A Qualitative Study of Patients' and Caregivers' Perspectives on Educating Healthcare Providers

Holly Lynne Adam

A thesis submitted in partial fulfillment of the requirements for the
Master of Arts degree in Health Professions Education

Faculty of Education
University of Ottawa

Acknowledgements

I would like to sincerely thank Dr. Katherine Moreau, my thesis supervisor, for her exceptional guidance and support during my educational journey. After completing my BScN, I had no idea I would pursue a master's degree, but Dr. Moreau's encouragement helped me take the leap to higher education. Her dedication to her students' successes is truly inspirational. Without her mentorship, my MA would not have been made a reality. Further, I would like to thank my thesis advisory committee, Dr. Douglas Archibald and Dr. André Samson, for their constructive feedback that helped guide my research. I would like to extend my sincere gratitude for their flexibility and understanding with regards to the unforeseen challenges COVID-19 caused to my original MA topic, which I am now planning to pursue as part of my PhD Thesis. I would also like to thank Dr. Ruth Kane, Director of Graduate Studies, for facilitating my thesis proposal and for offering support throughout my MA.

I would also like to acknowledge the Associated Medical Services (AMS) Phoenix Fellowship, which funded this study. Thank you for supporting this research. I also extend my gratitude to the patients and caregivers who chose to participate in this study.

To my friends and family, I would like to thank my husband, Josh, for his unwavering encouragement for me during my educational journey. His constant love and support has helped expand my goals beyond what I expected. I would like to thank my daughter, Phoebe, who was born at the beginning of my MA, for being my constant inspiration. To my mom and dad, I would like to thank them for always wanting the best for me in life. Finally, to my best friend, Anna, I would like to thank her for being by my side through it all.

for Phoebe

Abstract

My thesis examines patients' and caregivers' perspectives on educating healthcare providers (HCPs). Specifically, it examined two research questions: 1) What do patients think about their involvement in the education of HCPs? and 2) What roles do patients want to have in the education of HCPs? It is important for educational leaders and HCPs to understand answers to these questions, from patients' own perspectives, to make effective changes in current and future health professions education and ultimately, the delivery of patient-centred care. I conducted semi-structured interviews with 27 patients and caregivers for this study. Through conventional content analysis, I identified five themes for what patients think about their involvement in the education of HCPs. Namely, patient involvement in the education of HCPs: (1) is challenging because of power-differentials between themselves and HCPs; (2) requires patient training; (3) needs to start early in HCPs' education process; (4) can improve patient-HCP partnerships; and (5) requires compensation for patients. I also identified three roles that patients want to have in the education of HCPs. Specifically, they want to: (1) teach HCPs about patients' expectations, experiences, and perspectives through case studies, storytelling, and research; (2) provide direct feedback to HCPs; and (3) advise on curricula development and admission boards for HCPs. My research adds to the limited research on patients' and caregivers' perspectives on their involvement in the education of HCPs, identifies barriers to patient involvement, and provides a foundation that HCPs and educational leaders can use to improve patients' active involvement in the education of HCPs. Further, it highlights that patients' voices are important to the education of HCPs. It also illuminates my own perspectives on patient involvement in the education of HCPs, which I share as part of my positionality as a researcher who conducted this study.

Keywords: Qualitative, patient involvement, patient experience, health professions education, patient-centred care

Table of Contents

Acknowledgements …… ii
Dedication …… iii
Abstract …… iv
Table of Contents …… v

Introduction to my MA Thesis by Article **1**
Preface: **2**
Description of the Study Problem and Rationale …… 2
Objectives and Research Question …… 4
Background on Patient Involvement in the Education of Healthcare Providers 5
What is patient-centred care? …… 5
How do we teach PCC and SDM to HCPs? …… 6
What is active patient involvement in the education of HCPs?…… 7
Methodological Reflections …… 9
Philosophical Foundations
Foundations for Data Analysis
Methodological Rationale
Positionality and Trustworthiness …… 12
Potential Contributions of this Study …… 15
References …… 17
A Qualitative Study of Patients' and Caregivers' Perspectives on Educating Healthcare Providers **23**
Introduction …… 21
Method …… 25
Design and Context
Participant Recruitment
Data Collection
Data Analysis
Results …… 27
Participants ……
What do patients think about patient involvement in the education of HCPs? …… 27
From patients' perspectives, what roles can patients play in educating HCPs? …… 30
Discussion …… 33
Limitations …… 38
Conclusion …… 39
Acknowledgements …… 39
Funding …… 39
Declaration of Interests …… 39
Ethical Approval …… 39
References …… 45
Tables ……

1: Patients'/Caregivers' Perspectives about their involvement in HPE: Themes and Supporting Quotations ………………………………………. 45

2: Patients'/Caregivers' Perspectives about their roles in HPE: Themes and Supporting Quotations ………………………………………. 47

Appendices ……………………………………………………………….… 49

A: Participant Invitation Email

B: Participant Consent Form

C: University of Ottawa Certificate of Ethics Approval

Conclusion to my MA Thesis ……………………………………………………………… **53**

Lessons Learned ……………………………………………………………... 53

Implications of this study in a new technological age …………………………. 54

References ……………………………………………………………………. 56

Introduction to my MA Thesis by Article

I completed this MA thesis in article format. This thesis has three sections. The first section is a preface to my empirical thesis study (presented in article format) on patients' and caregivers' perspectives on active patient involvement in the education of healthcare providers (HCPs). In this first section, I introduce my empirical thesis study by describing the research problem that I explored, the purpose of the study, and the research questions that guided it. In this section, I also present a brief literature review on active patient involvement in the education of HCPs. Finally, in this first section, I describe the methodological paradigm that formed the foundation of my empirical thesis study. I present my positionality as a researcher, specifically, outlining my perspectives on patients' active involvement in the education of HCPs, as both a patient and a nurse, and how these perspectives have impacted the trustworthiness of my empirical thesis study. I end this first section with potential contributions that the empirical thesis study has for health professions education. Overall, this information provides readers with greater context to understand the empirical thesis study that I present in the next section.

In the second section, I present my empirical thesis study in article format. This article entitled, *A qualitative study of patients' and caregivers' perspectives on educating healthcare* providers, explores patients' and caregivers' perspectives, specifically with regards to what they think about patient involvement in the education of HCPs and what roles they think they should have.

In the final section, I conclude by summarizing what I learned as a patient, nurse, and researcher while engaging in the empirical thesis study that I presented in the above-mentioned section. I specifically highlight my personal benefits and challenges from exploring patients' and caregivers' perspectives on their involvement in the education of HCPs. I also suggest ways in which patients' and caregivers' perspectives on this topic may be applied to the fields of health professions education, specifically with regards to opening channels of communication and collaboration between patients and HCPs in virtual learning.

Section 1: Preface

Description of the Study Problem and Rationale

The Study Problem

In 1978, the World Health Organization created the first policy outlining patients' "rights and duties to participate in planning and implementing their [health]care" (Downe et al., 2007, p.393). This policy acknowledged that health care providers (HCPs) cannot provide appropriate and competent care to patients without including patients' voices in their decision-making and educational processes. Therefore, over the last 30 years, there has been increased emphasis on the importance of patients' active roles in the education of HCPs, such as in curricula design, admission boards, policy-development, and assessment (Towle et al., 2010; Towle and Godolphin, 2015). Unfortunately, however, patients' involvement in such roles are still "isolated events" (Towle and Goldphin, 2011, p.501) and their voices are not impactful at larger scales beyond the event in which they occur (Towle et al., 2016).

Patients and HCPs have both reported benefits from active patient involvement in the education of HCPs. Briefly, HCPs have reported improved clinical skills, interpersonal skills, and personal and professional development when patients are involved in their education (Spencer et al., 2000; Jha, et al., 2009b; Towle et al., 2010; Wykurz & Kelly, 2002). Patients have reported gaining a sense of empowerment, insight into their illnesses, improved patient-HCP relationships, and more autonomy in their own care when involved in the education of HCPs (Walters et al., 2003; Towle et al., 2010). Despite these benefits, educational leaders have little guidance on how to sustain patient involvement in the education of HCPs (Wykurz and Kelly, 2002; Rees et al., 2007; Towle et al., 2016).

From patients' perspectives, challenging hierarchies and power-differentials between patients and HCPs, the lack of HCPs' effective communication, and poor HCP-partnerships are barriers to their involvement in the education of HCPs (Towle et al., 2010; Towle and Godolphin, 2011). Further, patients have described the lack of compensation (Wykurz and Kelly, 2002; Rees et al., 2007), the lack of training they receive to be educators (Towle et al., 2010), the emotional strain associated with sharing their stories (Lauckner et al., 2012), poor diversity in representation (Rowland and Kamagai, 2018), and concerns about ethics and confidentiality (Towle et al. 2010; Towle and Godolphin, 2015) as barriers to their involvement in the education of HCPs. However, despite this knowledge there has been a lack of practical knowledge and guidance for HCPs as to how to involve patients in the education of HCPs, especially from their own perspectives (Wykurz and Kelly, 2002; Rees et al., 2007; Jha et al., 2009b; Towle et al., 2010; Dijk, 2017).

Patients have also reported feeling resistance from HCPs with regards to their involvement in health professions education (Felton and Stickley, 2004). Perhaps this feeling is due to a lack of meaningful dialogue between HCPs and patients that could otherwise help clear up misconceptions (Kumagai et al., 2018). For example, HCPs have reported feeling "uncomfortable revealing their lack of knowledge to [patients]" (Rees et al., 2007, p.379) because they fear that patients will "learn about their fallibility" (Langer et al, 2016, p.621) and this will damage their professional identity and credibility. Contrary to this fear from HCPs, however, patients have expressed that they "appreciate clinicians' accountability" (p.621) and transparency in communication because it helps them build respect and trust for HCPs.

Overall, there is lack of knowledge on patients' perspectives about their involvement in educating HCPs (Jha et al., 2009b; Towle et al., 2010; Dijk, 2017). As Sharma (2018) has stated, "patients' perceptions of their involvement have typically been assessed through satisfaction measures" (p.473) instead of descriptive inquiries into what patients think about and want to gain from their involvement. However, it has been acknowledged that understanding patients' perspectives on why and how they want to be involved in educating HCPs is imperative to the ability of education leaders to "considerably enhance" (Stacy and Spencer, 1999, p.694) patient involvement beyond teaching and assessing roles (Boudreau et al., 2008; Jha et al., 2009b).

Rationale for the Study

To establish patient-led initiatives that are sustained throughout the education of HCPs, more research into patients' perspectives on what they believe needs to change at institutional levels to facilitate their involvement in educating HCPs is needed (Spencer et al., 2000; Rees et al., 2007; Towle et al, 2016). Therefore, the rationale for my empirical thesis study, exploring patients' perspectives on their involvement in the education of HCPs, is two-fold. First, my study gives patients an opportunity to educate HCPs on what patients believe prevents and facilitates their active involvement in the education of HCPs. Towle et al. (2010) have emphasized that research into what patients believe on this topic can help educate HCPs on what needs to change in the educational system so that patients' involvement is improved and supported. Specifically, patients' perspectives on this topic has the potential to provide convincing evidence that could guide policy and institutional changes in support of patient involvement along the continuum of health professions education (HPE) (Towle et al., 2010; Tee, 2012; Towle et al., 2016). Second, by exploring patients' perspectives on the roles they want to have in the education of HCPs, my thesis study illuminates part of the meaning patients ascribe to 'active' involvement, specifically, what it means to them to be actively involved in the education of HCPs. This illumination is imperative in order for education leaders to enhance patient involvement, beyond passive teaching and assessment roles, and make meaningful changes to the education of HCPs that reflect patients' views and guidance on this topic (Boudreau et al., 2008; Jha et al., 2009b; Towle et al., 2016).

Objectives and Research Question

HCPs cannot learn how to practice in patient-centred ways without learning from patients themselves about how to do this (Hoffman et al., 2015). Therefore, the objective of my empirical thesis study is to highlight why patients believe their involvement in the education of HCPs is important and how they think they should be involved. This information will provide guidance for HCPs and educational leaders on how to effectively involve patients in the education of HCPs (Towle et al., 2010; Towle and Godolphin, 2011; Towle et al, 2016). As mentioned, there is limited research that explores patients' perspectives on their roles and involvement in the education of HCPs (Spencer et al., 2000; Jha et al., 2009a; Towle et al., 2010). Therefore, the purpose of my research is to explore this topic and how patient involvement in the education of HCPs can be improved, from patients' own perspectives.

The following research questions guided my research:

(1) What do patients think about the involvement of patients in the education of HCPs and

(2) From the patients' perspectives, what roles can patients play in the education of HCPs in formal (i.e classroom) or informal (i.e. hospital) settings?

Background on Patient Involvement in the Education of Healthcare Providers

What is patient-centred care (PCC)?

The term ‘patient’ is defined by Manafo et al. (2018) as “any individual or group with lived experience of a health or health systems issue, including family members and caregivers” (p.6). This definition serves as my definition of ‘patient’ herein. Next, patient-centred care (PCC) is “care [that] responds precisely to patients’ wants, needs, and preferences” (Institute of Medicine [IOM], 2001, p.49), based on each patient’s unique values in care. It is about providing patients with safe, competent, and comprehensive care that respects their autonomy and control over their own healthcare decisions (IOM, 2001). Ultimately, “to support interprofessional collaborative practice that is patient-centred, [patients are viewed] as integral partners by those health care personnel providing their care” (CIHC, 2010, p.13). Part of PCC relies on HCPs practising shared decision-making (SDM) with patients (Institute for Patient- and Family-Centred Care [IPFCC], n.d.), where HCPs help patients navigate and understand their healthcare options and choices, but they, ultimately, respect patients’ personal health goals and control over their informed decisions (Elwyn et al., 2012).

Thistlethwaite (2017) has critiqued the term, patient-‘centred,’ as implying that patients are a “different type of team member” (p.5) surrounded by health professionals from various disciplines. However, PCC is more about “[HCPs] and patients constructing meaning together” (p.5) so that patients feel empowered and engaged as active participants in their own care and health decisions. This concept of HCPs and patients ‘constructing meaning together’ is the foundation of SDM.

In the last 30 years, there has been a dramatic shift in medical education from focusing on the biomedical aspects to the social sciences and humanities of providing care (Elwyn et al., 2012). The Canadian *CanMEDS Framework* was one of the first frameworks to outline medical students’ competencies related to practising PCC and SDM (Kuper et al., 2017). Currently, there are six ‘non-medical expert’ roles, which include being an effective communicator, a strong interprofessional collaborator, a patient’s health advocate, a leader in SDM processes with patients and interdisciplinary teams, a professional committed to PCC and who is accountable for proving ethical care, and a scholar who can apply theory to practice, especially in the field of PCC (Royal College of Physicians and Surgeons of Canada

(RCPSC), 2020). These roles specifically focus on physicians' intrinsic competencies, such as communication, health literacy, and understanding worldviews from patients' perspectives (Thistlethwaite, 2017).

How do we teach patient-centred care (PCC) and shared decision-making (SDM) to HCPs?

Towle et al. (2010) have urged that patient involvement in the education of HCPs should be the main source of learning for HCPs on how to deliver PCC because patients are 'experts' in their own care. As Sharma (2018) has explained, patients are at a "unique vantage point" (Sharma, 2018, p.476) to provide HCPs with insight into how to deliver PCC because they can draw from their experiential knowledge on what HCPs should be doing to improve it. Specifically, patients are well-equipped to educate HCPs on how to communicate with patients in compassionate and empathetic ways (Haq et al., 2006; Bergus et al., 2009; King and Hoppe, 2013; Hoffman et al., 2015), on how to talk to them in ways that they will understand (Hoffman et al., 2015; Langer et al., 2016; Hanson and Hanson 2017), and on how to remain reflexive, understanding, and open-minded in practice so that inequalities in patient-care, related to power-differentials in healthcare, are diminished (Abadel and Hattab, 2014; Langer et al., 2016; Towle et al., 2016; Kuper et al., 2017; Sharma, 2018).

Healthcare providers' effective communication with patients is at the core of "authentic SDM" (Kunneman et al., 2019; Thomas et al., 2020, p.414) and PCC (Bergus et al., 2009; King and Hoppe, 2013**;** Hoffman et al., 2015; Sharma, 2018) because it is imperative to whether patients feel heard, listened to, and respected during their interactions with HCPs. However, clinical-educators have struggled to teach concepts of PCC and SDM in health professions education, such as communication and collaborative skills (Thomas et al., 2020), because these concepts are fairly new to assessment models in health professions education (Kunneman et al., 2019) and in the teaching and assessing of HCPs' intrinsic skills (Kuper et al., 2017).

Kumagai et al. (2018) have suggested a 'dialogical' approach, which focuses on conversations that are constructive and problem-based, to teaching HCPs' how to deliver PCC and practice SDM with patients. This approach aims to "open up [new ways] of thinking, understanding, perceiving, and being" (Kumagai et al., 2018, p.1781) that help HCPs respect that knowledge can be personal, subjective, and can come from patients' themselves. Further, it aims to engage HCPs in "critical reflexivity" (Thomas et al., 2020, p.414), where they come to understand their own position in the world, the position of others, and how differing worldviews can intermingle in ways that support "authentic SDM" (p.414) and overall PCC. Similarly, Badaczewski et al. (2017) have explained how creating dialogue with patients, such as through the use of the teach-back method, can lead to productive interactions between patients and HCPs that foster improved patient-centred communication and overall care.

The context, realism, and unstructured learning opportunities that patients provide to the education of HCPs supports HCPs on how to be reflexive and adaptable in their delivery of PCC (Bennett and Baikie, 2003; Crossley, et al., 2005; Towle and Godolphin, 2011; Thomas et al, 2020). It has been found that HCPs value these aspects of patient involvement in their education, as it teaches them to be more empathetic and understanding when caring for patients (Oswald et al., 2014; Langer et al., 2016). For instance, medical students have described learning from patients as a "more powerful way of teaching" (Jha et al., 2009b, p.453) compared to traditional textbook learning. Students in various disciplines of health professions education have also described how health-mentor programmes have helped them improve their communication and collaboration with patients, their delivery PCC, reflection upon their own assumptions about stereotypes associated with being a 'patient,' and the building of respectful and collaborative partnerships with patients (Towle et al, 2014). Moreover, Fritz et al. (2015) have emphasized that the voices of patients who have experienced disparities in healthcare should be the main contributors in the design of curricula that teaches HCPs about injustices in healthcare, because these patients' experiences reinforce HCPs' reflexivity in thinking about inequalities in healthcare and in the education of HCPs. Despite HCPs' acknowledgements that patients should be actively involved in their education, especially on how to deliver PCC and practice SDM (Jha et al., 2009b), active patient involvement is not a mainstream occurrence in health professions education (Towle and Godolphin, 2011).

What is active patient involvement in the education of healthcare providers?

As referenced in Towle and Godolphin (2011), William Osler, a founding father of medical education, said, "the best teaching is that taught by the patient himself" (p.496). The 'patient as teacher' idea arose in the 1960s, and patients began their involvement in the education of HCPs as 'teachers' of clinical skills (Towle et al. 2010). However, their 'teaching' roles mostly consisted of acting as a "teaching resource" (Wykurz and Kelly, 2002, p.821) or as a “medium through which the teacher [taught]” (Spencer et al, 2000, p.851); there were few opportunities for patients to offer feedback to HCPs about HCPs’ skills.

Although patients today may be given more ‘active’ roles in the education of HCPs, such as in patient-led initiatives, active patient involvement is still lacking (Wykurz and Kelly, 2002; Towle et al., 2010). For instance, patients have commonly been involved in “giving a presentation, facilitating seminars, demonstrating to small groups, providing personal tuition, giving feedback on performance” (Wykurz and Kelly, 2002; p.818), but these forms of occasional patient ‘as teacher’ encounters have done little for the sustainability of patient involvement in the education of HCPs and are not necessarily formal ‘active’ roles in the education of HCPs because patient s in these roles merely act as a teaching aide’ and have little autonomy to in meaningful ways to them (Bennett and Baikie, 2003; Rees et al., 2007; Towle et al., 2014).

‘Active’ patient involvement occurs when HCPs are taught *by* patients, instead of *about* patients and when patients engage with HCPs and educational leaders in collaborative partnerships throughout the education of HCPs (Towle and Godolphin, 2011; Thomas et al., 2020). As mentioned, patients’ active involvement in the education of HCPs teaches HCPs how to reflect on patients’ dialogues, which lead to their “understand[ing] of health beliefs and world views of their communities” (Thistlethwaite, 2017, p.5; Kumagai et al, 2018). This critical reflection by HCPs is essential to the practice of PCC and SDM. Given that health advocacy is outlined in the *CanMEDS Framework* (RCPSC, 2020) as a core competency of physicians, Thistlethwaite (2017) has argued that HCPs need to further reflect on the importance of involving patients in their education and advocate for patients’ sustained involvement so that there are improvements to the delivery of PCC.

Patients’ who are ‘actively’ involved in the education of HCPs are those who are involved in such roles as formal assessment of HCPs’ skills, evaluating educational strategies and HCPs’ skills, research processes and development, developing curricula, and being members on admission boards who help select future HCPs (Towle and Godolphin, 2015). The establishment of patient-led teaching initiatives have been a beginning to the establishment of more active roles for patients in the education of HCPs (Towle and Godolphin, 2011; Towle et al, 2014), but there is still much work to be done so that patients are engaged in collaborative partnerships with faculty and educational leaders along the continuum of health professions education (Downe et al. 2007; Towle et al., 2011).

Methodological Reflections

In this section, I explain the naturalistic paradigm (Guba, 1981) I use for my research study. This paradigm forms the foundation of my inquiry into patients' and caregivers' experiences in the education of HCPs. I also address how I collected the data and the theoretical foundations behind my data analysis. These methodological reflections support and expand on the shorter 'Methods' section in the article for my empirical thesis study that I present in the next section. They also provide context for my explanation of my positionality and potential biases that I bring to this study as a researcher.

Philosophical Foundations

In my research, I used a basic interpretive qualitative approach within the naturalistic paradigm (Merriam, 2002). This approach allows for the inductive analysis of participants' interview data and the development of descriptive accounts of patients' and caregivers' perspectives on and experiences of their involvement and roles in the education of HCPs, based on the researchers' interpretive analysis. Basic interpretive qualitative research aims to "understand a phenomenon...[based on] common patterns or themes that cut across the data" (Merriam, 2002, p.6), but unlike phenomenology, it does not aim to describe the contextual or complex meaning or 'essence' behind a lived experience. Instead, a basic interpretive qualitative approach allows for a level of interpretation to occur from the researcher (Merriam, 2002; Hsieh and Shannon, 2005).

A naturalistic inquiry into 'truth' served as the foundational paradigm for my research. It allows researchers to inquire about social/behavioural phenomena (Guba and Lincoln, 1982), such as the experiences of patients and caregivers in the education of HCPs. Within this paradigm, I assumed that patients' experiences and contexts naturally emerge through their interactions with HCPs, and "multiple realities" (Guba, 1981, p.77; Guba and Lincoln, 1982, p.237) exist based on peoples' unique experiences and contexts. Therefore, when patients interact with HCPs or recount experiences with them, their patient identity is naturally drawn to their conscious awareness and becomes a form of knowledge. It is also assumed that participants' and researchers' experiences are interrelated, but unique, and 'truth' exists from co-existing interactions of peoples' experiences and the interpretive meanings people assign to them

(Guba and Lincoln, 1982). Ultimately, ‘truth’ is context-bound and is based on peoples’ “intuitions, apprehensions, or feelings” (Guba, 1981, p.78). The naturalistic paradigm complements my research objective of exploring patients' and caregivers' perspectives on their roles and involvement in the education of HCPs because it respects that people will have unique experiences but will contribute to the phenomenon equally.

‘Truth’ will change among participants, but commonalities can be found (Guba, 1981). Creswell (2013) calls these commonalities “naturalistic generalizations” (p.200). To validate that these generalizations are accurate, we can do ‘member checks’ to confirm that the participants agree with researchers’ interpretations (Guba, 1981). Although member-checking was not done in my research due to time-constraints, cross-checking findings among different researchers served to help verify credibility and increase the rigour of this study (Guba, 1981; Creswell, 2013). Further, I used ‘bracketing as a technique to acknowledge how my thoughts may affect the interpretation of the data and to “monitor” (Merriam, 2002, p.5) my potential biases, rather than obliterate them completely. I present my positionality as way to provide the reader with greater context on how my awareness of my personal biases may affect my data collection and interpretation.

Foundations for Data Analysis

I chose to use conventional content analysis as the technique to analyze the participants’ interview data in my research because it allowed me to systematically “interpret meaning from the content of textual data” (Hsieh and Shannon, 2005, p.1277) and to describe the phenomenon directly from participants’ own words. Further, it allowed for the inductive analysis of common themes based on the identification of concepts present in more than one interview, which was the goal of the research.

Erlingsson and Brysiewicz (2017) outline the steps that I followed to perform my conventional content analysis. First, exact words from participants’ audio or video recording served as an initial foundation for the creation of common themes to describe the phenomenon. I transcribed participants’ significant statements pertaining to the guiding research questions and highlighted shared words that participants used to describe the phenomenon, in this case what participants thought about their involvement and what roles they wanted to have in in the education of HCPs. Second, I considered my interpretations and impressions of the data so that I became aware of my preconceived notions that may have impacted my analysis. Then, I assessed shared wording between participants and used these to develop codes that depicted commonalities. Finally, I sorted all codes into broad themes based on the meaning participants gave to their words and interpretations from the researchers. To increase trustworthiness, three researchers independently analyzed participants' audio or video-recordings using the conventional analysis described above, and discrepancies between themes were discussed until consensus in themes was reached (Bengtsson, 2016; Erlingsson and Brysiewicz, 2017).

Methodological Rationale

My reasons for using a basic interpretive qualitative approach (Merriam, 2002) with conventional content analysis (Hsieh and Shannon, 2005) for my research was two-fold. First, it allowed me to explore patients' and caregivers' thoughts about their involvement in the education of HCPs and how they would like to be involved openly and non-judgmentally, while also acknowledging that a degree of interpretation is expected from the researchers that cannot be removed from the subjectivity experience itself (Guba, 1981). Due to the existing research that is available concerning patients' involvement in the education of HCPs (Towle and Godolphin, 2016) and that I, as a researcher, approach this topic with my own biases, my aim was to approach the data in a systematic fashion. Conventional content analysis allowed me and the research team to interpret meaning based on what the participants' said (Hsieh and Shannon, 2005) rather than on deductive reasoning that may have emerged from the comprehensive literature review done before conducting this study. It also helped me remove myself from data interpretation, as I focused solely on the words of the participants themselves.

Second, this approach allowed me to respect that every participant had their own unique perspectives based on their diverse characteristics that may not match others, but they will all share in and equally contribute to the same phenomenon under study. This research involved participants purposely recruited from a provincial patient advisory program, *Health Quality Ontario*, that focuses on patient engagement in healthcare. This purposive sampling technique allowed me to investigate commonalities among participants with similar backgrounds in order to gain a comprehensive view of the phenomenon, unaffected by those who had not experienced involvement in the education of HCPs. Ultimately, content analysis allows me to find common themes that describe the phenomenon under study, based on participants' own words, while also allowing me to acknowledge that participants have experienced the phenomenon from different contexts and their experiences are unique (Bengtsson, 2016)

Positionality and Trustworthiness

Trustworthiness of the researcher as 'instrument'

The subjectivity of a researcher as an 'instrument' in qualitative research can affect how data is collected, interpreted, and presented (Tufford and Newman, 2010; Creswell, 2013). I am aware I come at this topic with a degree of bias, as I have experienced a lack of voice in the education of HCPs as a patient and have preconceived notions of why and how patients want to be involved in the education of HCPs. By making my preconceptions known however, this allows me to practice self-awareness and reflexivity so I can separate my own experiences from those of participants', and ultimately, increase the trustworthiness of my analysis.

I now present my positionality on patients' active involvement in the education of HCPs, from two unique lenses, first as a long-term patient in both pediatric and adult healthcare settings and second, as a nurse. I discuss my position as a patient because this position has built the foundation of how I view healthcare today, has illuminated for me the importance of incorporating patients' voices into the education of HCPs, and has influenced how I want to deliver care to patients as a HCP.

Positionality

In 1993, I was admitted to a pediatric hospital in Ottawa for a diagnosis of hemolytic uremic syndrome caused by E.Coli 0157:H7; this has left me needing continued encounters with HCPs into adulthood. As a pediatric patient, I spent approximately two-months in hospital and many years receiving out-patient care. My first month in the hospital was spent in the intensive-care unit receiving many life-sustaining measures, as most of my organs were failing. I received care from HCPs from many disciplines, some of which included physicians, nurses, physiotherapists and occupational therapists, and dietitians. My encounters with these HCPs continued after being discharged from the hospital and continued into my early adolescence. I am lucky to say that my encounters with HCPs as an adult-patient are minimal, but my long-term experiences as a patient have highlighted for me the importance of actively involving patients in the education of HCPs so that they can effectively deliver patient-centred care (PCC).

As a patient, I believe I am in an ideal position to educate HCPs on how to deliver PCC. For example, my experiential knowledge as a pediatric patient, who felt unheard or unlisted to by HCPs, and as an adult patient, who experienced more autonomy in the care but less overall communication and interprofessional collaboration from HCPs in my care, positions me well to do so. Specifically, I believe that I can educate HCPs about the intrinsic skills, including their cognitive, social, and personal skills, that contribute to safe, efficient, and high-quality healthcare (Bloom, 2002).

My position as a patient on patients' active involvement in the education of HCPs. I believe patients, like myself, are in an ideal position to help educators develop patient-simulations that focus on HCPs' intrinsic skills and assess HCPs in their interactions with patients during these simulations. For example, I can assess whether HCPs speak to me compassionately and in ways that I understand. Further, I am able to provide them with feedback on how to actively listen to patients, such as how to display positive body-language and an unrushed demeanour, so that patients feel comfortable sharing their experiences with HCPs and truly cared for.

I also have a strong belief that, in order to foster collaborative partnerships between patients and HCPs, active patient involvement in the education of HCPs needs to be normalized. To do this, patients need formal positions and titles in HPE that give them power and autonomy to teach HCPs in meaningful and in unstructured ways. These positions will contribute to HCPs' abilities be reflexive in practice and work *with* patients to reach agreements in SDM processes (Thomas et al., 2020).

My positionality as a patient has highlighted my beliefs that patients are needed to educate HCPs on the realism behind patient experiences and perspectives so that they can critically assess what they need to change in their practices in order to improve their delivery of PCC. Further, I believe that it absurd for anyone to think that HCPs can engage in SDM practices with patients without respecting them as integral partners in their education. Therefore, I believe that patients need to have formal roles in the classrooms, where they share their experiences with HCPs on healthcare and perspectives on how to improve it, as well as participate in the development of curricula and clinical scenarios that incorporate patients' experiences into the education of HCPs. Overall, my position as a patient clearly emphasizes that I believe patients need to have more active roles in the education of HCPs and a voice and presence at institutional levels so that they can implement meaningful changes to the education of HCPs and thus, improve the delivery of PCC.

My position as a nurse on patients' active involvement in the education of HCPs. As a nurse, I wanted to use my experiences as a patient to help deliver appropriate and compassionate care to patients. I wanted to take time to listen to patients' needs, provide them with care beyond their physical needs, and involve them as equal partners in their care. However, I was exposed to a harsh reality in clinical practice that the structure of our current healthcare education system makes it challenging to actively involve patients in the education of HCPs; yet, patients' experiential knowledge with illness and the healthcare system ideally position them to educate HCPs, especially on how to deliver PCC.

As a nursing student, patient involvement in my education mostly occurred in clinical practice. These clinical encounters helped me learn interpersonal skills, such as communication, empathy, active listening, and flexibility in care. They also helped me reflect on what I can do to improve the care I provide to patients, such as the importance of slowing down and truly listing to their needs. Simply, clinical experiences with patients kept my education as a nurse *real*, such that they reminded me that 'care' extends beyond medical care.

Unfortunately, however, I also became aware of the power-differential that existed between me and *my* patients in the clinical-setting. I emphasize '*my*' because I find many HCPs use this term to describe the patients they work *with* in clinical practice; it implies a sense of ownership, that, I believe, many HCPs are subconsciously unaware of. I also found many HCPs jaded from the pressures institutional demands put on them, such as maximum productivity within time constraints, which does little to support HCPs' respect for patients as partners in care. Ultimately, I quickly acknowledged that, when patients are given formal teaching positions, such as in classroom-settings, their voices become more powerful and respected by HCPs, compared to in the clinical-setting.

Being taught by a patient in the classroom, for example, about his physical, social, and socioeconomic challenges with schizophrenia and bipolar disorder helped me gain more respect and understanding for him, and others suffering from similar challenges, compared to when I treated patients with similar mental illnesses in clinical practice. His voice in the classroom was the only one I, as a student, was listening to wholeheartedly; he was given an opportunity to be heard, not just as a patient, but as a person with valuable experiential knowledge to share. I took from this experience, and others like it, although these classroom-encounters with patients were few, the worldview that there is no greater teacher than patients themselves to educate HCPs on how to communicate and collaborate in ways that foster partnerships in care. The only way patients will truly be heard by HCPs is if they have formal roles in the education of HCPs.

Overall, my experiences as a nurse and patient have highlighted that I believe that patients should be involved in formal and active roles as educators in HPE. Patients should teach courses on their experiences as patients; they should create curricula, such as simulations, case-studies and lectures that reflect patients' experiences; and they should have roles at the highest of institutional levels because this is the only way their voices will enforce effective and meaningful changes to the education of HCPs that improve the quality and patient-centredness of care.

Trustworthiness of this study, based on my positionality

Despite the claim that it is inevitable to have a degree to subjectivity from researchers who interpret another person's experiences, perceptions, and meaning they hold of a phenomenon, such as patients' experiences in the education of HCPs (Rolls and Relf, 2006; Tufford and Newman, 2010; Creswell, 2013) Guba (1981) explains that trustworthiness of data can occur when researchers maintain an "optimal distance" (p.77) from participants' perspectives and aim to understand the phenomenon from the participants' point of view. By separating my own perspectives from those of participants on patients' active involvement in the education, I help minimize the impact my own preconceived notions may have on data collection and analysis in this study and, ultimately, increase the trustworthiness of this study's results.

Potential Contributions of this Study

The potential contributions from my empirical thesis study are three-fold. First, it aimed to describe how patient involvement in the education of HCPs can be improved from patients' own perspectives. This information can provide new insight and knowledge for educational leaders and HCPs on how to reduce barriers to and improve patient involvement in the education of HCPs (Towle et al., 2010). Further, by highlighting patients' perceptions on what it means to them to be 'active partners' with regards to the roles they think they should have in the education of HCPs, educational leaders can make practice changes that align with patients' expectations of how they want to be involved in the education of HCPs.

Second, my empirical thesis study aimed to illuminate the importance of incorporating patients' voices into the education of HCPs. As I illustrate in the sections above, there has been limited research on patients' perspectives on their involvement in the education of HCPs (Jha et al., 2009a; Towle et al., 2010) or what they think their roles should be (Spencer et al., 2000; Jha et al., 2009). This knowledge, however, can help guide educational reform to support and sustain patient-led initiatives in health professions education (Spencer et al., 2000; Rees et al., 2007).

Finally, my study aimed to highlight that patients' voices in the education of HCPs are essential to improving PCC and teaching HCPs how to engage with patients in SDM processes. Given that communication and rich dialogue are at the core of PCC, it only seems natural to open dialogues between HCPs and patients by including patients in the education of HCPs (El-Haddad et al. 2017; Kumagai et al., 2018). Specifically, patients' can highlight competencies focused on HCPs intrinsic skills (Bergus et al., 2009; King and Hoppe, 2013**;** Hoffman et al., 2015; Sharma, 2018) that are important to interprofessional PCC and SDM, such as communication, critical-reflection, collaboration, teamwork, understanding of roles, and open-mindedness in practice (CIHC, 2010; Kunneman et al., 2019; Thomas et al., 2020) This has potential to improve competency-based medical education (CBME), an approach to learning that has aimed to set milestones in physicians' abilities and skills during their education and career, especially in ways that move the assessment of HCPs skills' away from 'task-oriented' to more problem-based assessment (Holmboe et al., 2010; Eva et al., 2016; Lockyer et al., 2017). This can help evolve CBME so that societal needs in healthcare and aspects of PCC are reflected in the education of HCPs (Downe et al al., 2007; Towle et al., 2010; Towle et al., 2016).

Overall, I hope this study helps improve the quality and sustainability of patient involvement in the education of HCPs. By exploring patients' perspectives on why and how they want to be actively involved in the education of HCPs, I hope it fosters HCPs' acknowledgements of the importance of communication and collaboration with patients as respected partners in care and in their education, and opens up avenues for such collaborative communication to occur (CIHC, 2020).

References

Abadel, F., & Hattab, A. (2014). Patients' assessment of professionalism and communication skills of medical graduates. *BMC Medical Education*, 14(1), 28. https://doi.org/10.1186/1472-6920-14-28

Badaczewski, A., Bauman, L., Blank, A., Dreyer, B., Abrams, M., Stein, R., Roter, D., Hossain, J., Byck, H., & Sharif, I. (2017). Relationship between Teach-back and patient-centered communication in primary care pediatric encounters. *Patient Education and Counseling*, *100*(7), 1345–1352. https://doi.org/10.1016/j.pec.2017.02.022

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*(C), 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Bennett, L., & Baikie, K. (2003). The client as educator: learning about mental illness through the eyes of the expert. *Nurse Education Today*, *23*(2), 104–111. https://doi.org/10.1016/S0260-6917(02)00193-4

Bergus, G., Woodhead, J., & Kreiter, C. (2009). Trained lay observers can reliably assess medical students' communication skills. *Medical Education*, *43*(7), 688–694. https://doi.org/10.1111/j.1365-2923.2009.03396.x

Bloom, B. (2002). Crossing the Quality Chasm: A New Health System for the 21st Century. *JAMA, The Journal of the American Medical Association*, *287*(5), 646–647. https://doi.org/10.1001/jama.287.5.646-a

Boudreau, D., Jagosh, D., Slee, D., Macdonald, D., & Steinert, D. (2008). Patients' Perspectives on Physicians' Roles: Implications for Curricular Reform. *Academic Medicine*, *83*(8), 744–753. https://doi.org/10.1097/ACM.0b013e31817eb4c0

Creswell, J.W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Crossley, J., Eiser, C., & Davies, H. (2005). Children and their parents assessing the doctor–patient interaction: a rating system for doctors' communication skills. *Medical Education*, *39*(8), 820–828. https://doi.org/10.1111/j.1365-2929.2005.02230.x

Dijk, W. (2017). Changing the Paradigm of Meaningful Patient Involvement in Medical Education. *Academic Medicine*, *92*(5), 576–577. https://doi.org/10.1097/ACM.0000000000001648

Downe, S., Mckeown, M., Johnson, E., Koloczek, L., Grunwald, A., & Malihi-Shoja, L. (2007). The UCLan community engagement and service user support (Comensus) project: valuing authenticity, making space for emergence. *Health Expectations*, *10*(4), 392–406. https://doi.org/10.1111/j.1369-7625.2007.00463.x

El-Haddad, C. P., Damodaran, A., McNeil, H., & Hu, W. (2017). A Patient-Centered Approach to Developing Entrustable Professional Activities. *Academic Medicine, 92*(6), 800-808.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of General Internal Medicine*, *27*(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6

Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, *7*(3), 93–99. https://doi.org/10.1016/j.afjem.2017.08.001

Eva, K., Bordage, G., Campbell, C., Galbraith, R., Ginsburg, S., Holmboe, E., & Regehr, G. (2016). Towards a program of assessment for health professionals: from training into practice. *Advances in Health Sciences Education, 21*(4), 897–913. https://doi.org/10.1007/s10459-015-9653-6

Felton, A. & Stickley T. (2004). Pedagogy, power and service user involvement. *Journal of Psychiatric Mental Health, 11*(1), 89–98.

Fritz, C., Naylor, K., Watkins, Y., Britt, T., Hinton, L., Curry, G., … Kim, K. (2015). Are We Missing the Mark? The Implementation of Community Based Participatory Education in Cancer Disparities Curriculum Development. *Journal of Racial and Ethnic Health Disparities*, *2*(2), 237–243. https://doi.org/10.1007/s40615-014-0072-9

Giroux, C., & Moreau, K. (2020). Leveraging social media for medical education: Learning from patients in online spaces. *Medical Teacher*, 1–6. https://doi.org/10.1080/0142159X.2020.1779920

Godolphin, W. (2003). The Role Of Risk Communication In Shared Decision Making: First Let’s Get To Choices. *BMJ: British Medical Journal*, *327*(7417), 692–693.

Guba, E. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ*, *29*(2), 75–91. https://doi.org/10.1007/BF02766777

Guba, E., & Lincoln, Y. (1982). Epistemological and methodological bases of naturalistic inquiry. *ECTJ*, *30*(4), 233–252. https://doi.org/10.1007/BF02765185

Hanson, F., & Hanson, R. (2017). Reflections from a Patient and Carer on Involvement in Research and Integrating Care in the Health System. *International Journal of Integrated Care*, *17*(2), 16. https://doi.org/10.5334/ijic.3088

Haq, I., Fuller, J., & Dacre, J. (2006). The use of patient partners with back pain to teach undergraduate medical students. *Rheumatology*, *45*(4), 430–434. https://doi.org/10.1093/rheumatology/kei167

Hoffman, K., Griggs, M., Donaldson, J., Rentfro, A., & Lu, W. (2015). Through patient eyes: Can third-year medical students deliver the care patients expect? *Medical Teacher, 37*(7), 684–692. https://doi.org/10.3109/0142159X.2014.947931

Holmboe, E., Sherbino, J., Long, D., Swing, S., & Frank, J. (2010). The role of assessment in competency-based medical education. *Medical Teacher*, *32*(8), 676–682. https://doi.org/10.3109/0142159X.2010.500704

Hsieh, H., & Shannon, S. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Institute of Medicine [IOM]. (2001). *Crossing the quality chasm: a new health system for the 21st century*. Washington, D.C: National Academy Press.

Institute for Patient-and Family-Centred Care [IPFCC]. (n.d.). *Patient-and Family-Centred Care*. Retrieved from https://www.ipfcc.org/about/pfcc.html#:~:text=Core%20Concepts%20of%20Patient%2D%20and,Information%20Sharing.

Jha, V., Quinton, N., Bekker, H., & Roberts, T. (2009a). Review of Strategies and interventions for the involvement of real patients in medical education: a systematic review. *Medical Education, 43*(1), 10–20. https://doi.org/10.1111/j.1365-2923.2008.03244.x

Jha, V., Quinton, N., Bekker, H., & Roberts, T. (2009b). What educators and students really think about using patients as teachers in medical education: a qualitative study. *Medical Education*, *43*(5), 449–456. https://doi.org/10.1111/j.1365-2923.2009.03355.x

King, A., Hoppe, R., & King, A. (2013). “Best practice” for patient-centred communication: a narrative review. *Journal of Graduate Medical Education*, *5*(3), 385–393. https://doi.org/10.4300/JGME-D-13-00072.1

Kumagai, A., Richardson, L., Khan, S., & Kuper, A. (2018). Dialogues on the Threshold: Dialogical Learning for Humanism and Justice. *Academic Medicine*, *93*(12), 1778–1783. https://doi.org/10.1097/ACM.0000000000002327

Kunneman, M., Henselmans, I., Gärtner, F., Bomhof-Roordink, H., & Pieterse, A. (2019). Do Shared Decision-Making Measures Reflect Key Elements of Shared Decision Making? A Content Review of Coding Schemes. *Medical Decision Making*, *39*(7), 886–893. https://doi.org/10.1177/0272989x19874347

Kuper, A., Veinot, P., Leavitt, J., Levitt, S., Li, A., Goguen, J., Schreiber, M., Richardson, L., & Whitehead, C. (2017). Epistemology, culture, justice and power: non-bioscientific knowledge for medical training. *Medical Education, 51*(2), 158–173. https://doi.org/10.1111/medu.13115

Langer, T., Martinez, W., Browning, D., Varrin, P., Sarnoff Lee, B., & Bell, S. (2016). Patients and families as teachers: a mixed methods assessment of a collaborative learning model for medical error disclosure and prevention. *BMJ Quality & Safety*, *25*(8), 615–625. https://doi.org/10.1136/bmjqs-2015-004292.

Lauckner, H., Doucet, S., & Wells, S. (2012). Patients as educators: The challenges and benefits of sharing experiences with students. *Medical Education, 46*(10), 992-1000.

Lockyer, J., Carraccio, C., Chan, M., Hart, D., Smee, S., Touchie, C., … Frank, J. (2017). Core principles of assessment in competency-based medical education. *Medical Teacher*, *39*(6), 609–616. https://doi.org/10.1080/0142159X.2017.1315082

Manafo, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada: a scoping review of the “how” and “what” of patient engagement in health research.[Report]. *Health Research Policy and Systems*, *16*(1), 5. https://doi.org/10.1186/s12961-018-0282-4

Merriam, S.B. (2002). *Qualitative Research in Practice* (1st ed.). San Francisco, CA: John Wiley & Sons

Oswald, A., Czupryn, J., Wiseman, J., & Snell, L. (2014). Patient-centred education: what do students think? *Medical Education*, *48*(2), 170–180. https://doi.org/10.1111/medu.12287

Rees, C., Knight, L., & Wilkinson, C. (2007). “User Involvement Is a Sine Qua Non, Almost, in Medical Education”: Learning with Rather than Just About Health and Social Care Service Users. *Advances in Health Sciences Education*, *12*(3), 359–390. https://doi.org/10.1007/s10459-006-9007-5

Rolls, L., & Relf, M. (2006). Bracketing interviews: addressing methodological challenges in qualitative interviewing in bereavement and palliative care. *Mortality*,*11*(3), 286–305. https://doi.org/10.1080/13576270600774893

Royal College of Physicians and Surgeons of Canada (RCPSC). 2020. *CanMEDS: Better standards, better physicians, better care*. Retrieved from http://www.royalcollege.ca/rcsite/canmeds/canmeds-framework-e

Rowland, P., & Kumagai, K. (2018). Dilemmas of Representation: Patient Engagement in Health Professions Education. *Academic Medicine, 93*(6), 869–873. https://doi.org/10.1097/ACM.0000000000001971

Sharma, M. (2018). “Can the patient speak?”: postcolonialism and patient involvement in undergraduate and postgraduate medical education. *Medical Education*, *52*(5), 471–479. https://doi.org/10.1111/medu.13501

Sherbino, J., Arora, V., Van Melle, E., Rogers, R., Frank, J., & Holmboe, E. (2015). Criteria for social media-based scholarship in health professions education. *Postgraduate Medical Journal, 91*(1080), 551–555. https://doi.org/10.1136/postgradmedj-2015-133300

Spencer, J., Blackmore, D., Heard, S., Mccrorie, P., Mchaffie, D., Scherpbier, A., … Southgate, L. (2000). Patient-oriented learning: a review of the role of the patient in the education of medical students. *Medical Education, 34*(10), 851–857. https://doi.org/10.1046/j.1365-2923.2000.00779.x

Stacy, R., & Spencer, J. (1999). Patients as teachers: a qualitative study of patients’ views on their role in a community-based undergraduate project. *Medical Education*, *33*(9), 688–694.

Tee, S. (2012). Service user involvement — Addressing the crisis in confidence in healthcare. *Nurse Education Today*, *32*(2), 119–120. https://doi.org/10.1016/j.nedt.2011.12.002

The Ottawa Hospital (TOH). 2020. *MyChart*. Retrieved from https://www.ottawahospital.on.ca/en/patients-visitors/mychart/

Thistlethwaite, J. (2017). Being centred in education and health care. *Clinical Teacher*, *14*(1), 5–7. https://doi.org/10.1111/tct.12618

Thomas, A., Kuper, A., Chin-Yee, B., & Park, M. (2020). What is “shared” in shared decision-making? Philosophical perspectives, epistemic justice, and implications for health professions education. *Journal of Evaluation in Clinical Practice*, *26*(2), 409–418. https://doi.org/10.1111/jep.13370

Towle, A., Bainbridge, L., Godolphin, W., Katz, A., Kline, C., Lown, B., … Thistlethwaite, J. (2010). Active patient involvement in the education of health professionals. *Medical Education*, *44*(1), 64–74. https://doi.org/10.1111/j.1365-2923.2009.03530.x

Towle, A., Brown, H., Hofley, C., Kerston, R., Lyons, H., & Walsh, C. (2014). The expert patient as teacher: an interprofessional Health Mentors programme. *Clinical Teacher*, *11*(4), 301–306. https://doi.org/10.1111/tct.12222

Towle, A., Farrell, C., Gaines, M., Godolphin, W., John, G., Kline, C., … Thistlethwaite, J. (2016). The patient's voice in health and social care professional education. *International Journal of Health Governance, 21*(1), 18–25. https://doi.org/10.1108/IJHG-01-2016-0003

Towle, A., & Godolphin, W. (2011). A meeting of experts: the emerging roles of non-professionals in the education of health professionals. *Teaching in Higher Education: Leaving the Academy, 16*(5), 495–504. https://doi.org/10.1080/13562517.2011.570442

Towle, A., & Godolphin, W. (2015). Patients as teachers: Promoting their authentic and autonomous voices. *Clinical Teacher, 12*(3), 149-154.

Tufford, L. & Newman. P. (2010). Bracketing in Qualitative Research. *Qualitative Social Work, 11*(1), 80-89. doi: 10.1177/1473325010368316

Walters, K., Buszewicz, M., Russell, J., & Humphrey, C. (2003). Teaching as therapy: cross sectional and qualitative evaluation of patients' experiences of undergraduate psychiatry teaching in the community. (Primary care). *British Medical Journal*, *326*(7392), 740.

Wykurz, G., & Kelly, D. (2002). Developing the role of patients as teachers: literature review. (Learning in practice). *British Medical Journal*, *325*(7368), 818–821.

Section 2: A Qualitative Study of Patients' and Caregivers' Perspectives on Educating Healthcare Providers

Introduction

Patients and caregivers (herein referred to as patients), can be actively involved in the education of healthcare providers (HCPs). However, HCPs have traditionally involved patients as passive educators and treated them as teaching or clinical 'material' on which to practice their skills (Towle and Godolphin 2011; Rowland et al. 2019). To move past this traditional involvement, we need to understand what patients think about their involvement in the education of HCPs and what roles they can play in the education of HCPs. Such an understanding will ensure that patients' involvement provides appropriate benefits and outcomes for all those involved (Bennett and Blaikie, 2003; Boudreau et al. 2008; Towle et al. 2010; Dijk 2017).

There are numerous benefits to patients and HCPs from patients' active involvement in the education of HCPs. Patients feel empowered, gain new insights into their conditions, improve their communication with HCPs, and report high satisfaction in their care (Towle et al. 2010). Healthcare providers have also reported that learning from patients increases their overall learning satisfaction, empathy and understanding for vulnerable populations, and confidence in clinical skills (Towle et al. 2010; Oswald et al. 2014; Sharma 2018). They have also explained how patients' experiential knowledge positively contributes to the realism and applicability of textbook learning (Bennett and Blaikie 2003, 2008; Oswald et al. 2014).

The integration of patients' voices into the education of HCPs is fundamental to improving the delivery of patient care (Towle et al., 2016) because patients educate HCPs on core concepts of patient-centred care (PCC), such as dignity, respect, communication, collaboration and how to involve patient in shared decision-making (SDM) processes (IPFCC, n.d.).The Institute of Patient-and Family-Centred Care (IPFCC, n.d.) has highlighted that "patients and families are essential allies...not only in direct care interactions [with HCPs], but also in...[the] education of health professionals" (p.1). For example, patient involvement in educating HCPs has brought "real learning experiences" (Langer et al., 2016, p.621) to HCPs' education that encourage HCPs to reflect on their attitudes towards patients, how patients may perceive them, patients' experiences with illness and the healthcare system, and how they should communicate in patient-centred ways (Langer et al., 2016;Oswald et al., 2014). Healthcare providers' abilities to learn how to practice in patient-centred ways have been attributed to patients' improved health outcomes, satisfaction in care, and in the establishment of HCP-patient partnerships in care, which are essential to the "authentic SDM" (Thomas et al., 2020, p.414) processes between HCPs and patients (IPFCC, n.d.). Despite the benefits from patient involvement in the education of HCP however, patients are still not consistently integrated along the continuum of health professions education [HPE], nor has there been the establishment of respectful collaborative partnerships between patients and HCPs as a mainstream occurrence (Towle et al., 2016).

The *Vancouver Statement*, which provides direction for HCPs on patient involvement in HPE, (Towle et al. 2016) has acknowledged that "institutional and educational barriers exist related to power [and] professional identity...which prevent patients from being heard" in the education of HCPs. Although Rees et al. (2007) have found that medical students feel that patient involvement in their education helps them "determine how they should act and feel as professionals" (p.374) and helps them build strong partnerships with patients, patients still feel that power-differentials between them and HCP makes their active involvement in the education of HCPs particularly difficult. For example, patients have expressed feeling "in the way," (Liput et al. 2016, p. 1195) of HCPs and how one of the greatest limiters to their contributions to the education of HCPs is when HCPs do not receive and validate their contributions in accepting and reflexive ways (Lauckner et al. 2012; Liput et al. 2016; Hanson and Hanson 2017). Many patients have also feared whether they will be able to provide anything valuable to the education of HCPs (Towle et al., 2010; Towle et al., 2014). In effect, the power-differential that exists between patients and HCPs leaves patient feeling like they cannot communicate or collaborate with HCPs in meaningful and transparent ways (Langer et al. 2016). However, these are elements of the patient-HCP partnerships that are essential to patients' active involvement in the education of HCPs and in the delivery of PCC overall (Thistlethwaite, 2017).

Moreover, what patients want to teach HCPs may not always align with what HCPs expect to learn from patients (Bennett and Blaikie 2003; Towle et al. 2016). Bennett and Baikie (2003) have explained how patient-educators bring "unplanned and unintended consequences to educational practices" (p. 105). Further, nurse-educators have described feeling that "it is difficult to predict what a [patients] will bring to the classroom" (Felton and Stickley, 2007, p.93), and this can be problematic to "ensuring certain material is covered in the curriculum" (p.93). Therefore, HCPs have expressed that patients should receive training when involved in their education because they want patient-educators to "clearly link [their teachings] to learning objectives" (Jha et al., 2009b, p.452). Overall, this acts as a barrier to patients' autonomy to teach HCPs on topics and in ways that truly matter to them, such as how to deliver PCC and effectively collaborate with patients as 'partners' in SDM processes (Repper and Breeze, 2007; Boudreau et al., 2008; Levinson et al., 2010).

Ahuja and Williams (2005) have emphasized that "patients and carers have first-hand experience of how the healthcare system [should] work... [and this makes them] a valuable resource as potential teachers at all stages of medical education" (p. 374). Further, the *Vancouver Statement* (Towle et al., 2016) suggests that, in order to effectively integrate and sustain patients' involvement in HPE, patients need to be involved early and throughout all stages of HPE, and their perspectives on their involvement in the education of HCP need to be incorporated into policies and practice. This involvement will help breakdown power-differentials between HCPs and patients and will help patients gain autonomy to educate HCPs in meaningful ways to them. However, despite there being an increase in research exploring patients' experiences educating HCPs over the last 20 years (Towle et al., 2010; Towle and Godolphin, 2011), there has been a lack of guidance for educational leaders on how to incorporate and sustain patients' active involvement in the education of HCPs (Downe et al., 2007; Mckeown et al., 2010), partly due to patients' own perspectives on this topic rarely being explored (Jha et al., 2009b; Towle et al., 2010; Towle and Godolphin, 2011; Dijk, 2017). Thus, this qualitative study focused on the following research questions:

1. What do patients think about patient involvement in the education of HCPs?
2. From patients' perspectives, what roles can patients play in the education of HCPs?

Method

Design and Context

To explore patients' perspectives on this topic, we conducted one-on-one semi-structured interviews with patients who have experience educating HCPs in informal or formal educational settings (e.g., in hospitals, classrooms, clinics, the community, bedside). We originally recruited patients for an interview to create content for a graduate course at a Canadian university. The course, aimed at HCPs, focused on strategies for actively involving patients in the education of HCPs.

Participant Recruitment

We purposively recruited adults who identified as patients and were associated with a provincial patient advisory program that focuses on patient engagement in healthcare. We then contacted the 28 interviewees by email (See Appendix A for *Participant Invitation Email*) to obtain informed consent for a secondary analysis of their interview data for the present study. Twenty-seven interviewees consented to the secondary analysis of their interviews (See Appendix B for *Participant Consent Form*).

Data Collection

Two authors (KM and HA) conducted interviews in person, by phone, or by video conference, depending on each patient’s preference. The semi-structured interviews ranged in length from 30 to 60 minutes, were audio or video recorded, and transcribed verbatim. All participants provided verbal consent prior to the interview. The interview guide consisted of twelve questions focusing on patient involvement in the education of HCPs and the roles patients can play in educating HCPs in formal or informal settings.

Data Analysis

We used conventional content analysis to analyze the interview data (Hsieh and Shannon 2005). Our goal was to identify themes present in more than one interview. Two authors (HA and CG) independently analyzed the interview data and noted their analytic processes to enhance the trustworthiness of the analysis. First, they listened to or viewed the interview recordings from start to finish. Second, using the transcribed interviews, they coded the data inductively, identifying themes across participants. Given that some participants did not participate by video, they did not analyze the non-verbal cues of participants who participated by video. Instead, they used the participants’ words to develop their individual initial coding schemes (Hsieh and Shannon 2005). Third, they used these schemes to code the data and identify themes. Fourth, they met to compare and merge their coding schemes. In this meeting, they resolved any discrepancies in their coding and identified themes. Together, they then decided on exemplar quotations for each theme. To further increase the trustworthiness of the analysis, two other authors (KE & KM) also independently listened to or viewed the interview recordings. The authors then met to engage in a peer debriefing process (Guba 1981), where they discussed and confirmed the identified themes as well as reached consensus on which exemplar quotations to use for reporting purposes.

Results

Participants

Throughout their interviews, participants positioned themselves as activists, advocates, parents, and partners in healthcare. Twenty (74.0%) participants identified as patients, five (18.5%) as caregivers, and two (7.5%) as both patients and caregivers. Twenty (74.0%) participants identified as female.

What do patients think about patient involvement in the education of HCPs?

The participants in this study believe that patient involvement in the education of HCPs: (a) is challenging because of power-differentials between themselves and HCPs; (b) requires patient training; (c) needs to start early in HCPs' education process; (d) can improve patient-HCP partnerships; and (e) requires compensation for patients. We summarize each of these themes herein and present additional supporting quotations in Table 1.

Patient involvement in the education of HCPs is challenging because of power-differentials between themselves and HCPs

The participants thought that patient involvement in the education of HCPs is challenging because HCPs are in positions of power over patients. The participants reflected on their past educational experiences with HCPs and believed that HCPs were, at times, condescending to them and viewed the information that they shared as an unnecessary hindrance. As one participant explained, "I think some [HCPs] certainly find [my involvement] a hindrance. I think the more experienced ones think, 'I've been there, done that" (P25). Further, the participants expressed how some patients feel intimidated at the prospect of educating HCPs. As, one participant articulated, "I was experienced enough to stand up for myself, you know, to talk at equal levels [with the HCP], but you have to be pretty sure of yourself in order to speak frankly" (P10). Overall, the participants noted that some patients are uncomfortable being involved in the education of HCPs given that power-differentials exist. Whereas, another stated, "I think that it's sometimes hard to get patients and people around them to contribute because they have a preconceived notion that trained HCPs know better and more than what they do and so they're reluctant to give their input” (P16). Overall, the participants noted that some patients are uncomfortable being involved in the education of HCPs given the existing hierarchy of healthcare.

Patient involvement in the education of HCPs requires patient training

The participants thought that patient involvement in the education of HCPs requires training for patients who are or want to be involved in it. They highlighted how patients have something to teach HCPs, but not all patients know how to approach the topic or communicate their stories in an educationally meaningful way to HCPs. As a participant exemplified:

> For patients, I think [the challenge] is how to tell our story so that it’s general enough for across patients and be useful across patient…We need education on how to [teach HCPs] too, as patients...Sometimes it’s been really easy for me to wear my patient hat, [but in] a meeting the other day, ‘I’m going, I don't have much to offer here’...and I didn’t want to pretend I had something to offer when I didn’t (P19).

The participants also raised the idea of the ‘right’ kind of patient to be an educator. They acknowledged that “you have to have patient speakers who are able to stay on track” (P21) and are “able to put their message into a format that will be suitable for the audience” (P18). Further, they noted, “When you get the right people involved in the system and in the classroom, [patient involvement] would be accepted [by HCPs]” (P05). Overall, the participants believed that training would provide patients with the support needed to become effective and valuable educators.

Patient involvement in the education of HCPs needs to start early in HCPs’ education process

The participants thought that patient involvement needs to start early in the education of HCPs in order to foster positive mindsets among HCPs and normalize patient involvement across educational settings. As one participant described:

> I think by introducing [patient involvement] into the education setting, it would help to take the fear out of it [for HCPs]... [Students] kind of say, it was a positive experience, we learned something...and it was done in a non-threatening way, and we welcome feedback in a clinical setting because we already had an exposure (P17).

In addition, the participants expressed that early patient involvement helps create a new generation of HCPs who value and respect such involvement in the education of HCPs. For instance, as one patient explained:

> As far as the involvement of patients, it needs to be at various levels [of training], like not at the final, but as an introduction when people are considering the healthcare profession for schooling...It is part of the new healthcare, so to embrace that, I think that's necessary and is a good part of their education (P28).

Throughout the interviews, participants highlighted this idea of a new health education system where patients' voices are embedded in all aspects of HPE.

Patient involvement in the education of HCPs can improve patient-HCP partnerships

The participants thought that their involvement in the education of HCPs can improve patient-HCP partnerships and thus, improve their satisfaction with the healthcare they receive. To elaborate on how patient involvement in the education of HCPs can improve patient-HCP partnerships, the participants recounted patients' clinical interactions with HCPs that were "meaningful, honest, [and those which portrayed] transparent communication in real-time" (P11). The participants believed that, when patients have opportunities to teach HCPs about how to effectively interact with patients, communication between them and HCPs "becomes richer" (P15) and thus, both patient-HCP partnerships and healthcare delivery improves. The participants also reflected on the importance of having patients teach HCPs about "[patients'] preferences, their cultural preferences, their financial situation, whatever's going on in their life, not just taking care of what's [medically] wrong with them" (P07). They argued that such teaching has tremendous impacts on how HCPs interact with patients, the quality of patient-HCP partnerships, and the care that patients receive.

Patient involvement in the education of HCPs requires compensation for patients

The participants advocated that patients need compensation for their involvement in the education of HCPs. They believe that such compensation encourages HCPs to view patients' involvement as a formal educational partnership. Participants articulated that patients do not have the same energy as HCPs and yet they are actively involved in curriculum and admission committees, in educational research, and in course delivery. For example, one participant expressed how:

> The biggest limiter to me not doing more is not getting paid. It devalues anything I say, my mere presence. It brings up tokenism. If patients are to be seen as integral parts of the healthcare system in educating HCPs, then they need to be paid for their expertise….
>
> Asking me to do more volunteer time is more a hardship on me than on someone healthy, but then someone healthy isn't going to give you the information you need (P06).

Other participants also reiterated the idea of tokenism in advocating for patient compensation. A participant explained, "patient involvement is seen as this tokenistic activity, rather than really acknowledging them as experts in their own subject" (P08). Ultimately, the participants think that patient compensation is one powerful way of showing patients and HCPs that patient involvement in the education of HCPs is valuable and important.

[INSERT TABLE 1 HERE]

From patients' perspectives, what roles can patients play in educating HCPs?

The participants identified the following roles that patients can play in the education of HCPs: (a) teaching HCPs about patients' expectations, experiences and perspectives through case studies, storytelling, and research; (b) providing direct feedback to HCPs; and (c) advising on curricula development and admission boards for HCPs. In addition to the descriptions below, Table 2 highlights key quotations associated with each category.

Teaching HCPs about patients' expectations, experiences, and perspectives through case studies, storytelling, and research

The participants highlighted how patients can teach HCPs about their expectations, experiences, and perspectives. Specifically, they view case studies as one important strategy to teach HCPs because they initiate dialogue between patients and HCPs that support HCPs' understanding of patients' perspectives. As described by one participant:

> I imagine that sort of case studies might be beneficial…. you know, we're going to sit down and assess, here's what the patient heard, here's what the patient understood, here's what the patient's expectations were… As the doctor, what did you see? And here's what the patient saw … [teaching the HCPs] to see if we can bridge the gap in communication (P25).

They also suggested that patients can use storytelling as a way to teach HCPs about patients' expectations, experiences, and perspectives. Many of the participants reflected on how they use storytelling at corporate orientations, in training videos, or in social media postings to teach

HCPs. Participants think storytelling helps HCPs understand, from patients' perspectives, what they need to change in practice to improve their delivery of care:

> In the academic setting, I think there should be a component where patients actually provide information to those healthcare providers, like they tell their patient stories. I think that's really powerful, certainly to hear a story in person of things that have gone wrong and also things that went well (P23).

Furthermore, the participants expressed their desires to teach HCPs through engaging in HPE research. They thought that it is important for patients to be involved in HPE research from the outset, including providing input on patient-oriented research objectives and priorities. As a participant summarized:

> I think, to meaningfully engage folks, to engage patients in research, you have to start from the beginning. Like, when you have an idea to do the research, that's when you bring in, not just one patient, a number [of patients]. You transparently say to them, 'you know, this is my research question, what are your research questions, what do you think this research ought to achieve?' It's really important for patients to be able to shape the trajectory of the research [because] you'd want to see a direct output that will lead to better patient care and better patient experiences (P02).

Overall, the participants highlighted that their roles in research are key to developing patient-centred and relevant research as well as a way of contributing to HPE.

Providing direct feedback to HCPs

The participants expressed the importance of being able to provide HCPs with immediate real-time feedback in the assessment of intrinsic skills, such as communication and empathy. In particular, they explained how involving patients as mentors or in role-playing capacities could provide HCPs with valuable, current, and relevant feedback on these skills. As one participant shared, "feelings aren't usually about 'did you look in my ear canal correctly?' It'll be more about how did the HCP make me feel? Were they empathetic?" (P26). Another participant outlined the importance of "recognizing that patients can't evaluate surgical techniques, but they can provide feedback on how a simulated clinical interview went" (P15). Overall, participants believed that their feedback provided insight to HCPs that they cannot learn from textbooks or academia alone.

Advising on curricula development and admission boards for HCPs

Participants expressed wanting to be involved, as advisors, in curricula development and on admissions boards for HCPs. In terms of curricula development, they noted a desire to review and improve existing curricula rather than develop it from scratch. They explained how "We weren't involved in the content [of the curriculum]. We were provided the content, to, then critique..." (P17). Another participant stated:

> "Have [the patient] review the curriculum...say, okay, this is where I think you can put this in, this is what I think you could do here...I'd be going through the curriculum, trying to find out what the objectives are and where I could insert patient experience to improve the curriculum" (P05).

Overall, participants thought their involvement in curricula development would help facilitate the integration of patients' perspectives and experiences and would help HCPs understand how patients' experiential knowledge can enrich curricula. The participants also expressed the importance of having patients advising on admission review boards for HCPs' programs (e.g., nursing schools, medical school), especially in regard to assessing potential HCPs' intrinsic skills. As one participant exemplified:

> Perhaps the patient partner could be part of a reviewing panel, looking at somebody's statement of intent, why they want to be involved in the program…. If candidates could be given feedback on what they expressed, [what it] feels like from the point of view of compassion and empathy from a patient's point of view, to give them an opportunity to learn and grow, that could be really helpful (P15).

In sum, the participants noted that their expertise offers invaluable knowledge for improving curricula as well as screening HCP applicants to ensure that they have appropriate intrinsic skills that will enhance healthcare delivery.

[INSERT TABLE 2 HERE]

Discussion

The participants in this study shared their perspectives on the involvement and roles of patients in the education of HCPs. The participants believed that patient involvement in the education of HCPs is challenging because of power-differentials that exist between HCPs and patients but that it can improve patient-HCP partnerships. Further, they highlighted how patient involvement requires support, training, and compensation. They also noted that it needs to start early in the education of HCPs. Regarding roles, patients want to teach HCPs about their expectations, experiences, and perspectives through case studies, storytelling, and research. They also want to provide real-time feedback on HCPs' intrinsic skills as well as advise educators on curricula development and admission criteria.

These study findings align with those of others. For example, researchers suggest that power-differentials between patients and HCPs are barriers for patient involvement in HPE (Towle et al. 2010; Langer et al. 2016). Moreover, the participants in the present study alluded to the notion of creating a 'new generation' of HCPs who are accustomed to active patient involvement in the education of HCPs. Similarly, Rees et al. (2007) describe how patient-educators often use words such as "fresh and new" (p. 372) to describe the malleability of medical students when patients are involved from the onset in their education. This idea is also supported by Towle et al. (2010) who acknowledge that HCPs need to become used to active patient involvement in education processes so that they can accept it as the norm and not believe that patients are devaluing or challenging their medical or health training. In order to facilitate and develop this new generation of HCPs, the participants in the present study suggested that patient involvement should start at the onset of education for HCPs. Such early involvement can help to normalize patient involvement in the education of HCPs and prevent negative mindsets about it (Brett et al. 2014; Towle et al. 2014).

Participants also thought that patients need training to be involved in the education of HCPs. In alignment with other studies, patients value "knowing the learning needs" (Boylan et al., 2011; p.141) of HCPs they are educating so that they can adequately prepare discussions and teaching material. They also feel that training helps reduce their anxieties about educating HCPs, helps HCPs view patient-educators as legitimate partners in their education, and helps patients provide HCPs with specific feedback that they can then use to modify their practices (Wykurz and Kelly 2002; Bokken et al. 2010). Further, when patient-educators are trained to teach and assess HCPs' examination skills, medical students demonstrate improved skills on objective structured clinical examinations (OSCEs) (Barley et al 2006; Allen et al. 2011). Alike patients in this study, many others value training to act as educators.

In contrast to participants' support for training however, it has been suggested that training for patients takes away from their authentic voices, as they become too "professionalized" (Jha et al., 2009b, p.454) when influenced by academic worldviews. However, Cheng and Towle (2017) have found that patients, while they feel that their personal experiences help them in patient-educator roles, training is still a necessary support. Therefore, many studies have suggested a 'peer-led', rather than a 'faculty-led', approach to patient-educator training because this will help preserve the authenticity of patients' voices and perspectives (Aamodt et al., 2006; Boylan et al., 2011; Cheng and Towle, 2017; Hanson and Hanson, 2017). However, Jha et al. (2009a) have found that only about 10% of studies on active patient involvement in HPE have identified 'patient-led' training initiatives, which suggests that current patient-training policies are in need of reform.

Alongside this training, the participants in the present study advocated for compensating patients for their involvement in the education of HCPs. Other studies describe how compensation, especially in the form of payment, for patients helps HCPs recognize and legitimize patients' active involvement in the education of HCPs (Towle et al. 2010), as well as helps make patients feel like equal partners in education processes (Wykurz and Kelly 2002; Brett et al. 2014). As Wykurz and Kelly (2002) explain, payment leads to patients being "colleagues in medical training" (p. 821), which helps mitigate tokenistic involvement. Patients also explain how being compensated for their efforts increases their satisfaction in teaching medical students and makes it more likely they will continue to act as educators in the future (Gecht, 2000).

Although both medical-educators and patients have agreed that patients should be compensated for their involvement in HPE (Downe et al., 2007; Rees et al., 2007), how and what patients are paid is still up for debate (Rees et al., 2007). Some patients have expressed that their compensation needs to be monetary (Rees et al., 2007), while others say they would contribute in order to gain an academic title (Towle et al., 2010, p.70). Further, some patients argue that compensation needs to cover more than just their contact time with students; it needs to cover preparation, debriefing time (Rees et al., 2007), and any travel-expenses (Coleman and Murray, 2002). In contrast, others express concerns that compensation removes the altruistic act of ‘giving back’ to the community (Coleman and Murray, 2002; Towle et al., 2010). Overall, this study supports that patients value monetary compensation and most studies support this finding (Downe et al., 2007; Rees et al., 2007; Morgan and Jones, 2009). However, more research into patients’ perspectives on this topic could help guide faculty on how to fairly compensate patients for their involvement in educating HCPs (Rees et al., 2007; Towle et al., 2010).

In addition, the participants in this study emphasized that patient involvement can improve patient-HCP partnership, especially through improved communication and better understandings of patients’ needs and satisfaction with care. Simply, findings from this study support that patients feel that their involvement in the education of HCPs will improve HCPs’ abilities to deliver PCC. Other studies report similar findings and show that patient involvement in the education of HCPs leads to strengthened relationships and partnerships between patients and HCPs (Gecht 2000; Langer et al. 2016; Moreau et al. 2019) because it eases communication challenges and provides HCPs with greater understandings of patients’ contexts and care expectations (Oswald et al. 2014). This is essential to HCPs abilities to truly hear, actively listen, and involve patients during SDM processes in their own care (Thomas et al., 2020), where they have “productive interactions” (Badaczewski et al., 2017, p.1346) that support open and transparent dialogue (Kuper et al., 2017; Kumagai et al., 2018). Further, many studies emphasize that collaboration between patients and HCPs in HPE creates strong partnerships (Clinton 1999; Bennett and Blaikie 2003; Felton and Stickley 2004), which are key to breaking down challenging power-dynamics and hierarchies that get in the way of such partnerships in SDM processes, and in PCC in general (IPFCC, n.d.).

To further improve patient-HCP collaborative partnerships in care, the participants also emphasized patients’ abilities to teach and assess HCPs’ intrinsic skills, including empathy and communication, through case studies and storytelling. Cheng and Towle (2017) support the use of such strategies and describe how they can stimulate HCPs’ self-reflection. Spiro (1992) explains that as medical students move through their education, they “harden themselves against empathy...[but the] mind and spirit of the patient...can [open up] conversation[s]" (p.844) that help physicians restore empathy by stimulating reflection and insight into patients' experiences. Self-reflection or reflexivity in practice, where HCPs aim to become aware of their own worldview so they can minimize how it impacts others', is also central to HCPs abilities to provide patients with PCC (Crossley et al., 2005; Kuper et al., 2017; Thistlethwaite, 2017; RCPSC, 2020). As Kilgour (2016) summarizes, clinicians' critical reflection on patients' healthcare experiences is essential to their ability to re-construct their values so they align with the values of PCC. This idea is also emphasized in other studies where HCPs improve their empathy, compassion, and overall understanding for patients who face stigmas, such as those with mental illnesses, by engaging in ongoing communication and collaboration with them and enabling them to teach and provide direct and immediate feedback on their skills (Gecht 2000; Barley et al. 2006). Moreover, the literature notes that HCPs view feedback from patients, especially on their intrinsic skills, as positive learning experiences (Langer et al. 2006; Manafo et al. 2018; Moreau et al. 2019) that provide them with insights into their skills that may be overlooked or not witnessed by educators who are faculty members (Jha et al. 2009b; Cheng and Towle 2017). HCPs can then use this patient feedback to modify their clinical practices and meet patients' needs (Towle and Godolphin 2011; Moreau et al. 2019).

The participants also believed that patients' expectations, experiences, and perspectives can guide HPE research. There has been recent emphasis to include them as partners on research teams, study boards, and advisory councils (Domecq et al., 2014; Manafo et al., 2018); patients feel empowered when they are involved in the design of patient-oriented research projects that have the potential to improve patients' health outcomes and quality of care (Hanson and Hanson, 2017). Further, researchers report a "better alignment of research objectives" (p.11) and "improved research effectiveness" (Manafo et al., 2018, p.11) when patients are involved on research teams. They also describe how patients' involvement on research teams "steer agendas and outcomes" (Shippee et al., 2015, p. 1155) based on patients' needs, which "improves study designs and applicability" (p.1155). A review of the impact of patient involvement in research also suggests that early involvement helps funders identify patient-pertinent research proposals (Brett et al. 2014). Overall, many agree that patients' voices in research "increases the legitimacy and rationality of decision-making [in health research] and improves [patient]-centred care" (Domecq et al., 2014; Shippee et al., 2015; Manafo et al., 2018, p.11).

Finally, the participants in this study described how patients can play advising roles on admission committees to assist programs in selecting future HCPs with excellent intrinsic skills. While studies have supported that patients can effectively teach and assess HCPs intrinsic skills (Barley et al. 2006; Allen et al. 2011; Moreau et al. 2016), others have highlighted that patients' participation in the admission interview process can help identify candidates who exemplify the core components of PCC (Sims and Lynch 2016; Towle et al. 2016), such as effective communication, collaboration, and respect for patients' autonomous voices in their own care (IPFCC, n.d.). Moreover, the participants noted that patients can advise on the development of curricula for HCPs. Although research emphasizes that patients' roles in curricula development are lacking (Jha et al. 2009a; Towle et al., 2010), researchers advocate that this role is important and beneficial (Towle and Godolphin 2015). For example, Towle and Godolphin (2011) and Bennett and Baikie (2003) emphasize that patient involvement in curricula development promotes student-centred learning and brings aspects of critical reflection and patient insight into HPE that faculty-led education fails to offer. Furthermore, Towle et al. (2016) explain that patients' involvement in HPE at institutional levels, including participation in both curricula development and on admission boards, is key to changing accreditation standards that reflect improvements to PCC, as well as promoting policy and institutional changes that support patients' involvement in HPE.

Overall, a common theme presented among participants in this study was that the lack of communication between patients and HCPs is the central barrier to patients' active involvement in the education of HCPs. The Canadian Interprofessional Health Collaborative (CIHC, 2010) framework, which outlines competencies HCPs should strive for in order to practice in patient-centred ways, also emphasizes that communication is key to appropriate team functioning, collaborative leadership, HCPs understanding what patients expect from HCPs' roles, and conflict resolution. It also emphasizes that patients and HCPs must communicate and collaborate in trusting, respectful ways that support SDM and partnerships. However, in order to educate HCPs on these elements of collaborative practice, interprofessional education requires patient involvement so that HCPs learn the attitudes and behaviours needed to practice collaboratively with patients in care (CIHC, 2020). Therefore, it is imperative that HCPs listen to patients themselves with regards to why and how they want to be involved in the education of HCPs (Felton and Stickley, 2004; Rees et al., 2007).

Limitations

This study has three main limitations. First, several participants reflected on their involvement in medical education rather than in the education of other HCPs. Thus, we recommend further explorations of patients' perspectives and roles in other specific health disciplines (e.g., nursing, allied health). However, despite these limitations, this study highlights that patients want to be involved in the education of HCPs. Third, patient-participants in this study were not involved along the research process. Literature supports that such involvement enriches research objectives, outcomes, and effectiveness (Domecq et al., 2014; Shippee et al, 2015; Manafo et al., 2018). However, this study illuminates that patients want to be involved as partners along the health research process. Finally, patients' and caregivers' perspectives were presented together. Given that there were five participants in this study who identified as caregivers, rather than patients, it would be interesting to delve deeper into whether there are differences in experiences based on whether participants identified as a patient or a caregiver.

Conclusion

This study provides direction to educational leaders on how to involve patients meaningfully and appropriately in the education of HCPs. It suggests that patients' involvement in the education of HCPs can be challenging but that it can improve patient-HCP partnerships and enrich patients' healthcare experiences, especially if we introduce it early in HCPs' education process and strive to sustain it. Ultimately, patients hold unique knowledge and perspectives that HCPs and faculty-educators do not, and thus, they have much to offer to the education of HCPs. Educational leaders need to listen to patients' perspectives and act on this topic so that we can effectively and appropriately change patient involvement and patients' roles in HPE.

Acknowledgements

None

Funding

Associated Medical Services (AMS) Phoenix Fellowship funded this study.

Declaration of Interest

The authors declare no potential conflicts of interest with respect to the research, authorship, or publication of this article.

Ethical Approval

This study received REB approval from the University of Ottawa (REB # S-10-19-5137) on 18-11-2019. (See Appendix C for *University of Ottawa Certificate of Ethics Approval*)

References

Aamodt, C., Virtue, D., Dobbie, A., & Aamodt, C. (2006). Trained standardized patients can train their peers to provide well-rated, cost-effective physical exam skills training to first-year medical students. *Family Medicine*, 38(5), 326–329. http://search.proquest.com/docview/67932677/

Ahuja, S., & Williams, S. (2005). Involving patients and their carers in educating and training practitioners. *Current Opinion in Psychiatry*, *18*(4), 374–380. https://doi.org/10.1097/01.yco.0000172054.25284.bb

Allen, S., Miller, J., Ratner, E., & Santilli, J. (2011). The educational and financial impact of using patient educators to teach introductory physical exam skills. *Medical Teacher*, *33*(11), 911–918. https://doi.org/10.3109/0142159X.2011.558139

Badaczewski, A., Bauman, L., Blank, A., Dreyer, B., Abrams, M., Stein, R., Roter, D., Hossain, J., Byck, H., & Sharif, I. (2017). Relationship between Teach-back and patient-centered communication in primary care pediatric encounters. *Patient Education and Counseling*, *100*(7), 1345–1352. https://doi.org/10.1016/j.pec.2017.02.022

Barley, E., Fisher, E., Dwinnell, E., & White, E. (2006). Teaching Foundational Physical Examination Skills: Study Results Comparing Lay Teaching Associates and Physician Instructors. *Academic Medicine*, *81*(10 Suppl), S95–S97.

Bennett, L., & Baikie, K. (2003). The client as educator: learning about mental illness through the eyes of the expert. *Nurse Education Today*, *23*(2), 104–111. https://doi.org/10.1016/S0260-6917(02)00193-4

Bokken, L., Rethans, J., Jöbsis, Q., Duvivier, R., Scherpbier, A., & Van Der Vleuten, C. (2010). Instructiveness of Real Patients and Simulated Patients in Undergraduate Medical Education: A Randomized Experiment. *Academic Medicine, 85*(1), 148–154. https://doi.org/10.1097/ACM.0b013e3181c48130

Boudreau, D., Jagosh, D., Slee, D., Macdonald, D., & Steinert, D. (2008). Patients' Perspectives on Physicians' Roles: Implications for Curricular Reform. *Academic Medicine, 83*(8), 744–753. https://doi.org/10.1097/ACM.0b013e31817eb4c0

Boylan, O., Loughrey, C., & Donaghy, F. (2011). Learning from the expert patient's voice: implications for training. *Education for Primary Care, 22*(3), 140–143. https://doi.org/10.1080/14739879.2011.11493987

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations, 17*(5), 637-650.

Cheng, P., & Towle, A. (2017). How patient educators help students to learn: An exploratory study. *Medical Teacher, 39*(3), 308–314. https://doi.org/10.1080/0142159X.2017.1270426

Canadian Interprofessional Health Collaborative (CIHC). (2010). *CIHC National Competency Framework*. Retrieved from http://www.cihc-cpis.com/publications1.html

Clinton, M. (1999). Collaborative education and social stereotypes. *Australian and New Zealand Journal of Mental Health Nursing, 8*(3), 100–103. https://doi.org/10.1046/j.1440-0979.1999.00139.x

Coleman, K., & Murray, E. (2002). Patients views and feelings on the community-based teaching of undergraduate medical students: a qualitative study. *Family Practice, 19*(2), 183–188. https://doi.org/10.1093/fampra/19.2.183

Crossley, J., Eiser, C., & Davies, H. (2005). Children and their parents assessing the doctor–patient interaction: a rating system for doctors' communication skills. *Medical Education, 39*(8), 820–828. https://doi.org/10.1111/j.1365-2929.2005.02230.x

Dijk, W. (2017). Changing the Paradigm of Meaningful Patient Involvement in Medical Education. *Academic Medicine, 92*(5), 576–577. https://doi.org/10.1097/ACM.0000000000001648

Domecq, J., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., … Murad, M. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research, 14*(1), 89. https://doi.org/10.1186/1472-6963-14-89

Downe, S., Mckeown, M., Johnson, E., Koloczek, L., Grunwald, A., & Malihi-Shoja, L. (2007). The UCLan community engagement and service user support (Comensus) project: valuing authenticity, making space for emergence. *Health Expectations*, *10*(4), 392–406. https://doi.org/10.1111/j.1369-7625.2007.00463.x

Felton, A. & Stickley T. (2004). Pedagogy, power and service user involvement. *Journal of Psychiatric Mental Health, 11*(1), 89–98.

Gecht, M. (2000). What Happens to Patients Who Teach? *Teaching and Learning in Medicine*, *12*(4), 171–175. https://doi.org/10.1207/S15328015TLM1204_2

Guba, E. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ*, *29*(2), 75–91. https://doi.org/10.1007/BF02766777

Hanson, F., & Hanson, R. (2017). Reflections from a Patient and Carer on Involvement in Research and Integrating Care in the Health System. *International Journal of Integrated Care*, *17*(2), 16. https://doi.org/10.5334/ijic.3088

Hoffman, K., Griggs, M., Donaldson, J., Rentfro, A., & Lu, W. (2015). Through patient eyes: Can third-year medical students deliver the care patients expect? *Medical Teacher, 37*(7), 684–692. https://doi.org/10.3109/0142159X.2014.947931

Hsieh, H., & Shannon, S. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Institute for Patient-and Family-Centred Care [IPFCC]. (n.d.). *Patient-and Family-Centred Care*. Retrieved from https://www.ipfcc.org/about/pfcc.html#:~:text=Core%20Concepts%20of%20Patient%2D%20and,Information%20Sharing.

Jha, V., Quinton, N., Bekker, H., & Roberts, T. (2009a). Review of Strategies and interventions for the involvement of real patients in medical education: a systematic review. *Medical Education*, *43*(1), 10–20. https://doi.org/10.1111/j.1365-2923.2008.03244.x

Jha, V., Quinton, N., Bekker, H., & Roberts, T. (2009b). What educators and students really think about using patients as teachers in medical education: a qualitative study. *Medical Education*, *43*(5), 449–456. https://doi.org/10.1111/j.1365-2923.2009.03355.x

Kilgour, J. (2016). Power of the patient voice in medical education. *Clinical Teacher*, *13*(6), 451–453. https://doi.org/10.1111/tct.12487

Kumagai, A., Richardson, L., Khan, S., & Kuper, A. (2018). Dialogues on the Threshold: Dialogical Learning for Humanism and Justice. *Academic Medicine*, *93*(12), 1778–1783. https://doi.org/10.1097/ACM.0000000000002327

Kuper, A., Veinot, P., Leavitt, J., Levitt, S., Li, A., Goguen, J., Schreiber, M., Richardson, L., & Whitehead, C. (2017). Epistemology, culture, justice and power: non-bioscientific knowledge for medical training. *Medical Education*, *51*(2), 158–173. https://doi.org/10.1111/medu.13115

Langer, T., Martinez, W., Browning, D., Varrin, P., Sarnoff Lee, B., & Bell, S. (2016). Patients and families as teachers: a mixed methods assessment of a collaborative learning model for medical error disclosure and prevention. *BMJ Quality & Safety*, *25*(8), 615–625. https://doi.org/10.1136/bmjqs-2015-004292.

Lauckner, H., Doucet, S., & Wells, S. (2012). Patients as educators: The challenges and benefits of sharing experiences with students. *Medical Education, 46*(10), 992-1000.

Levinson, W., Lesser, C., Epstein, R., & Levinson, W. (2010). Developing physician communication skills for patient-centered care. *Health Affairs (Project Hope)*, *29*(7), 1310–1318. https://doi.org/10.1377/hlthaff.2009.0450

Liput, A., Kane-Gill, L., Seybert, L., & Smithburger, L. (2016). A Review of the Perceptions of Healthcare Providers and Family Members Toward Family Involvement in Active Adult Patient Care in the ICU. *Critical Care Medicine*, *44*(6), 1191–1197. https://doi.org/10.1097/CCM.0000000000001641

Manafo, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada: a scoping review of the "how" and "what" of patient engagement in health research. (Report). *Health Research Policy and Systems*, *16*(1), 5. https://doi.org/10.1186/s12961-018-0282-4

Mckeown, M., Malihi-Shoja, L., & Downe, S. (2010). *Service User and Carer Involvement in Education for Health and Social Care* (pp. vii–viii). https://doi.org/10.1002/9781444323764

Moreau, K., Eady, K., Frank, J., Hamstra, S., Karwowska, A., Murnaghan, A., … Jabbour, M. (2016). A qualitative exploration of which resident skills parents in pediatric emergency departments can assess. *Medical Teacher*, *38*(11), 1118–1124. https://doi.org/10.3109/0142159X.2016.1170783

Moreau, K., Eady, K., & Jabbour, M. (2019). Exploring residents' reactions to and use of parent feedback in a pediatric emergency department: A grounded theory study. *Medical Teacher*, *41*(2), 207–214. https://doi.org/10.1080/0142159X.2018.1460658

Oswald, A., Czupryn, J., Wiseman, J., & Snell, L. (2014). Patient-centred education: what do students think *Medical Education*, *48*(2), 170–180. https://doi.org/10.1111/medu.12287

Rees, C., Knight, L., & Wilkinson, C. (2007). "User Involvement Is a Sine Qua Non, Almost, in Medical Education": Learning with Rather than Just About Health and Social Care Service Users. *Advances in Health Sciences Education*, *12*(3), 359–390. https://doi.org/10.1007/s10459-006-9007-5

Repper, J., & Breeze, J. (2007). User and carer involvement in the training and education of health professionals: A review of the literature. *International Journal of Nursing Studies*, *44*(3), 511–519.

Royal College of Physicians and Surgeons of Canada (RCPSC). 2020. *CanMEDS: Better standards, better physicians, better care*. Retrieved from http://www.royalcollege.ca/rcsite/canmeds/canmeds-framework-e

Rowland, P., Anderson, M., Kumagai, A., McMillan, S., Sandhu, V., & Langlois, S. (2019). Patient involvement in health professionals' education: a meta-narrative review. *Advances in Health Sciences Education*, *24*(3), 595–617. https://doi.org/10.1007/s10459-018-9857-7

Rowland, P., & Kumagai, K. (2018). Dilemmas of Representation: Patient Engagement in Health Professions Education. *Academic Medicine*, *93*(6), 869–873. https://doi.org/10.1097/ACM.0000000000001971

Sharma, M. (2018). "Can the patient speak?": postcolonialism and patient involvement in undergraduate and postgraduate medical education. *Medical Education*, *52*(5), 471–479. https://doi.org/10.1111/medu.13501

Shippee, N., Domecq Garces, J., Prutsky Lopez, G., Wang, Z., Elraiyah, T., Nabhan, M., … Murad, M. (2015). Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expectations*, *18*(5), 1151–1166. https://doi.org/10.1111/hex.12090

Sims, S., & Lynch, J. (2016). Medical educational culture: introducing patients to applicants as part of the medical school interview: feasibility and initial impact show and tell. *Medical Education Online*, *21*(1), 31760. https://doi.org/10.3402/meo.v21.31760

Spiro, H. (1992). What Is Empathy and Can It Be Taught? *Annals of Internal Medicine, 116*(10), 843–. https://doi.org/10.7326/0003-4819-116-10-843

Thistlethwaite, J. (2017). Being centred in education and health care. *Clinical Teacher*, *14*(1), 5–7. https://doi.org/10.1111/tct.12618

Thomas, A., Kuper, A., Chin-Yee, B., & Park, M. (2020). What is “shared” in shared decision-making? Philosophical perspectives, epistemic justice, and implications for health professions education. *Journal of Evaluation in Clinical Practice*, *26*(2), 409–418. https://doi.org/10.1111/jep.13370

Towle, A., Bainbridge, L., Godolphin, W., Katz, A., Kline, C., Lown, B., … Thistlethwaite, J. (2010). Active patient involvement in the education of health professionals. *Medical Education*, *44*(1), 64–74. https://doi.org/10.1111/j.1365-2923.2009.03530.x

Towle, A., Brown, H., Hofley, C., Kerston, R., Lyons, H., & Walsh, C. (2014). The expert patient as teacher: an interprofessional Health Mentors programme. *Clinical Teacher*, *11*(4), 301–306. https://doi.org/10.1111/tct.12222

Towle, A., Farrell, C., Gaines, M., Godolphin, W., John, G., Kline, C., … Thistlethwaite, J. (2016). The patient ’ s voice in health and social care professional education. *International Journal of Health Governance*, *21*(1), 18–25. https://doi.org/10.1108/IJHG-01-2016-0003

Towle, A., & Godolphin, W. (2011). A meeting of experts: the emerging roles of non-professionals in the education of health professionals. *Teaching in Higher Education: Leaving the Academy*, *16*(5), 495–504. https://doi.org/10.1080/13562517.2011.570442

Towle, A., & Godolphin, W. (2015). Patients as teachers: Promoting their authentic and autonomous voices. *Clinical Teacher, 12*(3), 149-154.

Wykurz, G., & Kelly, D. (2002). Developing the role of patients as teachers: literature review. (Learning in practice). *British Medical Journal*, *325*(7368), 818–821.

Tables

Table 1

Patients'/Caregivers' Perspectives on their involvement in HPE: Themes and Supporting Quotations

Theme	Supporting Quotation
Patient involvement in the education of HCPs is challenging because healthcare is hierarchical	There are some healthcare professionals who regard [patient involvement in HPE] as an opportunity, but there are many others who sort of say, well, what qualifications does a patient have to provide feedback on that and tell us what to do? And I think the answer to that is, no, a patient can't tell the professional what to do, but they may have some say in how they do it. (P15)
	I think, sometimes, you know, there is a bit of a power dynamic, where, obviously, I'm not trained in medical education, but I think my opinion is valid and my views are valid, and I think there is a place for always being open to hearing from different perspectives. (P01)
	I think also that it's sometimes hard to get patients and people around them to contribute because they have a preconceived notion that the trained healthcare providers know better and more than what they do and so they're reluctant to give their input. (P16)
Patient involvement in the education of HCPs requires patient training	You have to be armed with, you know, some skill, and how to speak to a senior , and you know, take an interest in them, and ask them personal questions, like take an interest in their well-being, and then you ask questions. You just keep asking questions...You have to have the right candidate [to be involved in HPE] (P09)
	There's a kind of power-imbalance in the sense that you're asking for help from someone who has particular training and occupies a particular role, and it's a bit intimidating. Unless you've got some prior working relationship with that person…[it's] very hard to do. So, involving patients in the education of healthcare professionals is going to require some preparation of those patient partners…(P15)

Patient involvement in the education of HCPs needs to start early in the HCPs' education process	When you bring in a patient on your very first day of five years of residency, it sends a very different message about the role that patients play in your medical education than, if you just throw them in half way through your 4th or 5th year [of medical school]. So, I think we need to start early and normalize it. (P02)
	If you're saying that patients are at the center of everything we do, it has to be taken further to the education aspect because, in the education of healthcare workers, it's better for them to learn before they get out and develop some bad habits. The only way to create a new healthcare system is involving them [patients and caregivers] in an updated educational plan. (P05)
Patient involvement in the education of HCPs can improve patient-HCP partnerships	I feel more empowered when I'm in that [patient involvement] setting because I really feel like I'm being heard, I'm being understood, and I feel like it's a two-directional conversation that we're having... and the dialogue is much more warmer. I feel like I have a better relationship and partnership with them [medical students]. (P24)
	We are probably at a stage now in many healthcare organizations where there is the opportunity for patients and family members to express their views, but I think that this relationship is evolving from talking to one another, to engaging with one another, and truly starting to develop a partnership of care…I do believe that (P11)
Patient involvement in the education of HCPs requires compensation for patients	Compensation is another factor, like, I'm already spending tons of money for my child who has disabilities, and I can't afford to, you know, spend more money, just out of my own pocket. And, I think it is something that researchers should value...If you're going to involve a parent or a family member, you should also compensate them somehow (P01)
	It takes a lot of work [to be involved in health professional education], so, you know, naming this work as such, compensating people fairly for their energies, emotional labour and time they spend in doing the work is really really important (P02)

Table 2

Patients'/Caregivers' Perspectives about their roles in HPE: Themes and Supporting Quotations

Theme	Supporting Quotations
Teaching HCPs about patients' expectations, experiences, and perspectives through case studies, storytelling, and research	The work of teaching medical professionals, in any kind of a way, is an emotional labour. And, I think we have to name it as such. Storytelling shouldn't be the only form of educating that we're doing, but inevitably, storytelling plays an important role. And to tell one's story, and to present it in a 'palatable and socially acceptable way,' it takes a lot of work. (P02)
	I think we're doing it [involving patients and caregivers] in real time, in the hospital floors, in doctors' offices...that is one method of doing it. I think though…[we] need to identify ways and means of consciously incorporating it into the curriculum and in the teaching process… I think that case studies offer one mechanism to bring to the attention of aspiring healthcare workers, how a certain situation, a certain challenge, was confronted and how the involvement of patients and their families made that a more satisfactory…I would be a strong proponent of engaging patients and their families in working with healthcare providers to develop case studies that can then become the content for certain coursework. (P11)
Providing direct feedback to HCPs	What if students had a safe manner in providing direct feedback to the students? Setting that up may be challenging to make it safe, and my one concern is that it be non-evaluative [pause]. I don't feel comfortable if I'm giving feedback to say you did a good job [or] you did terrible. What I am perhaps more effective and trained in is to say this made me uncomfortable [or] this part made me feel really comfortable [pause]. So, content-based feedback, but not evaluative. (P19)
	I think being able to get patient feedback before they leave the hospital or wherever they are..Give them the opportunity to provide feedback, whether they're given an ipad, they can quickly check things off, whether they prefer to fill out a short form, which helps to indicate to us

	[HCPs] how to ask those relevant questions as far as whether their HCPs are engaging them more in their care process (P23)
Advising on curricula development and admission boards for HCPs	I think having a focus group or a group of patients review the curriculum to see what aspects of it touch on patient engagement…For example, if they are having to learn a clinical skill, how do they engage the patient in the care process, and the treatment process, the discharge process? Because I think, certainly that's a challenge for many healthcare providers now. (P23)
	For admission criteria, I'd be inclined to have expert patients sitting in on interviews or the designing of the process. One of the things that [you could do] is a role-play, and just see how they interact. Do they have that empathy? So that's something I would definitely be looking for in healthcare workers. (P06)

Appendix A

Participant Invitation Email

Thank you again for participating in the creation of a video- or audio-recording for our graduate course that focuses on current evidence as well as strategies for actively involving patients/caregivers in health professions education at the University of Ottawa.

Given the high-quality and important information provided in the video- or audio-recordings, we would like to thematically analyze them for research purposes and publish a paper on the findings.

In order to use your video- or audio-recording for research purposes we need to obtain your consent. To provide us with your consent to use your previously developed video- or audio-recording, we ask that you review the attached consent form and then **respond to this email with the following statement**:

"**I have read and understand the attached consent form, and I am giving my consent for the use of my video- or audio-recording for the purpose of the research project entitled, A Thematic Analysis of Patients'/Caregivers' Video- and Audio-Recordings for a Health Profession Education Course, which is being conducted by Katherine Moreau and Holly Adam from the Faculty of Education at the University of Ottawa.**"

In your response email, you may also indicate whether you would like to receive an email with a summary of the study findings.

If you have any questions or require more information about the study itself, you may contact Katherine Moreau, by email at kmoreau@uottawa.ca or by telephone at (613) 562-5800 ext. 2808.

Thank you in advance for your time.

Sincerely,

Dr. Katherine Moreau and Holly Adam

Appendix B
Participant Consent Form

uOttawa

Université
d'Ottawa
Faculté
d'éducation

University
of Ottawa
Faculty of
Education

Consent Form

Title of the study:	A Thematic Analysis of Patients'/Caregivers' Video- and Audio-Recordings for a Health Profession Education Course
Principal Investigator:	Dr. Katherine Moreau Associate Professor Faculty of Education University of Ottawa Ottawa, ON (613) 562-5800 ext. 2808
Co-investigator:	Ms. Holly Adam MA Student in Health Professions Education University of Ottawa Ottawa, ON (613) 562-5800 ext. 2808

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by conducted by Katherine Moreau and Holly Adam.

Purpose of the Study: The purpose of this study is to explore patients'/caregivers' perspectives on the importance and value of involving patients/caregivers in the education of healthcare providers (e.g., nurses, medical students, physicians, allied health workers). It also aims to explore patients'/caregivers' opinions on the roles that patients/caregivers can play in educating healthcare providers in formal or informal settings (e.g., in hospitals, classrooms, clinics, the community).

Participation: My participation will consist of allowing Katherine Moreau and Holly Adam to use a previously developed video- or audio-recording of me that was created for a graduate course in the Faculty of Education at the University of Ottawa for the abovementioned research purposes.

Risks: There are no known risks to participating in this study.

Benefits: The results from this study will provide healthcare providers with guidance and information, from patients'/caregivers' perspectives, on how to effectively involve patients/caregivers in the education of healthcare providers. These healthcare providers can also teach their current and future trainees about the importance of active patient/caregiver involvement in health professional education as a means of creating a community of practice in this area and promoting compassionate healthcare. In addition, by documenting and sharing these insights from patients/caregivers, healthcare providers can heed recommendations from, for example, the Royal College of Physicians and Surgeons of Canada and the Institute for Patient- and Family-Centered Care that advocate for patient/caregiver involvement in health professional education.

Confidentiality and Anonymity: I have received assurance from the researchers that the information I have previously shared in the video- or audio-recording will remain strictly confidential. I understand that the contents of the video- or audio recording will be used only for the graduate course in the Faculty of Education at the University of Ottawa and for the present research study. The only people who will have access to the research data for this study are Katherine Moreau, Holly Adam, and a University of Ottawa Research Assistant. In order to protect my anonymity, any identifying information in the video- or audio-recording including, my name, image, voice, or the names of my affiliated institutions will not be included in the study findings or study publications. All findings from the analysis of the video- and audio-recordings will be published in pooled (aggregate) format.

Tel/Tél : 613-562-5804
Fax/Téléc : 613-562-5144

145, Jean-Jacques Lussier
Ottawa ON K1N 6N5
Canada

www.education.uOttawa.ca

Conservation of Data: The research data will be stored on a password-protected computer in the office of Katherine Moreau at the University of Ottawa for a period of 5 years after the publication of research findings, at which time the data will be securely deleted.

Voluntary Participation: I am under no obligation to participate in this research study and if I choose to participate, I can withdraw my video-or audio-recording from the analysis at any time, without suffering any negative consequences, by emailing Katherine Moreau or Holly Adam at the emails mentioned herein.

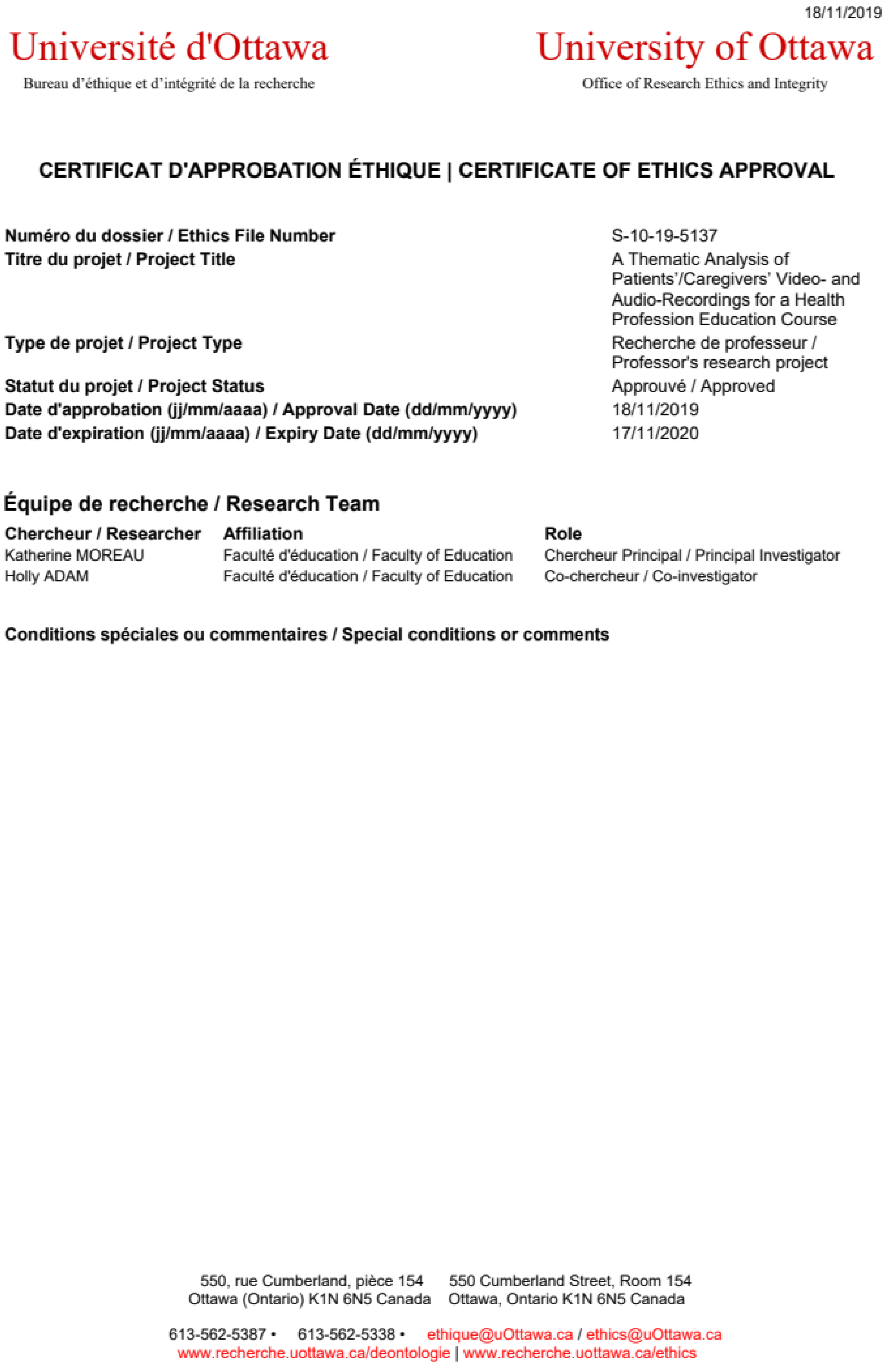
If I have any questions or require more information about the study itself, I may contact the Katherine Moreau (Principal Investigator) at the number mentioned herein.

If I have any questions regarding the ethical conduct of this study, I 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

To provide the researchers with my consent to use the previously developed video- or audio-recording of me, I will respond to this email with the following statement:
"I have read and understand the attached consent form, and I am giving my consent for the use of my video- or audio-recording for the purpose of the research project entitled, A Thematic Analysis of Patients'/Caregivers' Video- and Audio-Recordings for a Health Profession Education Course, which is being conducted by Katherine Moreau and Holly Adam from the Faculty of Education at the University of Ottawa."

In my response email, I may indicate whether I would like to receive an email with a summary of the study findings.

Appendix C
University of Ottawa Certificate of Ethics Approval



18/11/2019

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	S-10-19-5137
Titre du projet / Project Title	A Thematic Analysis of Patients'/Caregivers' Video- and Audio-Recordings for a Health Profession Education Course
Type de projet / Project Type	Recherche de professeur / Professor's research project
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	18/11/2019
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	17/11/2020

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Katherine MOREAU	Faculté d'éducation / Faculty of Education	Chercheur Principal / Principal Investigator
Holly ADAM	Faculté d'éducation / Faculty of Education	Co-chercheur / Co-investigator

Conditions spéciales ou commentaires / Special conditions or comments

550, rue Cumberland, pièce 154
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street, Room 154
Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Section 3: Conclusion -Lessons learned from conducting research exploring patients' perspectives on their involvement in the education of HCPs and implications to health professions education

Lessons Learned

Exploring patients' perspectives on their involvement in the education of HCPs has been a personal, professional, and academic journey for me. It has brought me an immense amount of insight into patients' involvement in the education of HCPs. Specifically, it has challenged my own thoughts and perceptions on such patient involvement. It has also helped teach me the foundation of conducting qualitative research, especially with regards to the need for researchers to remain open and reflexive during the research process.

From my patient perspective, hearing other patients express the need for more active patient involvement in the education of HCPs has been a validating and empowering experience for me. Like other patients, I have often questioned whether my experiences with illness and healthcare would be of value to the education of HCPs (Lauckner et al., 2012). However, hearing other patients express determination to educate HCPs on how to improve PCC has been an inspiration for me to have my own voice heard in the education of HCPs. Overall, I realize that I am not alone in wanting to teach HCPs on how to improve the delivery of quality care and that my voice, along with other patients' voices, can have a powerful impact on HCPs' learning experiences, if given such opportunities.

From my perspective as a nurse, I appreciated patients' honesty and openness in sharing their positive and negative experiences in healthcare with me. It highlighted for me the importance of staying open-minded and accepting of patients' worldviews when providing care to them. Further, it highlighted for me the challenges, as a nurse, I face when it comes to working *with* patients as partners in care while also working under the institutional constrains of high demands versus limited time. In effect, it illuminated for the importance of HCPs advocating for patients' involvement in HPE at institutional levels so that powerful and effective changes to healthcare policies can occur that support patients' active involvement in the education of HCPs, and in PCC in general.

Finally, working with patient-participants in research provided me two valuable lessons in qualitative research. First, it instilled in me the importance of remaining open-minded and reflexive as a researcher. For example, despite being prepared with a set of open-ended questions to guide my interviews, I learned that patients can take interviews in unexpected directions. Some patients chose to answer questions by elaborating on their stories and teaching me important lessons about providing patient-centred care. At first when this occurred, I attempted to steer patients back to the guiding questions that led my study, but I quickly learned that, when given space to express themselves freely, patients' descriptions of their experiences became richer and more meaningful. Therefore, I have learned the importance of researchers staying engaged with participants throughout the interview process, clarifying with participants what they are saying when it is not clear, and giving participants the power to guide research in directions that are meaningful to them.

Second, engaging with patients in research has highlighted for me the challenges associated with being reflexive as a researcher when interpreting patients' interviews. Exploring patients' perspectives on their involvement in the education of HCPs proved challenging for me because it required me to constantly reflect on my biases from my perspectives as both a patient and a nurse, and challenge my own preconceived notions of why and how patients should be involved in the education of HCPs. However, by practising self-awareness of my biases, this helped me understand the process of qualitative research and highlighted for me the importance of involving patients in research processes to help clarify and validate researchers' interpretations.

Implications of this study in a new technological age

As mentioned, this study provides a foundation for HCPs to work from in order to improve patients' involvement in the education of HCPs, and in PCC in general. Amidst a healthcare system where patients feel that HCPs' communication and collaboration with them needs improvements, health information technology "has great potential for increasing patient engagement (Runaas et al., 2017, p.813) and thus, PCC. For example, the emergence of *MyChart* (TOH, 2020), an online patient portal for patients to access their medical information, gives patients opportunities to view their medical records and engage with their HCPs in meaningful discussions about their health. Similarly, Runaas et al. (2017) have described how caregivers with access to a similar kind of database, called BMT Roadmap, facilitated meaningful communication between patients, caregivers, and HCPs that "facilitated positive interactions...[and helped caregivers gain a] personable understanding of their child's healthcare" (p.815). These advances suggest that health information technology helps patients stay informed about their own health and helps facilitate meaningful dialogues that lead to greater collaboration and educational opportunities with HCPs. However, HCPs still have to understand, from patients' own perspectives, what patients expect from their interactions with HCPs for health information technology to be successful.

As indicated in this study, patients want a 'safe' place where they can communicate with HCPs without overarching power-differentials. Technology, such as social media platforms and health information technology, can help with this. For example, patients have explained that face-to face interactions with HCPs who show defensive posturing or who portray general unwillingness to learn from patients in their education negatively affects patients' confidence to educate HCPs (Stacy and Spencer, 1999; Lauckner et al., 2012). Patients have also explained that, while teaching in classroom-settings allowed them to gain confidence to educate HCPs because they view themselves as a 'teacher' rather than just a 'patient,' many still struggled with intimidating power-differentials between themselves and HCPs (Rees et al., 2007). However, when these face-to-face interactions are moved to virtual interactions, patients can educate HCPs on their 'own turf,' such as in their homes (Spencer et al., 2000). This provides them with a shift in power and a 'safe space' to communicate with HCPs openly and honestly (Giroux & Moreau, 2020) so that they can "provide feedback [to HCPs] in a transparent fashion that informs wider discussion" (Sherbino et al., 2015, p.552) without the risk of "jeopardizing rapport" (Godolphin, 2003, p.693).

Further, the representation of patients' collective voices can be challenging when only a "privileged few" (Rowland and Kamagai, 2018, p.869) or a 'right' kind of patient is chosen to represent many. Understanding that this is a challenge for patients who want to engage in HPE but who do not have access to do so, also illuminates the power technology can have in improving this situation. For example, social media provides a way for most patients, beyond the ones 'chosen' by HCPs, to act as educators and to bring diverse perspectives and insights to HCPs' learning (Sherbino et al., 2015; Giroux & Moreau, 2020). Particularly, it opens up communities of practice (Sherbino et al., 2015) where diverse audiences are offered "unique opportunities for broad dissemination and active engagement" (p.553) in HPE.

Overall, constructive learning is essential to HCPs' reflexivity in practice and their abilities to display understanding and empathy for patients' experiences and respect them as collaborative partners in their education (Spiro, 1992; Kumagai et al., 2018). Technology has opened up avenues for patients' voices to be heard at breadth and has created new possibilities to how patients are involved in the education of HCPs. As outlined in the Canadian Interprofessional Health Collaborative (2010), communication is imperative to the success of interprofessional collaboration, teamwork, and to the partnerships with HCPs necessary for patients' active involvement in the education of HCPs (CIHC, 2020). Technology can help bridge the communication gap between patients and HCPs by providing patients with platforms to educate HCPs about what patients truly value in care and how they want to be involved in the education of HCPs. Thus, my study is only part of the beginning of understanding patients' and caregivers' perspectives on educating HCPs, but it offers valuable insight into the fact that patients want HCPs to hear their voices in their education and beyond.

References

Canadian Interprofessional Health Collaborative (CIHC). (2010). *CIHC National Competency Framework*. Retrieved from http://www.cihc-cpis.com/publications1.html

Giroux, C., & Moreau, K. (2020). Leveraging social media for medical education: Learning from patients in online spaces. *Medical Teacher*, 1–6. https://doi.org/10.1080/0142159X.2020.1779920

Godolphin, W. (2003). The Role of Risk Communication In Shared Decision Making: First Let's Get To Choices. *BMJ: British Medical Journal*, *327*(7417), 692–693.

Lauckner, H., Doucet, S., & Wells, S. (2012). Patients as educators: The challenges and benefits of sharing experiences with students. *Medical Education, 46*(10), 992-1000.

Rees, C., Knight, L., & Wilkinson, C. (2007). "User Involvement Is a Sine Qua Non, Almost, in Medical Education": Learning with Rather than Just About Health and Social Care Service Users. *Advances in Health Sciences Education*, *12*(3), 359–390. https://doi.org/10.1007/s10459-006-9007-5

Rowland, P., & Kumagai, K. (2018). Dilemmas of Representation: Patient Engagement in Health Professions Education. *Academic Medicine*, *93*(6), 869–873. https://doi.org/10.1097/ACM.0000000000001971

Runaas, L., Hanauer, D., Maher, M., Bischoff, E., Fauer, A., Hoang, T., Munaco, A., Sankaran, R., Gupta, R., Seyedsalehi, S., Cohn, A., An, L., Tewari, M., & Choi, S. (2017). BMT Roadmap: A User-Centered Design Health Information Technology Tool to Promote Patient-Centered Care in Pediatric Hematopoietic Cell Transplantation. *Biology of Blood and Marrow Transplantation*, *23*(5), 813–819. https://doi.org/10.1016/j.bbmt.2017.01.080

Sherbino, J., Arora, V., Van Melle, E., Rogers, R., Frank, J., & Holmboe, E. (2015). Criteria for social media-based scholarship in health professions education. *Postgraduate Medical Journal*, *91*(1080), 551–555. https://doi.org/10.1136/postgradmedj-2015-133300

Spencer, J., Blackmore, D., Heard, S., Mccrorie, P., Mchaffie, D., Scherpbier, A., … Southgate, L. (2000). Patient-oriented learning: a review of the role of the patient in the education of medical students. *Medical Education*, *34*(10), 851–857. https://doi.org/10.1046/j.1365-2923.2000.00779.x

Spiro, H. (1992). What Is Empathy and Can It Be Taught? *Annals of Internal Medicine*, *116*(10), 843–. https://doi.org/10.7326/0003-4819-116-10-843

Stacy, R., & Spencer, J. (1999). Patients as teachers: a qualitative study of patients' views on their role in a community-based undergraduate project. *Medical Education*, *33*(9), 688–694.

The Ottawa Hospital (TOH). 2020. *MyChart*. Retrieved from https://www.ottawahospital.on.ca/en/patients-visitors/mychart/