be developed. The laptop will be solely used for this research project. The hard drive and each participant's file will only be accessed by a secret user ID and password. Digital files of the stories, audio recordings of interviews, electronic and paper copies of transcriptions and research notes will be kept secure in a locked research office at the University of Ottawa, Nursing Best Practice Research Center (NBPRC). Only the researchers named in the consent form will have access to the raw data. After completion of the study, data will remain stored in this manner for five years (e.g.2018-2023), then it will be destroyed.

COMPENSATION:

You will receive a compensaiton of \$30 which will be paid in full at the beginning of the first interview. You will keep the compensation even if you choose to withdraw from the research.

VOLUNTARY PARTICIPATION:

You are under no obligation to participate and if you choose to participate you can withdraw from the study at any time and/or refuse to answer any questions without suffering negative consequences. If you withdraw from the study, you can choose to have all your data destroyed. Your signature on this form indicates that you understand the information in this consent form and that you agree to participate. By signing this form, you are neither waiving your legal rights as a research participant nor are you releasing the investigators from their legal and professional responsibilities.

If you have any questions about the study, you may contact the researcher, Liquaa Wazni. This study has received ethics approval from the Research Ethics Board of the University of Ottawa. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, Tel.: (613) 562-5387. Email: ethics@uottawa.ca

CONSENT

I, _____ (*Name of participant*) have read and understood this consent form and I agree to participate in the above research study conducted by Liquaa Wazni RN, PhD(c), School of Nursing, Faculty of Health Sciences, University of Ottawa. All my questions and concerns were addressed to my satisfaction. I may contact the investigators of the study at any time for further information.

I accept to have my interview digitally recorded: Yes ☐ No ☐

I consent to have my digital story shared with:

1) the primary researcher and supervisors Yes ☐ No ☐

2) the primary researcher, supervisors and nurses and healthcare managers who will participate in the focus group Yes ☐ No ☐

I consent to be identified in:

Photographs Yes ☐ No ☐

Videos Yes ☐ No ☐

I accept to be quoted directly, as long as any identifying information is removed: Yes ☐
No ☐

I agree to participate in this study. There are 2 copies of this consent form, one of which is mine to keep.

Participant's signature: _____

Investigator's signature: _____

Date: _____

Lettre d'information & consentement

La narration numérique: une méthodologie pour engager les personnes atteintes de schizophrénie dans une approche de recherche participative

Chercheuse principale

Liquaa Wazni, IA, PhD (c)
École des sciences infirmières
Faculté des sciences de la santé
Université d'Ottawa

Directrices de thèse

Wendy Gifford, IA, PhD
Professeure agrégée
École des sciences infirmières
Co-directrice, Nursing Best Practice Research Center (NBPRC)
Faculté des sciences de la santé
Université d'Ottawa
Téléphone (613) 562-5800 poste 8975
wgifford@uottawa.ca

Amélie Perron, IA, PhD
Professeure agrégée
École des sciences infirmières
Faculté des sciences de la santé
Université d'Ottawa
Téléphone (613) 562-5800 poste 8433
amelie.perron@uottawa.ca

INVITATION À PARTICIPER:

Vous êtes invité(e) à participer à une étude de doctorat menée par Liquaa Wazni, IA, PhD(c). Cette étude comporte deux objectifs : 1) aider les personnes diagnostiquées avec de la schizophrénie à exprimer leurs préoccupations et leurs besoins de santé physique, à travers un processus créatif de narration numérique, et 2) déterminer comment des infirmières et gestionnaires de soins répondent à ces narrations numériques. Les histoires numériques consistent en des vignettes audiovisuelles qui durent de 2 à 5 minutes et qui présentent un récit à la première personne à l'aide de matériel audiovisuel (photos, images, bandes sonores etc.). Le but de cette étude est d'explorer dans quelle mesure le processus de narration numérique peut servir de moyen d'expression pour des personnes atteintes de schizophrénie.

PARTICIPATION:

Votre participation à cette recherche implique d'assister à des sessions individuelles avec la chercheuse principale (LW) pour créer une narration numérique. Les sessions se tiendront à un endroit qui vous convient. Cet endroit doit fournir une pièce calme et privée pour assurer la confidentialité. Vous avez l'option d'assister à ces sessions à l'Université d'Ottawa dans une salle de rencontre à la bibliothèque ou une salle de conférence mais vous pouvez suggérer d'autres options. Plusieurs sessions peuvent être nécessaires, selon vos besoins, pour compléter le récit. Chaque session durera entre 60 et 90 minutes. Les sessions se tiendront à une date et une heure convenues d'un commun accord. Cela peut inclure pendant les heures régulières de travail ou en-dehors de celles-ci (ex : samedi). Votre participation consiste en 2 étapes:

Étape 1 : Développement d'un récit numérique

Vous serez invité(e) à rencontrer la chercheuse principale (LW) de manière individuelle pour construire votre histoire. Pendant cette rencontre, vous serez invité(e) à discuter de vos préoccupations et de vos besoins en lien avec votre santé physique. La chercheuse principale vous aidera à développer votre récit pour refléter vos préoccupations de santé physique, mais aussi les facteurs sous-jacents. Vous recevrez ensuite de l'aide en un-à-un de la part de la chercheuse pour composer, éditer, réviser et produire une histoire qui est significative pour vous. En collaboration avec la chercheuse, vous identifierez des thèmes et élaborerez des scènes qui seront centrales à votre récit. Pour donner du contexte et du contenu émotif à votre histoire, vous serez encouragé(e) à choisir des images ou des photos qui évoquent directement ou indirectement les situations décrites. Dans ce processus collaboratif, la chercheuse principale naviguera le logiciel pour vous aider à développer votre récit numérique. Vous serez aussi accompagné(e) pour l'enregistrement d'une bande sonore (audio) pour votre récit. Une fois la bande sonore enregistrée et les images/photos assemblées, la chercheuse vous guidera à travers un tutoriel simple permettant d'éditer des vidéos. Une version finale de votre narration numérique vous sera remise en copie électronique et sur support DVD. La chercheuse fournira l'ordinateur portable et le logiciel servant à créer les narrations numériques.

Étape 2 : Évaluation du processus

Lorsque votre récit numérique sera terminé, vous serez invité(e) à participer à **une** entrevue individuelle pour évaluer le processus de développement d'un récit numérique. Cette entrevue durera environ 30 à 40 minutes, et elle aura lieu à un moment décidé d'un commun accord. L'entrevue sera enregistrée en format audio puis retranscrite. L'enregistrement audio sera alors effacé.

L'un des objectifs de cette étude est d'explorer l'impact potentiel des récits numériques sur les pratiques de soins. Plusieurs récits numériques seront présentés à 6 à 8 infirmières et gestionnaires en santé pendant un groupe focus. Si vous y consentez, votre récit sera inclus dans le visionnement. Les participants au groupe focus visionneront les histoires et discuteront de la manière dont de tels récits peuvent servir de source significative d'information et de donnée probante pour l'avancement des pratiques et des politiques de soins auprès des personnes atteintes de schizophrénie.

RISQUES:

Votre participation dans cette étude implique que vous partagiez des informations qui pourraient révéler votre identité. Vous pourriez aussi ressentir de l'anxiété pour produire un récit que la chercheuse (LW) trouvera « satisfaisant ». Tous les efforts seront faits pour minimiser ces risques. La présentation de votre récit au groupe focus dépendra de votre consentement. Vous déterminerez si votre récit sera partagé avec 1) la chercheuse principale et ses directrices de thèse; ou 2) la chercheuse principale, ses directrices de thèse et les participants du groupe focus. Le consentement peut être reconsidéré une fois votre histoire numérique terminée. Être identifié dans la vidéo numérique révélera votre maladie aux membres du groupe de discussion (infirmières / gestionnaires en santé).

Votre participation est entièrement volontaire et vous pouvez vous retirer de l'étude à tout moment sans aucune conséquence négative pour vous. Pendant le déroulement de l'étude, la chercheuse principale (LW) vérifiera avec vous de temps à autre si vous désirez toujours participer.

CONFIDENTIALITÉ ET ANONYMAT:

L'information partagée dans les histoires numériques ne peut pas être entièrement confidentielle. Compte tenu de la nature de la narration numérique, vous utiliserez votre voix et possiblement des images de votre choix qui pourraient révéler votre identité. Vous aurez l'option de rester anonyme dans votre histoire. Si vous choisissez de demeurer anonyme, vous vous ferez assigner un pseudonyme (nom fictif) et votre information personnelle sera modifiée (par exemple, les photos seront brouillées). Vous aurez l'option d'utiliser votre vrai nom dans votre histoire. Vous déterminerez dans quelle mesure votre histoire sera partagée : avec 1) la chercheuse principale et ses directrices de thèse seulement; ou 2) la chercheuse principale, ses directrices de thèse et les participants du groupe focus seulement. Votre histoire ne sera partagée avec aucune personne, ou dans aucun autre contexte. Toute information recueillie pendant l'entrevue d'évaluation sera **strictement** confidentielle et ne sera utilisée qu'aux fins de l'étude. Les données recueillies pendant les entrevues seront protégées et votre anonymat sera maintenu de la manière suivante :

- Votre nom ne sera associé d'aucune manière avec cette étude;
- Votre nom n'apparaîtra pas dans les données recueillies. Un code numérique sera utilisé pour identifier la transcription de votre entrevue et la copie électronique de vos données.
- Votre nom et le code numérique correspondant seront conservés dans un bureau de recherche verrouillé à l'Université d'Ottawa au Nursing Best Practice Research Center.
- Tous les noms (personnes, milieu de soins, ville, etc.) seront éliminés de la transcription d'entrevue. Aucun nom n'apparaîtra dans le rapport de recherche ou les publications. Le code numérique sera utilisé.

- Les extraits d’entrevue utilisés dans le rapport de recherche ou les publications ne révéleront pas votre identité.

BÉNÉFICES:

Participer à cette étude pourrait vous donner un sentiment d’accomplissement créatif et d’autonomie. Vous aurez l’occasion de créer une histoire numérique que vous serez libre de partager avec vos proches. Votre participation vous donnera également l’occasion d’exprimer vos préoccupations et vos besoins en lien avec votre santé physique et, si vous y consentez, partager ceux-ci avec des fournisseurs de soins de santé d’une manière novatrice. De nombreuses personnes atteintes de schizophrénie affirment ne pas se sentir écoutées ou comprises. Votre participation aidera à déterminer si la narration numérique peut servir de moyen d’expression et à faire entendre votre voix auprès de fournisseurs de soins de santé. Être identifié dans la narration numérique peut vous donner un sentiment d’accomplissement pour posséder votre histoire.

CONSERVATION DES DONNEES:

La chercheuse principale (LW) fournira l’ordinateur portable et le logiciel à partir desquels les histoires numériques seront développées. L’ordinateur portable ne sera utilisé que pour ce projet de recherche. Le disque dur et les fichiers pour chaque participant ne seront accessibles que par un code d’identification et un mot de passe secrets. Les histoires numériques, les enregistrements audio, les copies électroniques et papier des transcriptions et les notes de recherche seront conservés de manière sécuritaire dans un bureau de recherche verrouillé à l’Université d’Ottawa au Nursing Best Practice Research Center. Seules les chercheuses dont le nom apparaît sur le présent formulaire de consentement auront accès aux données de recherche. Lorsque l’étude sera terminée, les données seront conservées ainsi pendant 5 ans (2018-2023) puis elles seront détruites.

COMPENSATION:

Vous aurez une compensation de 30 \$ que vous recevrez intégralement au début du groupe de discussion. Vous conserverez cette compensation même si vous choisissez de vous retirer de la recherche.

PARTICIPATION VOLONTAIRE:

Votre participation à cette recherche est entièrement libre, et si vous décidez de participer vous pouvez vous retirer en tout temps et/ou vous pouvez refuser de répondre à des questions sans subir de conséquences négatives. Si vous choisissez de vous retirer de l’étude, vous pouvez demander que toutes vos données soient détruites. Votre signature sur ce formulaire indique que vous avez compris l’information dans ce formulaire de consentement et que vous acceptez de participer. En signant ce formulaire, vous ne renoncez pas à vos droits en tant que participant(e) de recherche et vous ne libérez pas les chercheuses de leurs responsabilités légales et professionnelles.

Si vous avez des questions au sujet de cette étude, vous pouvez contacter Liguiaa Wazni. Ce projet de recherche a reçu l’approbation éthique du Comité d’éthique de la recherche de l’Université d’Ottawa. Toute question sur la conduite éthique de cette recherche peut être communiquée au responsable de l’éthique de la recherche, Université d’Ottawa, Pavillon

Tabaret, bureau 154, 550 rue Cumberland, Ottawa, ON K1N 6N5; téléphone (613) 562.5387;
ethique@uottawa.ca.

CONSENTEMENT:

Je, _____ (nom en lettres moulées), déclare avoir lu et compris les termes du présent formulaire et je consens à participer à cette étude menée par Liguana Wazni IA, PhD(c), École des sciences infirmières, Faculté des sciences de la santé, Université d'Ottawa. On a répondu à toutes mes questions et préoccupations à ma satisfaction. Je peux contacter les chercheurs de cette étude en tout temps pour de l'information supplémentaire.

J'accepte d'être enregistré(e) sur bande audio : Oui ☐ Non ☐

Je consens à partager ma narration numérique avec:

1) la chercheuse principale et ses directrices de thèse Oui ☐ Non ☐

2) la chercheuse principale, ses directrices de thèse et les participants du groupe focus Oui ☐
Non ☐

Je consens à être identifié dans:

Vidéo Oui ☐ Non ☐

Photographie Oui ☐ Non ☐

J'accepte que mes propos puissent être cités de manière intégrale à condition que toute information pouvant m'identifier soit éliminée : Oui ☐ Non ☐

Je consens à participer à cette étude. Il y a deux copies de ce formulaire de consentement et je peux garder l'une d'elles.

Signature du participant: _____

Signature de la chercheuse: _____

Date: _____

Appendix E: Recruitment Poster for the Digital Storytelling Participants



Living with Schizophrenia/Schizoaffective Disorder? Interested in Talking About Your Physical Health Needs & Concerns? Do You Want to Make Your Voice Heard?



Liquaa Wazni RN, PhD (c), Wendy Gifford RN, PhD, & Amélie Perron RN, PhD

Invitation to participate: You are invited to participate in a doctoral research study being conducted by Liquaa Wazni, a Registered Nurse and PhD candidate at the University of Ottawa. This research aims to help people with schizophrenia express their physical health needs and concerns through a creative process known as digital storytelling, which includes using photos, images, soundtracks, and a computer software to tell a story.

Process of digital storytelling: As a participant in the study, you will take part in four to six, one-on-one sessions with the researcher (LW) to construct a digital story about your physical health needs and concerns. Following the completion of your digital story, you will participate in one interview to evaluate the process of digital storytelling.

Inclusion criteria:

- Primary diagnosis of schizophrenia or schizoaffective disorder
- 18 years or older
- English speaking
- Living in the community (in the region of Ottawa)
- Able to provide consent

Time commitment: Number of digital storytelling sessions will be based on your need to construct your story. Each session will take 60 to 90 minutes. Sessions will be scheduled at a convenient location of your choice and a time mutually agreed upon.

You will receive a compensation of \$30 in appreciation of your time
Snacks and beverages will be provided at each session

For more information about the study, or to volunteer for this study please contact

Primary investigator:

Liquaa Wazni BScN, PhD (c)

This study has received ethics approval from the Research Ethics Board of the University of Ottawa.



Appendix F: Interview Guide for Digital Storytelling with Participants

Pre-interview

1. Review process and purpose
2. Describe process of digital storytelling from conception to post-production
3. Review consent form

Phase I-Brainstorming Narrative Session

- *Identifying the story:* what's the story you want to tell?
 - When were you diagnosed with schizophrenia/schizoaffective disorder? What happened?
 - How do you think your mental illness is being managed? What about your physical health? How is your physical health?
 - Do you have any concerns about your physical health?
 - How and when did it begin?
 - How does it affect your daily life?
 - How do you cope with this problem?
 - What is the hardest thing about managing your physical health/this specific physical problem? Tell a story?
 - What keeps you from managing your physical health/this specific problem?
 - Do you think you have the available resources to manage your physical health/deal with this specific problem? Explain?
 - Do you think healthcare providers (doctors, nurses... etc) help you manage your physical health effectively? If yes how, if no why do you think so? Tell a story
 - Do you think the available services, programs, and treatments meet your physical health needs? If yes how, if no why do you think so? Tell a story
 - What do you need to better manage your physical health
 - How do you like the healthcare providers and leaders to address the concerns that you have about your physical health?
 - Do you have any any suggestions?

Phase II-Building A Digital Story

1. *Setting up the story:* what would you like to put into your story to help tell it?
 - As you share your story, what emotions did you experience? If you were to draw or paint those motions what would they look like?
 - What images come to mind when talking about your physical health needs? When moments of change happened? Do you have these images somewhere (e.g., in a photo, painting, etc.)?
 - Could you find/create these images? How could you use these images to help tell your story?
 - What sounds come to mind when talking about your experience?

Appendix G: Interview Guide for Evaluating the Digital Storytelling Process with Participants

Participant ID# _____ Site code _____ Date of interview: _____
Start time _____ End time _____ Length of interview _____

Introduction:

I am conducting this study to explore your experiences with the digital story making.

-We are not evaluating you, so there are no right or wrong answers. We will not judge your responses and all the information that you give us will be confidential.

-Have you read the information and consent form for this interview? Do you have any questions?

-Please sign the consent form

I would like to record our conversation to ensure that we have an accurate summary of your opinions. May I have consent to record this interview? (if yes, turn recorder on). If you want me to turn off the tape recorder at any time during the interview, please let me know.

There will be 2 parts to this interview:

Process Evaluation Questions

How was your experience with the digital storytelling?

What was difficult?

What was easy?

Would you repeat this again? Why or why not?

Do you have any recommendation for researchers who want to make digital stories?

How do you feel about going through the process of making a digital story? [empowered (what does that mean to you), produced information that can be used, catharsis (relief), sense of accomplishment)

Were you able to tell everything you wanted without any worries or fear? Would you not share what you said in the videos with some people? Whom? Why?

Who do you think should listen to your story? Why?

How do you feel about your story being shared with the nurses and healthcare leaders?

Additional thoughts and comments

Finally, if there was one thing that you could change to improve the digital story making process, what would that be?

Do you have any additional thoughts or comments you would like to make in relation to the process of digital story making?

Appendix H: Reflective Questions

1. What ethics and/or values were challenged in this session? How did this affect my actions?
2. In which situation did I used my skills most effectively? What skills were developed or strengthened?
3. What did I/ the participants struggle with the most in this session? If encountered with a similar situation, what would I do differently in the future?
4. What areas do I need to improve upon? What can I do to improve upon these skills?
5. What has been most difficult? What has been most positive?
6. How does participants' feedback compare to my observations?
7. Did I take any risks in this session? What happened and what did I learn?
8. What supports and experiences could be helpful to me in digital story making? What can I do to access these supports and experiences?
9. How did I prepare for facilitation this week? What type of supervision am I most comfortable with?
10. What are the different styles and approaches I used as a facilitator? What can I learn from these different approaches?
11. What questions or concerns do I have that I plan to address with my supervisor/ committee members?

Appendix I: Justification of Inclusion/Exclusion Criteria for Focus Groups

Inclusion	Justification
- Nurses (RN, RPN, NP)- with a minimum of six months of current experience in mental health, including with people with psychotic disorders	- Nurses are the largest healthcare professional group and have a central role in health service delivery. Therefore, they represent an adequate sample of healthcare providers to address the research question (Canadian Institute for Health Information, 2017). -The purpose is to generate knowledge about the meaningfulness of people with psychotic disorders' voice. Nurses are required to have a minimum of six months experience in mental health, specifically with people with psychotic disorders, to ensure generation of data from healthcare providers who are familiar with patients. -six months experience is necessary for nurses to move from novice to advanced beginners who have "enough experience to discern recurring, meaningful patterns in a situation or to have had them pointed out by a mentor...they can create their own guidelines that can determine their actions...they possess the knowledge, skills, and understanding..." (Sitzman, 2017, p. 168).
- Healthcare managers (frontline & senior managers)- currently practicing, mental health experience not required	-Leaders can facilitate change as they are strategically positioned to obtain funding, allocate and disperse resources, enforce policies and procedures, foster organizational learning climates, develop infrastructure and strategies to support innovation, encourage and engage staff, role model and create a culture that values research use and is receptive to change. Healthcare managers were included to understand the extent to which digital storytelling can be used as a form of evidence to inform practices and policies in the current configuration of psychiatric system.
-English speaking	-The focus group will be delivered in English
Exclusion Criteria	Justification
-No experience in mental health	- Participants are required to reflect on the content and format of the stories and therefore require some experience in mental health for meaningful input
-People who do not meet the inclusion criteria	-Participants who do not meet the inclusion criteria are excluded because they are not suitable for the purpose or the design of the study

Appendix J: Recruitment Poster for Focus Groups

 Nursing Best Practice Research Centre Advancing care through knowledge	Calling for Focus Group Volunteer for Digital Storytelling Screening Liquaa Wazni RN, PhD (c), Wendy Gifford RN, PhD, & Amélie Perron RN, PhD	 uOttawa
<u>Invitation to participate:</u> You are invited to participate in a doctoral research study being conducted by Liquaa Wazni who is a mental health registered nurse and a PhD student. As a participant in the study, you will take part in one 60-90 minute group discussion with a sample of 6-8 nurses and/or healthcare managers. You will be required to watch 6-8 digital stories that were created by people with schizophrenia in relation to their physical health needs and then reflect on the content and format of the stories. Digital stories are an audio-visual vignette of approximately 2 to 5 minutes in length, which present a first-person story in conjunction with audiovisual material. <u>Inclusion criteria:</u> ➤ Nurses (RN, RPN, NP)-Should have a minimum of six months of current experience in mental health, including people with schizophrenia ➤ Healthcare manager (Frontline or Senior managers)-Experience in mental health NOT required ➤ English speaking <u>Time commitment:</u> ○ The group sessions will take place at the Creative Practice Centre, University of Ottawa, Roger Guindon, room 1125, June 01, 2018 from 11:30-1:00 You will receive a compensation of \$10 in appreciation of your time snacks and beverages will be provided for the session For more information about the study, or to volunteer for this study please contact Primary investigator: Liquaa Wazni BScN, PhD (c) This study has received ethics approval from the Research Ethics Board of the University of Ottawa. 		



uOttawa

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences
infirmières

University of Ottawa
Faculty of Health
Sciences

School of Nursing

Appendix K: Information Letter & Consent for Focus Groups

Digital Storytelling-A Methodology for Engaging People with Schizophrenia in a Participatory Research Approach

RESEARCHERS

Principal Investigator

Liquaa Wazni RN, PhD (c)
School of Nursing
Faculty of Health Sciences
University of Ottawa

Supervisors

Wendy Gifford, RN, PhD
Associate Professor
School of Nursing
Co-Director, Nursing Best Practice Research Center (NBPRC)
Faculty of Health Sciences
University of Ottawa
Phone (613) 562-5800 ext. 8975
wgifford@uottawa.ca

Amélie Perron, RN, PhD
Associate Professor
School of Nursing
Faculty of Health Sciences
University of Ottawa
Phone (613) 562-5800 ext. 8433
amelie.perron@uottawa.ca

613 562-5473
613 562-5443

451 Smyth
Ottawa ON K1H 8M5 Canada

www.uOttawa.ca

INVITATION TO PARTICIPATE:

You are invited to participate in a focus group discussion that will be conducted by Liguiaa Wazni RN, PhD(c) as part of her doctoral research. The purpose of this study is two-fold : 1) to help people with schizophrenia express their physical health needs and concerns through a creative process known as digital storytelling, and 2) to determine how nurses and healthcare managers respond to these digital stories. Digital stories are an audio-visual vignette of approximately 2-5 minutes in length which present a first-person story in conjunction with audiovisual material (photos, images, soundtracks, etc.). The purpose of this research is to explore the process of digital storytelling with people diagnosed with schizophrenia as a means of expressing their voice. Your participation relates to the second aim of the study.

PARTICIPATION:

As a participant in the study, you will take part in one 60-90 minute group discussion with a sample of 6-8 nurses and/or healthcare managers. You will be required to watch 6-8 digital stories that were created by people with schizophrenia in relation to their physical health needs and then reflect on the content and format of the stories. The discussion will be audio-recorded and transcribed for analysis. The focus group will be held at the Creative Practice Centre, University of Ottawa, during regular working hours (over the lunch hour).

RISKS:

You might feel discomfort watching the digital stories or partaking in the discussions. Your participation in this study entails that you share personal opinions in a group session; therefore, you might feel uneasy reflecting on conflicting opinions and/or revealing practices or policies that might be conflicting with professionals' or organizations' mission. You are not obligated to answer questions or share experiences that make you uncomfortable. You are not to reveal organizations' names or practitioners' identities in the focus group. Participation in the study is **voluntary**, and the choice to participate or not will not impact you negatively. If something in the focus group causes you discomfort and you wish to seek counseling, you will be referred to your employee assistance program.

CONFIDENTIALITY AND ANONYMITY:

Your data will remain confidential. All participants are also required to keep the identity of participants and the information shared in the discussions confidential. **Please note that researchers cannot guarantee that participants will uphold confidentiality.**

All information collected will only be used for the purposes of this study. Data collected will be protected and kept **anonymous** in the following ways:

- ♦ Your name will not be associated in any way with the study;
- ♦ Focus group discussions will be transcribed. During the transcription process, participants will be identified with the designation “Nurse” or “Manager” and a number (e.g. RN-1; M-2).
- ♦ Any other identifying information (e.g. name, position title, place of work, etc.) will be eliminated and will not be revealed in any presentation, publications, or reports.
- ♦ Your name and corresponding identification code will be kept in a locked research office at the University of Ottawa, Nursing Best Practice Research Center.
- ♦ Quotes used in reports or publications will only be identified with the designation “Nurse” or “Manager” and a code (e.g. RN-1; M-2). No identifying information will be disclosed.

CONFIDENTIALITY AGREEMENT:

All participants are asked not to disclose anything said within the context of the discussion. Your identity will be known to other focus group participants and the researchers cannot guarantee that they will respect the confidentiality of the group. By agreeing to participate, you agree to keep all comments made during the focus group confidential and not discuss the content of the discussions outside the meeting.

CONSERVATION OF DATA:

The audio recording of the discussion, electronic and paper copies of transcriptions and research notes will be kept secured. Only the researchers named in the consent form will have access to the raw data. Names of participants will be kept separated from the data in a locked research office at the University of Ottawa, Nursing Best Practice Research Center (NBPRC). Data will be stored for five years (e.g., 2018 – 2023), then destroyed.

BENEFITS:

Participating in a focus group will provide you with an opportunity to share your experiences, perceptions, feelings, beliefs and understandings in relation to the physical health of people with schizophrenia. Since digital storytelling helps to uncover voices of marginalized people and bring their ideas to light, watching and reflecting on the stories could potentially increase awareness, enhance empathetic understanding, promote compassion, transform attitude and behaviour, and/or create the intention to use digital stories for change and innovation. Your participation in this study will further help understand how nurses and healthcare managers engage with the digital stories.

COMPENSATION:

You will receive a compensation of \$10 which will be paid in full at the beginning of the first interview. You will keep the compensation even if you choose to withdraw from the research.

VOLUNTARY PARTICIPATION:

You are under no obligation to participate and if you choose to participate you can withdraw from the study at any time and/or refuse to answer any questions without suffering negative consequences. Please note that, given the dynamic nature of group discussions, if you choose to withdraw from the study it will not be possible to eliminate the information you shared in the focus group.

Your signature on this form indicates that you understand the information in this consent form and that you agree to participate. By signing this form, you are neither waiving your legal rights as a research participant nor are you releasing the investigators from their legal and professional responsibilities.

If you have any questions about the study, you may contact the researcher, Liquea Wazni. This study has received ethics approval from the Research Ethics Board of the University of Ottawa. If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, Tel.: (613) 562-5387. Email: ethics@uottawa.ca

CONSENT

I, _____ (*Name of participant*) have read and understood this consent form and I agree to participate in the above research study conducted by Liguaa Wazni RN, PhD(c), School of Nursing, Faculty of Health Sciences, University of Ottawa. All my questions and concerns were addressed to my satisfaction. I may contact the investigators of the study at any time for further information.

I accept to be quoted directly, as long as any identifying information is removed: Yes ☐
No ☐

I agree to participate in this study. There are 2 copies of this consent form, one of which is mine to keep.

Participant's signature: _____

Researcher's signature: _____

Date: _____

Appendix L: Focus Group Facilitation Questions

Facilitator Introduction and Purpose of Group

Facilitator: “Hello, my name is Liquaa Wazni and I’m going to conduct the discussion today and this is Y who will be taking notes. I’d like to start by thanking each of you for taking the time to participate today. We’ll be here for about 1.5 hours. We will take a 5-minute break halfway.

We invited you today to show you X number of digital stories that were created as part of this research project. The videos are 2-5 minutes in length and are related to physical health needs of people with schizophrenia/schizoaffective disorder. The purpose of this focus group is to gather your opinions and perceptions about digital storytelling.

I’m going to lead our discussion today. I will be asking you questions and then encouraging and moderating our discussion.

As we informed you before, we’ve planned to tape record this session. The identities of all participants will remain confidential. The recording allows us to revisit our discussion for the purposes of developing research papers and presentations.

Is everything clear about the course of the focus group discussion?

Ground Rules

To allow our conversation to flow more freely, I’d like to go over some ground rules.

1. Only one person speaks at a time. This is important as our goal is to make a written transcript of our conversation today. It is difficult to capture everyone’s experience and perspective on our audio recording if there are multiple voices at once
2. Please avoid side conversations.
3. Everyone doesn’t have to answer every single question, but I’d like to hear from each of you today as the discussion progresses.
4. This is a confidential discussion in that I will not report your names or who said what to your colleagues or supervisors. Names of participants will not even be included in the final report about this meeting. It also means, except for the report that will be written, what is said in this room stays in this room.
5. We stress confidentiality because we want an open discussion. We want all of you to feel free to comment on each other’s remarks without fear your comments will be repeated later and possibly taken out of context.
6. We ask you to respect each other’s opinions.
7. There are no “wrong answers”, just different opinions. Say what is true for you, even if you’re the only one who feels that way. Don’t let the group sway you. But if you do change your mind, let me know.
8. Let me know if you need a break. The bathrooms are [location]. Feel free to enjoy a beverage and a snack.

Are there any questions?

Introduction of Participants

Before we start, I’d like to know a little about each of you. Please tell me, only if you are comfortable sharing:

1. Your name
2. Your position
3. Years of experience
4. What you are responsible for and who you are accountable to within your organization?

Focus group

Raw Reaction to the stories & Perception about the content/format

[engagement, awareness, empathy, attitude, perceptions, beliefs]

- What do you think about the stories?
- What was strong? Why?
- What stayed with you? Why?
- What did you like/dislike about the digital story?
- What do you think about the content of the stories?
- What do you think the digital story says about the physical health needs of people with psychotic disorders?
- Are you surprised by these stories or you are aware of these problems?
- How well do you think the physical health of people with psychotic disorders is being managed? Within nursing specifically? And more generally within other disciplines and at an inter-disciplinary level?
- Is physical health of people with psychotic disorders an organizational priority?
 - a. If yes, what structures and processes are in place?
 - b. If no, explore reasons why you think this.
- What do you think about the format of the stories?
- Do you think the stories provided a forum for people with psychotic disorders to express their voice?
- Do you think the stories provided a forum for people with psychotic disorders to represent themselves as capable, creative, and knowledgeable people? In what way?
- Do you think that digital storytelling is a successful method for people with psychotic disorders to be heard?

Use of digital stories

- How do you think these digital stories can be used? [prompts: teaching& research resource, tool for social advocacy, change in policy and practices]
- Do you think the healthcare system (psychiatry) is ready to use digital stories as a form of evidence? If yes how? If no why?
- Do you think digital stories can be used to inform/change practices and policies? In what way? How?

Closing (2 minutes)

Thanks for coming today and talking about these issues. Your comments have given us lots of different ways to see this issue. I thank you for your time.