

**The Role of Social Workers in Working with Dialysis Patients  
Who Choose to Live at Risk**

By: Holly Elaine Pankhurst

Mémoire submitted to  
The School of Social Work  
To obtain a Master of Social Work Degree

Under the supervision of Marjorie Silverman

University of Ottawa

August 2018

## **Acknowledgements**

I want to express my sincerest gratitude to my family, friends, and mentors who have supported me throughout this journey.

To my fiancé and partner Mark, you have stood by my side through this entire journey and I cannot begin to express how much I appreciate everything you've done. You've been there for me to bounce ideas off of, you edited every single one of my papers, you held me when I cried because I was so frustrated, and had so much faith in me, even when I didn't believe in myself. Thank you for loving and supporting me through it all.

To my wonderful parents, Stephen and Wanda, the sacrifices you have both made in order for me to get to this point in life mean the world to me. You said that if I stayed in school I would find my way, and I finally have found my true calling in life. You have believed in me and loved me unconditionally through it and I am so proud to be your daughter.

To my research supervisor Marjorie Silverman, thank you for being my guiding light in this entire process. You let me have the reins from day one and supported me in all the successes and setbacks we encountered. You have been such a supportive and helpful mentor and I cannot begin to thank you enough for all you have done.

Special thanks to the amazing and supportive team at TOH, Michele Holwell, Geneviève Côté, and Pat deJong, who made this all possible by supporting my research. Thank you from the bottom of my heart.

## **Abstract**

This study, completed as part of a major research project in the obtainment of a Master of Social Work, examines the role of social workers in working with dialysis patients who choose to live at risk. The objectives of this study were threefold: 1) to explore how social workers perceive and respond to risk within a renal context; 2) to determine what interventions social workers carry out in working with these dialysis patients who choose to live at risk; and 3) to explore the ethical implications of working with these patients. The results indicated that social workers feel their roles are to advocate for dialysis patients who choose to live at risk, collaborate with patients, their families, and the healthcare team, provide information and referrals to patients, and support patients in their decision to live at risk by educating them on the potential consequences. Furthermore, they stated that they support the patient's families and their healthcare team in helping them understand why the patient may be living at risk and advocate for others to respect the patient's autonomy.

**Keywords:** biopower, dialysis, renal disease, risk, social work.

Cette étude, complétée dans le cadre d'un mémoire pour l'obtention d'une Maîtrise en Travail Social, examine le rôle des travailleurs sociaux en travaillant avec les patients dialysés qui choisissent de vivre à risque. Les objectifs de cette étude étaient triples: 1) explorer comment les travailleurs sociaux perçoivent et réagissent aux risques dans un contexte rénal; 2) déterminer quelles interventions les travailleurs sociaux effectuent en travaillant avec ces patients dialysés qui choisissent de vivre à risque; et 3) explorer les implications éthiques en travaillant avec ces patients. Les résultats indiquent que les travailleurs sociaux estiment que leur rôle est la défense des droits des patients dialysés qui choisissent de vivre à risque, de collaborer avec les patients, leur famille et l'équipe de soins, de fournir des informations et des références au patient et de soutenir le patient dans sa décision de vivre à risque en les éduquant sur les conséquences potentielles. De plus, elles ont indiqué qu'elles soutiennent les familles des patients et leur équipe soignante en les aidant à comprendre pourquoi les patients vivent à risque et en préconisant le respect de l'autonomie du patient.

**Mots clés:** biopouvoir, dialyse, maladie rénale, risque, travail social

# Table of Contents

Acknowledgements.....	i
Abstract.....	ii
Table of Contents.....	iii
List of Acronyms and Abbreviations.....	vi
Introduction.....	1
1. Research Problem.....	5
1.1 A Life at Risk.....	5
1.1.1 From a Death Sentence to a Chronic Illness.....	6
1.1.2 A Chronic Illness: The Push for Self-Management.....	7
1.2 Perspectives of Risk.....	8
1.2.1 Risk as a Cultural Construct.....	8
1.2.2 A Constant State of Risk.....	9
1.2.3 Risk as a Social Construct.....	10
1.2.4 Risk within a Biomedical Context.....	11
1.2.5 Risk within a Renal Context.....	12
1.2.6 Social Work Perception of Risk.....	13
1.2.7 Dialysis Patients' Institutional Experiences of Risk.....	16
1.3 The Right to Live at Risk.....	18
1.3.1 The Ethical Implications of Risk.....	20
2. Theoretical Framework.....	23
2.1 Power and Biopower.....	23
2.2 Biopower and the Right to Live at Risk.....	24
2.3 Biopower and Social Work Values.....	27
3. Methodology.....	31
3.1 Grounded Theory.....	31
3.2 Data Collection.....	32
3.3 Selection Criteria.....	33
3.4 Recruitment.....	33

3.5	Potential Ethical Implications .....	33
3.6	Data Analysis .....	35
4.	Results.....	37
4.1	Introduction to the Participants .....	37
4.2	How do social workers define living at risk?.....	38
4.2.1	Medical Recommendations.....	38
4.2.2	Housing.....	39
4.2.3	Substance Abuse .....	41
4.2.4	Collateral Damage .....	41
4.3	What do social workers perceive as people’s reasons for living at risk?.....	44
4.3.1	Barriers.....	44
4.3.2	Beliefs .....	45
4.3.3	Lack of Comprehension.....	46
4.3.4	Choices.....	47
4.4	What do social workers think about individuals that live at risk? .....	48
4.4.1	Respect for autonomy .....	48
4.4.2	Autonomy versus Beneficence .....	49
4.4.3	Beneficence.....	50
4.4.4	Competence.....	52
4.4.5	Confidentiality .....	53
4.5	What interventions do social workers carry out regarding individuals that live at risk?.....	54
4.5.1	Collaboration.....	54
4.5.2	Services .....	56
4.5.3	Support.....	58
5.	Discussion.....	60
5.1	Defining Living at Risk.....	60
5.2	Reasons for Living at Risk.....	63
5.3	Ethical Dilemmas .....	66
5.4	Interventions with Those Who Live at Risk.....	72
	Conclusion .....	76
	Implications.....	76

Limitations .....	77
Future Research .....	77
References.....	79
Annex 1 – Interview Guide.....	89
Annex 3 – Ethics Approval Letter, University of Ottawa .....	92
Annex 4 – Consent Form .....	93
Annex 5 – Recruitment Email.....	96

## **List of Acronyms and Abbreviations**

**AIHW**

Australian Institute on Health and Welfare, 11, 12

**BCRA**

British Columbia Renal Agency, 19, 20

**CASW**

Canadian Association of Social Workers, 21, 22, 25, 27, 29, 72, 73

**CKD**

Chronic Kidney Disease, 2, 5, 7, 12, 19

**ESRD**

End-Stage Renal Disease, 7, 12, 16, 17, 19, 65

**KFOC**

The Kidney Foundation of Canada, 7, 16, 17, 25, 32, 63

**MWF**

Monday, Wednesday, Friday, 18

**NACA**

National Advisory Council on Aging, 5, 14, 19, 20

**RRT**

Renal Replacement Therapy, 7, 16

**TTS**

Tuesday, Thursday, Saturday, 17, 18

## Introduction

“He’s not compliant.” “I’ve tried talking to her and she doesn’t listen.” “If they keep it up they’re going to die.” These are just some sentences I heard while carrying out my placement in a hemodialysis unit in 2017. Many of the discussions regarding these nonadherent patients never included them but nonetheless related to how they were eating foods that they should not be, drinking too many fluids that were overloading into their heart and lungs, or that they had missed another dialysis treatment session. These patients were labelled as being noncompliant, as trouble-makers, as people who were sending themselves to an early grave and choosing to live at risk. However, I noticed that there was often more than meets the eye; there were often extenuating circumstances as to why these patients were nonadherent. For some, they were relying on an insufficient transit system, so they would be late getting to appointments or would have to leave early to ensure they were not at the hospital for an additional hour. For others, so much had been taken away from them due to their illness that eating food outside of their diet improved their quality of life. The more time I spent with these patients, the more I understood that they were well-informed about the risks they were taking but chose to take them anyways because they considered them to be positive risks. During my placement, there were often discussions surrounding the patient’s right to live at risk, yet there seemed to be a lack of literature on this subject. While there is research regarding why dialysis patients are nonadherent and what social workers can do to help them become adherent (Christensen, Wiebe, Benotsch, & Lawton, 1996; Dantas et al., 2013; Gagnon, Jacob, & Guta, 2013; Ghimire, Castelino, Lioufas, Peterson, & Zaidi, 2015; Gibson, Held, Khawnekar, & Rutherford, 2016; Kammerer, Garry, Hartigan, Carter, & Erlich, 2007; Amani A Khalil, Darawad, Al Gamal, Hamdan-Mansour, & Abed, 2013; Amani Anwar Khalil & Frazier, 2010; Nabolsi, Wardam, & Al-Halabi, 2015; Rosenthal Asher, Ver Halen,

& Cukor, 2012; Tohme et al., 2017; Umeukeje et al., 2016; Vélez-Vélez & Bosch, 2016; Wileman et al., 2015), there is no research on a social worker's role when dialysis patients choose to live at risk. Motivated by the above experiences, I chose to focus on the following research question:

***What is the role of social workers in working with dialysis patients who choose to live at risk?***

Historically, receiving a diagnosis of kidney disease and renal failure was a death sentence as there was no way to treat it prior to the invention of hemodialysis and peritoneal dialysis machines in the mid 20<sup>th</sup> century (Heidland, Klassen, Vienken, & Ritz, 2012). With the widespread availability and cost coverages of dialysis treatments, kidney disease was transformed into a chronic illness. This led to the healthcare system's attempting to cut costs by having patients begin to self-manage their chronic illness. With the increased burden of symptoms, pill count, treatment schedule, along with fluid and dietary restrictions, patients can become overwhelmed in their ability to self-manage Chronic Kidney Disease (CKD), leading them to be nonadherent regarding their treatment plan, and thus be labelled as living at risk.

While risk is often quantified and presented as being imminent, dangerous, and undesirable, there are times when it can be positive, necessary, desirable, and beneficial for those choosing to take risks. Current research on risk within a renal context focuses on defining risk, defining living at risk, determining how healthcare professionals view risk, how dialysis patients view risk, why these patients might choose to live at risk, and, most importantly, what healthcare professional can do to ensure dialysis patients are adherent (Dantas et al., 2013; Gagnon et al., 2013; Ghimire et al., 2015; Amani A Khalil et al., 2013, 2013; Nabolsi et al., 2015; Rifkin et al., 2010; Rosenthal Asher et al., 2012; Tohme et al., 2017; Umeukeje et al., 2016; Vélez-Vélez & Bosch, 2016; Wileman et al., 2015). However, it fails to discuss what interventions can be and are carried out to ensure dialysis patients can choose to live at risk while enjoying the quality of life

that comes from positive and desired risks. The objectives of this study were threefold: 1) to explore how social workers perceive and respond to risk within a renal context; 2) to determine what interventions social workers carry out in working with these dialysis patients who choose to live at risk; and 3) to explore the ethical implications of working with these patients (i.e. a requirement to respect patient autonomy versus beneficence and the duty to provide care).

In Chapter 1, I discuss kidney disease and its movement from a death sentence to a chronic illness. Following this, I present various perspectives of risk and what it means to live at risk. I then present information regarding individual perspectives of risk as they relate to dialysis patients and social workers. Finally, I present the concept of the right to live at risk, how it pertains to dialysis patients, and the ethical implications of living at risk.

In Chapter 2, I discuss the theoretical framework for this study, which is Foucault's theory of biopower. I discuss the foundations of biopower as it relates to the right to live at risk and present the Foucauldian biopower perspective in relation to social work values.

In Chapter 3, I discuss the methodology used for this study. I carried out individual semi-structured interviews with three renal social workers who were recruited from a local hospital through the Social Work Department. Participants had to have completed a Master of Social Work and had to have worked with dialysis patients for a minimum of two years. The interviews built on themes such as defining living at risk within a renal context, the reasons why dialysis patients live at risk, and the ethical dilemmas encountered by social workers in working with dialysis patient who live at risk. The interviews were transcribed and analyzed thematically.

In Chapter 4, I discuss the results of the study. I begin by describing the three participants and relevant information regarding their status as renal social workers. I then describe what the participants reported from their interviews. The participants provided their definition of living at

risk, the reasons they feel dialysis patients live at risk, the ethical dilemmas they have encountered working with these patients, and what they perceive as their role in working with dialysis patients who choose to live at risk.

In Chapter 5, I discuss my interpretation of the results by analyzing the data using the theoretical framework, biopower, and by putting the results into dialogue with other relevant research. First, I discuss the participants' definitions of living at risk and relate them to previously identified research. Second, I discuss the participants' reasons behind why they feel dialysis patients live at risk and demonstrate the link between these reasons and biopower. Third, I discuss the ethical implications of working with dialysis patients who live at risk and the implications of a power-knowledge relationship between patients and their healthcare team. Last, I present the interventions carried out by social workers and how these interventions relate to biopower.

I conclude this research paper by discussing the implications of the results, the possibilities for future research, and the limitations of this study. Social workers stated that they feel their roles are to advocate for dialysis patients who choose to live at risk, collaborate with patients, their families, and the healthcare team, provide information and referrals to patients, and support the patients in their decisions to live at risk by educating them on the potential consequences. Furthermore, they stated that they support the patient's families and their healthcare team in helping them understand why the patient may be living at risk and advocate for others to respect the patient's autonomy.

# 1. Research Problem

In this chapter, I provide a brief overview of kidney failure and its movement from a death sentence to a chronic illness and present current issues surrounding self-management. Following this, I present various perspectives of risk and relate them to CKD. I then present information regarding individual perspectives of risks as they relate to dialysis patients and social workers. Last, I present the concept of the right to live at risk, how it pertains to dialysis patients, and the ethical implications of living at risk.

## 1.1 A Life at Risk

Discussions surrounding risk are present within any society. At the mention of risk, certain topics come to mind such as the identification of those at risk, risk factors at the individual, familial, communal, societal, and global levels, risk assessments and prevention, and the hazards imposed by risk. Risk is viewed as a threat, a menace, a vulnerability, as a danger, and as something that should be avoided at all cost (Webb, 2006). While there are individuals who live at risk, there are also those who choose to live at risk, knowing the consequences and implications of their actions. The first literature I encountered in my search to further understand those who choose to live at risk was published by The National Advisory Council on Aging (NACA) in 1993 and states that:

*Every person is exposed to potential harm simply by living; some people engage in activities - smoking, motorcycling, jaywalking, etc. - that are clearly risky. The extent of risk, of course, depends upon the seriousness of the potential harm and the probability that harm will occur. People generally are free to live at risk, as long as their rights do not infringe upon the rights of others or expose them to harm.*  
(p. 1)

Risk is often quantified and presented as being imminent, dangerous, and undesirable; however, there are times when it can be positive and desirable, usually in the eyes of the individuals taking

those risks. For dialysis patients, living at risk refers to three specific factors: not taking all prescribed medications, not following diet and fluid restrictions, and missing or shortening treatments (Dantas et al., 2013; DeOreo, 1997; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2002; Gagnon et al., 2013; Ghimire et al., 2015; Amani A Khalil et al., 2013; Rosenthal Asher et al., 2012; Tohme et al., 2017; Wileman et al., 2015).

### **1.1.1 From a Death Sentence to a Chronic Illness**

In the early 19<sup>th</sup> century, little was known about the kidney or its functions besides the fact that it performed simple filtration (Wise, 2012). It was not until 1827 when Dr. Richard Bright released his book entitled *Reports of Medical Cases* that kidney disease became classified as its own illness. Very little was understood about what caused kidney disease and how to test for it besides Bright's discovery that a urinalysis could be performed to check for protein molecules, a test still used today to determine kidney damage. While scientists and doctors were beginning to better understand the purpose and function of the kidney during this period in history, they still did not know what caused kidney disease, and with no known cure, it was considered a death sentence.

The study of kidney disease advanced drastically throughout the 19<sup>th</sup> century and early 20<sup>th</sup> century, with researchers in the United States and Europe attempting to treat uremia, which is an excess of waste products in the body due the kidney's inability to eliminate them (Heidland et al., 2012). In 1946, the first dialysis machine became available in Canada and "was used successfully in clinical trials on four patients at the Toronto General Hospital" (ibid., paragr. 2). Although hemodialysis had proven to be a life saving therapy, it was extremely expensive and not readily available in Canada until the 1960s. In 1967, the first dialysis unit was set up at the Kingston General Hospital with four machines. Since then, dialysis programs across Canada have continued to expand to keep up with the increasing number of individuals who require renal replacement

therapy. Once dialysis became a readily available treatment in Canada, kidney disease then became classified as a chronic disease.

### **1.1.2 A Chronic Illness: The Push for Self-Management**

While kidney disease was once considered a life-threatening illness, the invention of the dialysis machine drastically transformed this disease from being a death sentence to a chronic illness. According to Bernell & Howard (2016), a chronic disease is “one lasting 3 months or more” (p. 1). The Kidney Foundation of Canada (KFOC) defines CKD as “the presence of kidney damage, or a decreased level of kidney function, for a period of three months or more. Kidney disease can range from mild to severe and in some cases, lead to kidney failure” (2017, paragr. 2). Kidney failure occurs in stage five of CKD, which is also referred to as end-stage renal disease (ESRD) in which renal replacement therapy (RRT) is required in order to prevent death. There are three options for RRT: hemodialysis, peritoneal dialysis, or a kidney transplant. While a transplant is the preferred option, only 11% of ESRD patients are eligible for a transplant due to numerous factors such as a suitable match, uncontrolled additional health concerns, and ability to undergo surgery (ibid.).

With changes in the healthcare structure, “patient autonomy is stressed rather than professional autonomy” (Bury, 2010, p. 175) which tends to put a great deal of pressure on the patient to manage their symptoms and take a more active role in the management of their illness. The goal of self-management, however, has come from healthcare cuts and the desire to keep individuals with a chronic illness out of formal care systems as a cost saving measure (ibid.). Richard & Shea (2011) define self-management as “the ability of the individual, in conjunction with family, community, and healthcare professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” (p. 261).

Schulman-Green et al., (2012) explain that self-management for individuals with a chronic illness can be challenging as it includes “recognizing symptoms and taking appropriate actions, using medications effectively, managing complex regimens, developing strategies to deal with the psychological consequences of the illness, and interacting with the healthcare system over time” (p. 136). Furthermore, they state that “optimal self-management entails the ability to monitor the illness and to develop and use cognitive, behavioral, and emotional strategies to maintain a satisfactory quality of life” (ibid., p. 137).

## **1.2 Perspectives of Risk**

Risk is a multidisciplinary term used in numerous fields of study. In order to present various perspectives of risk in relevant fields, I carried out a literature review to examine different perspectives of risk.

### **1.2.1 Risk as a Cultural Construct**

One of the first well-known works on risk is Douglas & Wildavsky's *Risk and Culture* (1982) in which they state that there are numerous risks present within the world of which we are unaware, but we must act as if we are aware of them in order to assess the risks that we should and should not take. They state that “there is no single correct conception of risk” (ibid., p. 4). They elaborate on this by stating that “risk should be seen as a joint product of *knowledge* about the future and *consent* about the most desired prospects” (ibid., p. 5), In this sense, a risk assessment can be carried out to determine if there is sufficient knowledge available and complete consensus on what is desired in order to produce the best outcomes to avoid unnecessary risks. Furthermore, they state that perceived risks are part of a social process and that “different social principles that guide behavior affect the judgement of what dangers should be most feared, what risks are worth taking, and who should be allowed to take them. (ibid., p. 6). Douglas & Wildavsky state that these

social principles, along with social environment and the individuals themselves who perceive various risks, together create one system which they state is the cultural theory of risk perception. This theory and perspective of viewing risk aims to discover the ways in which “different characteristics of social life elicit different responses to danger” (ibid., p. 8) and how certain dangers, fears, and aversions are co-constructed within a cultural analysis of risk. Anthropologists, such as Douglas & Wildavsky, see risk as being culturally defined and selected throughout history such as in Douglas’ cultural theory of social order with risk being defined in accordance to cultural norms, beliefs, and values. Furthermore, anthropologists generally feel that as a culture evolves, so too does the definition of risk (Boholm & Corvellec, 2011).

### **1.2.2 A Constant State of Risk**

Sociologist Ulrich Beck is one of the biggest names in risk theory. His work focuses on how society responds to risk and how society has evolved over time to deal with risk. He demonstrates that in the past, risks were related to a lack of hygiene due to improper sewage systems and a misunderstanding of the transmission of diseases and that modern risks relate to an industrial overproduction (such as deforestation, toxins in foodstuffs, soil, and water, nuclear threats, etc.). While the nature of risk has changed, Beck states that the “risks and hazards of today thus differ [...] through the global nature of their threat (people, animals and plants) and through their modern causes. They are risks of modernization” (Beck, 1992, p. 21) Furthermore, he defines risk as “a systemic way of dealing with hazards and insecurities induced and introduced by modernization” (ibid., p. 21). He furthers this definition in his 2009 book entitled *World at Risk* by stating that “risk means the *anticipation* of the catastrophe [...] the moment risks become real, when a nuclear power station explodes or a terrorist attack occurs, they become catastrophes. Risks are always *future* events that *may* occur, that *threaten* us” (p. 9). In this sense, Beck explains how

we constantly live in a state of risk, that we are always at risk and anticipating a catastrophe, followed by times when risk transforms and becomes a catastrophe resulting in harm. Ian Culpitt built on Beck's research in his 1999 book entitled *Social Policy and Risk*, stating that risk has "become public, pervasive, compelling, and inescapable [...and] given the obvious fragility of life, and its randomness, individual perception of risk typically provoked reflex responses to private sets of complex fear about health, safety and survival" (ibid., p. 3). Along with Beck's definition of risk and his perspective of a risk society, Culpitt states that risk is no longer about these individual and private fears, but that risk and risk society has established itself as a "central defining motif of late modernity [and] offers a new perspective for social policy theory. Currently, the debate is much more about minimizing risk than ensuring justice" (ibid., pg. 4). Thus, risk has altered social policies and societal principles. Sociologists see risk as being situated in a social context with theories such as Beck's theory of reflexive modernization and the risk society (i.e. ways in which society organizes itself in response to risk), and Culpitt's demonstration on how risk has affected societal principles and social policies.

### **1.2.3 Risk as a Social Construct**

The work of sociologist Frank Füredi has focused not on the nature of risk itself, but rather why we are concerned with risk and what this concern signifies. He states that when discussing risk, it is important to differentiate between the likelihood of risk occurring (injuries, illness, death, etc.) versus the perception of risk and its perceived dangers: "often people's perception of what constitutes danger has little to do with the real likelihood that they will suffer a misfortune from that source" (Füredi, 2006, p. 23). With this, he defines risk as "the probability of damage, injury, illness, death or other misfortune associated with a hazard. Hazards are generally defined to mean a threat to people and what they value" (ibid., p. 25). Füredi states that it is not just the obvious

threats such as “poison, bacteria, toxic waste or hurricanes [... but] at various times peanuts, tampons, automobiles and contraceptive pills – to name a few – have been represented as hazards” (ibid., p. 25). In this, he demonstrates how risks present themselves in a variety of forms and can range from an individual level of threat to a global scale; however, risks need to be examined in terms of reality versus probability. Füredi presents an example of this from research from the USA in how Americans have continually placed nuclear power as the most prominent risk in their country. Similarly, Poushter & Manevich (2017) from the Pew Research Center, presented results from a survey that stated Canadians see global climate change, ISIS, cyberattacks from other countries, the USA’s power and influence, and conditions of the global economy as the top five major threats to Canadians, respectively. As Füredi relates, while it is impossible to say that there are no deaths related to these threats, these fears influence public opinion of what we believe we are at risk of, what hazards may take place, and what we must do to avoid them.

#### **1.2.4 Risk within a Biomedical Context**

In examining risk within a biomedical perspective, the focus is on the health and well-being of individuals, families, communities, and societies. The World Health Organization (2017) defines a risk factor as:

*any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury. Some examples of the more important risk factors are underweight, unsafe sex, high blood pressure, tobacco and alcohol consumption, and unsafe water, sanitation and hygiene. (paragr. 1)*

Risk within a biomedical context tends to focus on the possibility and potential of harm occurring, or risk factors that put individuals and communities at risk of developing an illness or disease (Van Ness, 2001). The Australian Institute on Health and Welfare (AIHW) defines biomedical risk factors as “bodily states that can contribute to the development of chronic disease. Abnormal levels

of the three biomedical factors in this snapshot—blood pressure, blood lipids and blood glucose—pose direct and specific risks to health” (AIHW, 2016, p. 175). Factors included within this biomedical context can be related to “blood pressure, cholesterol levels and body weight, to behavioural factors such as smoking, alcohol consumption and exercise” (ibid., p. 4). As this demonstrates, risk within a biomedical context is much more concrete than in other disciplines: it relies on physical bodily evidence to state whether an individual is at risk of developing an illness or disease.

### **1.2.5 Risk within a Renal Context**

As previously mentioned, Webb (2006) states that each discipline has its own definition of risk; furthermore, even each illness can have its own definition of risk and CKD is no different. There are various forms of risk within a renal context: one can be at-risk for developing CKD due to factors such as diabetes, hypertension, or genetic predisposition; one can be at-risk of renal failure; and an ESRD patient can be at risk of death due to a nonadherence to their treatment plan (Dobrof et al., 2002). Nonadherence, sometimes referred to as noncompliance, refers to three specific factors for ESRD patients within their treatment plan: not taking all prescribed medications, not following diet and fluid restrictions, and missing or shortening treatments (Dantas et al., 2013; DeOreo, 1997; Dobrof et al., 2002; Gagnon et al., 2013; Ghimire et al., 2015; Amani A Khalil et al., 2013; Rosenthal Asher et al., 2012; Tohme et al., 2017; Wileman et al., 2015). For ESRD patients who are classified as nonadherent or noncompliant, and who can “understand the information, and can appreciate the risks and benefits of their decisions” (Newfoundland & Labrador Association of Social Workers, 2012, p. 2), they are classified as individuals choosing to live at risk.

### 1.2.6 Social Work Perception of Risk

Stephen Webb, a well-known risk researcher within the field of social work, defines risk within Beck's risk society as "the recognition and assessment of the uncertainty as to what to do, with risk judgement being the degree of distance a course of action may be at from certain success" (Webb, 2006, p. 34). Additionally, Webb states that "the concept of risk thus provides the basis for understanding the relation between judgement and uncertainty" (ibid.). Webb argues that "reconfigurations between state, politics, science and people, as a result of responses to risk, are particularly felt in the world of social work. This is because social work invariably deals with vulnerable, dangerous and challenging populations under conditions of uncertainty and crisis" (Webb, 2007, p. 380). Social work as a discipline works to regulate risk and to create risk assessment and management techniques, while trying to control and govern risk within a neoliberalist society. The result is "the development of what Power (1997) describes as an 'audit society' in which performance, accountability, quality control and transparency becomes key elements of risk regulation in social work" (p. 381).

Warner & Sharland (2010) discuss how the concept of risk in social work is reflective of the perceptions and analyses of risk within the related social sciences. They discuss how the concept of risk within social work theory, research, education, and practice has evolved substantially within the past two decades:

*encompassing an increasingly wide range of questions and areas of enquiry. These have included, at the micro level, empirical work on the processes of risk assessment with specific service user groups, at the meso level organisational and cross-organisational strategies for risk management, and at the macro level theoretical analysis of social work in a risk society. (ibid., p. 1035)*

Additionally, Smith (2010) adds to this by stating that current ideas and strategies regarding risk and power are "significant and dynamic influences in social theory and social action, and they can

therefore be expected to have a substantial impact on the ways in which social work is constituted, practiced and evaluated” (p. 1). Smith elaborates by stating that due to the nature of social work as a practice, it could be considered a natural site in which risk would occur: “‘risk’ and ‘danger’ are endemic features of the field of practice, given its primary concerns with disadvantage and oppression and its specific responsibilities in areas such as child protection, mental health and youth offending” (ibid., p. 6). However, due to the nature of social work, Smith states that it has become an expectation of the field and its practitioners to demonstrate expertise when it comes to responding to risk. Not only are social workers supposed to respond to current risk, but France, Freiberg, & Homel, (2010) relate that social workers are often sought out to help prevent future risks, such as working with vulnerable children. The hope of early mediation for those who are at-risk currently or in the future is that an “intervention in the early years would reduce risks and the likelihood of future social problems” (ibid., p. 1195); therefore, tools such as risk assessment, management, and analysis tools have been developed. However, it should be noted that a “risk assessment is subjective; that is, it is influenced by personal fears or desires” (NACA, 1993, p. 3).

While there are times when social workers may be able to work to prevent future risks, there are other times when they are confronted with current risks and ethical dilemmas. These dilemmas often pertain to a conflict between the health and safety of an individual and their autonomy (Badger, Ladd, & Adler, 2009; DeWolf Bosek, 2007; Dobrof et al., 2002; Entwistle, Carter, Cribb, & McCaffery, 2010; Sasson, 2000; Umeukeje et al., 2016). In each case in which there is a conflict between beneficence and autonomy, the following question arises: “it is ever ethically justifiable to overrule a patient’s [autonomy] for the ‘patient’s own good’” (DeWolf Bosek, 2007, p. 46). This is where, as Barsky (2015) relates, risk management comes into effect for social workers, in order to handle such ethical dilemmas: social workers “should identify the

risks of various courses of action so they can determine which course of action to take” (paragr. 1). Furthermore, Barsky states that by carrying out a risk management strategy and “by preempting and managing risks, workers and agencies can make strategic choices about which types of risks to accept and which to avoid” (ibid., paragr. 4).

To determine how risk is perceived in practice, MacLeod & Stadnyk (2015) carried out a study with 12 Canadian community practitioners and social workers to determine how they “defined, perceived, assessed and managed risk and how they balanced their client’s safety and autonomy” (p. 46). From their research, “seven factors emerged which participants said influenced their assessment of the severity of risk, issues relating to capacity, occurrence, severity, imminence, frequency, support and complexity” (ibid., p. 55). MacLeod & Stadnyk state that each of these seven factors occur along a continuum which can be used to determine the level of risk by asking the following questions: is the individual capable of making a decision; is the harmful event occurring now; how severe are the consequences of the events; how imminent is the event; how often does this event occur, does the individual have consistent and reliable support in place; and are there other harmful events co-occurring? In defining living at risk, they cite Adam & van Loon (2000) and state that it is:

*a multidimensional concept, comprised of both a source of risk (the client’s impairment or environment or an event) and/or the outcome of risk (an adverse consequence), [and] is in contrast to the essence of risk being something that might happen rather than something that has happened.* (ibid., p. 58)

As demonstrated, risk and risk management have many elements which require examination in order for a social worker to determine their perceived level of a client’s risk. In this sense, a situation has to be analyzed to determine whether the social worker should respect the patient’s autonomy or protect them from the harm they may inflict upon themselves (or potentially on others). This needs to be done on a case-by-case basis with consultation from other professionals

to ensure that as many options and risk factors as possible are analyzed in order to determine what is in the patient's best interest (Barsky, 2015).

### **1.2.7 Dialysis Patients' Institutional Experiences of Risk**

As previously mentioned, Bury (2010) relates that life-threatening illnesses have become chronic ones due to technological advances and that the emphasis on patient autonomy puts pressure on the patient to manage their symptoms and take an active role in managing their illness. The goal of self-management, however, has come from healthcare cuts and the desire to keep individuals with chronic illness out of formal care systems (ibid.). This can be further complicated since "clients and family members may have differing values and opinions around the potential for risk and the perceived or real consequences of the identified risk" (Baker, Campton, Gillis, Kristjansson, & Scott, 2007, p. 20) causing conflicts with family members and patients. Furthermore, values can come into conflict between ESRD patients, social workers, and other healthcare professionals regarding the patient's well-being versus respecting their autonomy (Badger et al., 2009).

When an individual's kidneys fail, and they are diagnosed with ESRD, they are faced with the option of choosing or foregoing RRT. Factors such as age, additional health concerns, and quality of life often determine which form of dialysis a patient may choose or whether they will opt for conservative care in which attempts are made to preserve kidney function through medication and diet without the use of dialysis (KFOC, 2015). Individuals who opt for dialysis are then faced with a minimum of three dialysis treatments a week for four hours at a time, with additional appointments with doctors, dieticians, social workers, and treatment nurses. Dialysis patients often experience a great deal of physical and psychological distress along with financial challenges due to "loss of income, coupled with increased transportation and medication costs"

(KFOC, 2018, p. 2); Khalil & Frazier (2010) state that “patients with end-stage renal disease who receive hemodialysis have high rates of psychosocial distress” (p. 324). Factors such as these, along with the challenge of adjusting to a treatment plan, can lead to patients becoming depressed or anxious, making it difficult for them to adapt to being on dialysis (Ghimire et al., 2015).

While renal healthcare professionals label patients as nonadherent if they do not take their medications, do not follow their diet, and do not stay for the entire length of their treatments, patients rarely share this view (Dobrof et al., 2002). Ghimire et al. (2015) state that contributing factors, such as being prescribed multiple medications and a demanding treatment schedule, can make adjustment to life as a dialysis patient difficult for these individuals. Furthermore, additional factors related to the social determinants of health can affect how well an ESRD patient will adapt to being a dialysis patient: younger age, low education, non-Caucasian ethnicity, smoker, employment status, a history of family problems, depressive symptoms, being separated, divorced, or widowed, and medication factors such as the number of prescribed medications, knowledge about the medications, and the total pill burden. Additionally, Washington, Zimmerman, & Browne (2016) state that dialysis patients often experience challenges related to self-management, including exercising, communicating with physicians, cognitive symptom management, fluid and diet management. This can be further complicated when factors such as age, cognitive status, and self-efficacy levels are taken into account, which can make following a treatment plan seem extremely difficult for a dialysis patient.

Another concern for dialysis patients relates to their treatment schedule; Obialo, Hunt, Bashir, & Zager (2012) discuss the implications of having a Tuesday, Thursday, Saturday (TTS) dialysis run versus a Monday, Wednesday, Friday (MWF) run. In their study, they compared a total 53 individuals on the MWF run versus 61 on the TTS to determine the differences; the TTS

run showed higher rates of no-shows, shortened treatment runs, higher use of cocaine, higher interdialytic weight gain, higher mortality rates, and lengthier hospital stays. They concluded by stating that the TTS patients were less adherent compared to the MWF patients; however, they do not provide any theories as to why this is the case.

### **1.3 The Right to Live at Risk**

As previously mentioned, Douglas & Wildavsky (1982) see risk as being culturally defined in accordance to cultural norms, beliefs, and values. Furthermore, they state that a risk assessment enables individuals to determine if there is sufficient knowledge available and complete consensus of these risks provided to produce the best outcomes to avoid unnecessary risks. What complicates matters for dialysis patients is that what constitutes risk for them is different from the beliefs, values, and norms set out by today's society. While doctors, healthcare professionals, and the patient's family members or friends might see certain risks as unnecessary and undesired, the patient sees them as necessary and desired. Although Douglas & Wildavsky's position and analysis of risk is a more global viewpoint stating that risk is culturally defined, it can be seen that the perception of risk changes as an individual's norms change, just as an individual's perception of risk would change if there was a change in their culture. For someone who has gone from independence to having a chronic illness, their new normal, which constitutes dialysis treatments, multiple doctor's appointments, and a new medication and dietary regimen, changes their perception of risks, and therefore what may seem like unnecessary risks on a societal level are very much necessary and positive risks for dialysis patients (Croisdale-Appleby, 2011).

Dialysis patients who choose to live at risk can be classified as self-endangerers (Beck, 2009) as their actions only endanger themselves and not others. Beck discusses how smoking was once seen as self-endangering but when further research demonstrated the effects of second-hand

smoke, smoking transformed into something that not only endangered the individual, but others as well. In the case of a dialysis patient, their choice to live at risk by not adhering to their treatment plan does not endanger others, and the endangerment towards themselves is not imminent. As previously stated, as long as these risky actions do not infringe upon the rights of others and does not harm them in any way, then people are free to live at risk (NACA, 1993).

While living at risk does not pose an imminent threat to dialysis patients, it should be noted that Statistics Canada reports state that in 2000, and between 2010-2013, kidney diseases were one of the top ten leading causes of death in Canada, causing an average of 3,000 deaths per year (Government of Canada, 2014, 2017). According to the British Columbia Renal Agency (BCRA) (2015), the number of patients with ESRD has tripled in Canada over the last two decades. Furthermore, diabetes and heart diseases have been respectively the sixth and second leading cause of death of Canadians from 2000-2013 (ibid.) which are the two leading causes of CKD; diabetes is the primary cause of CKD (around 45% of cases) and hypertension being the secondary cause (around 30% of cases) (National Institute of Diabetes and Digestive and Kidney Diseases, 2014). A report by the United States Renal Data System in 2016 stated that from 1995 to 2015, the prevalence of hypertension and diabetes at the time of a first dialysis run had increased from 67.9% to 87.6 % and from 43.1% to 59.6%, respectively, in CKD patients. Additionally, cancer is the leading cause of death in Canada (Government of Canada, 2017) and Butler et al. (2015) relate that during a study of hemodialysis patients over a five-year period, approximately 9.5% of patients developed some form of cancer, which is a much higher rate than the general population. According to the BCRA (2015), cardiovascular syndrome is the leading cause of death for dialysis patients (approximately 50%), with withdrawal from dialysis being the second leading cause (approximately 25%), and infection being the third (approximately 13%). While dialysis patients

are able to withdraw from treatment, which results in death within a week to a month depending on retained renal function, these deaths are not noted in Canadian statistics and could be classified under deaths related to diabetes, heart disease, cancer, kidney disease, or suicide. However, Roberts (2014) explains that withdrawal from dialysis is the third leading cause of death in the United States. As previously mentioned, Füredi (2006) states that “often people’s perception of what constitutes danger has little to do with the real likelihood that they will suffer a misfortune from that source” (Füredi, 2006, p. 23). This can be seen by Canadians stating that global climate change, ISIS, cyberattacks from other countries are the largest threats to their well-being (Poushter & Manevich, 2017), when in fact Canadians should be far more concerned about cancer, heart disease, strokes, lung diseases, accidents, diabetes, pneumonia, Alzheimer’s, and kidney diseases as these have been the top ten causes of death in Canada for almost two decades (Government of Canada, 2017).

What Canadians constitute and define as risk in relation to our norms, beliefs, and values does not always coincide with the largest risks we face or how risk can change in relation to one’s situational context. It should also be reiterated that “the freedom to make choices in life is a primary source of personal dignity and is a cornerstone of a democratic society. To uphold the right of competent persons to live at risk is to reaffirm this value” (NACA, 1993, p.7). Therefore, many risk researchers, myself included, feel that an individual’s right to live at risk should be respected as long as they are capable of understanding and appreciating the risks they are taking and as long as those risks are not likely to harm others in the process.

### **1.3.1 The Ethical Implications of Risk**

Healthcare professionals’ ethical codes often focus on the duty to provide care and they have a “professional obligation and legal duty to provide their clients with safe, competent and

ethical care” (Adlersberg, 2006, p. 38). Adlersberg elaborates by stating that the duty to provide care for a patient only ends when the care of that patient is transferred to another healthcare professional. In not providing care to a patient, a healthcare professional and/or the organization can be found negligent and be charged if something happens to the patient while under their care.

In his article *Autonomy vs. Beneficence*, Pantilat (2008) states that:

*Some of the most common and difficult ethical issues to navigate arise when the patient’s autonomous decision conflicts with the [healthcare provider]’s beneficent duty to look out for the patient’s best interests. For example, a patient who has had bypass surgery may want to continue to smoke or a patient with pneumonia may refuse antibiotics. In these situations, the autonomous choice of the patient conflicts with the [healthcare provider]’s duty of beneficence and following each ethical principle would lead to different actions. As long as the patient meets the criteria for making an autonomous choice (the patient understands the decision at hand and is not basing the decision on delusional ideas), then the [healthcare provider] should respect the patient’s decisions even while trying to convince the patient otherwise. (paragr. 8)*

The Canadian Association of Social Worker’s (CASW) Code of Ethics states that “a core social work value that refers to the right to self-direction and freedom of choice without interference from others. Self-determination is codified in practice through mechanisms of informed consent” (2005, p. 28). However, it should be noted that “social workers may be obligated to limit self-determination when a client lacks capacity or in order to prevent harm” (ibid.). Furthermore, the Code states that a client’s right to self-determination might be limited by the duty to provide care and social workers are obligated to prevent any forms of serious, foreseeable, and imminent harm that could come about to clients or others. Additionally, one of a social worker’s roles is to determine an individual’s capacity to understand and appreciate their decisions (Newfoundland & Labrador Association of Social Workers, 2012). The CASW Code of Ethics (2005) states that capacity is “the ability to understand information relevant to a decision and to appreciate the reasonably foreseeable consequences of choosing to act or not to act” (p. 26). Determining an

individual's risk can be complicated by their capacity and it is a social worker's duty to determine if they understand and appreciate the consequences that a particular risk involves. Social workers must protect the "rights and interests of clients who have limited or impaired decision-making capacity when acting on their behalf, and/or when collaborating with others who are acting for the client" (ibid., p. 4).

In this chapter, I examined the concept of risk and related it to my research problem. I presented how risk within a renal context relates to risk theories and presented the ethical implications of living at risk. In the next chapter I outline the theoretical framework used during my research and its relation to dialysis patients who choose to live at risk.

## 2. Theoretical Framework

In this chapter, I discuss the theoretical framework, biopower, used in this study. I chose to focus on the concept of biopower, as it helps illustrate the power relationship between dialysis patients and healthcare professionals, including social workers. I begin by presenting the concept of biopower, a term coined by French philosopher Michel Foucault, and then I explore how it links to dialysis patients who live at risk. Lastly, I present how biopower aligns with social work values and the concept of living at risk.

### 2.1 Power and Biopower

The concept of biopower originates from Michel Foucault, a French philosopher. He considered himself to be an archeologist in that he would look into the past to understand how our historical culture has shaped the present (Solomon & Sherman, 2003). Foucault was also a historian as he took current ideas and worked backwards to determine where they originated. Foucault states that “power is not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategic situation in a particular society” (Foucault, 1978, p. 93). Furthermore, Foucault states that “power is not something that is acquired, seized, or shared, something that one holds on to or allows to slip away; power is exercised from innumerable points, in the interplay of nonegalitarian and mobile relations” (ibid., p. 94). In this sense, power is not a ‘thing’ but rather a relationship or a dynamic. Foucault states in *Discipline and Punish* (1979) that:

*We must cease once and for all to describe the effects of power in negative terms: it ‘excludes’, it ‘represses’, it ‘censors’, it ‘abstracts’, it ‘masks’, it ‘conceals’. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production. (p. 194)*

This relationship of power can also be related to people's bodies, which Foucault called biopower.

In Foucault's chapter entitled *Right of Death and Power of Life* in *The History of Sexuality Volume 1: An Introduction* (1978), he discusses the concept of biopower, which he defines as the "numerous and diverse techniques for achieving the subjugation of bodies and the control of populations" (p. 140). Foucault discusses how historically it was a sovereign power that had the ability to decide who lived and who died and was seen as "the right to *take* life or *let* live" (ibid., p. 136). However, this ancient right was replaced by a ruler's "power to *foster* life or *disallow* it to the point of death" (ibid., p. 138). Foucault states that the subjugation of bodies relates to the *anatomo-politics of the human body* which is a disciplinary power that centers on the body which could be seen as a machine that can be refined and optimized to ensure it is working at its full capacity (Chambon, Irving, & Epstein, 1999). In this sense, the disciplinary power over the body is to ensure that the body is as efficient as possible; even if there are pre-existing or already issues with that body, the remaining functions must be optimized to disallow death from occurring prematurely.

## **2.2 Biopower and the Right to Live at Risk**

The idea of rulers having the "power to *foster* life or *disallow* it to the point of death" (Foucault, 1978, p. 138) is a relevant concept in the medical field, as healthcare providers have a legal obligation to preserve life and to do everything in their power to keep their patient alive. While healthcare professionals have a legal obligation to prolong a patient's life, and to "disallow to the point of death" (ibid.), the duty to provide becomes extremely complex when an individual chooses to live at risk. In terms of a dialysis patient, when they choose to live at risk (i.e. by not taking their medications, not following their renal diet, and/or by skipping or shortening their treatments) they are made aware their actions and behaviours are detrimental to their health and

their well-being (Dantas et al., 2013; DeOreo, 1997; Dobrof et al., 2002; Gagnon et al., 2013; Ghimire et al., 2015; Amani A Khalil et al., 2013; Rosenthal Asher et al., 2012; Tohme et al., 2017; Wileman et al., 2015). While the doctor holds a disciplinary power over the patient, in that they desire the patient to be adherent in order to “optimize [the body’s] capabilities, efficiency, [and] usefulness” (Chambon et al., 1999, p. 132), they cannot optimize they body’s remaining abilities efficiently if the patient chooses to live at risk. For example, when the kidneys stop functioning, they are unable to remove any excessive potassium in the body and a dialysis machine cannot completely compensate to remove a build up of nutrients in the body. An individual who does not restrict potassium intake will have a buildup of it in their system and an excess which can lead to hyperkalemia (an extreme elevated level of potassium) which causes cardiac arrest (KFOC, 2015). Therefore, by not following a dietary restriction of potassium intake, the dialysis patient is not following their treatment plan and thus actively contributing to their failing health (DeOreo, 1997; Ghimire et al., 2015; Amani A Khalil et al., 2013; Obialo et al., 2012; Rosenthal Asher et al., 2012; Tohme et al., 2017). This affects the relationship between the doctor, who holds a disciplinary power over a patient’s body as they do everything in their power to disallow death, and the patient’s right to autonomy to have the right to live at risk.

Having worked with renal patients for two years and having done a placement in a hemodialysis unit, I would often see the complex relationships that formed between dialysis patients and their healthcare providers. There is a very distinct power dynamic that exists between a doctor and a patient, with the doctor having an expertise in bodily functions and a patient often relying on the doctor for medical advice. However, when a patient decides to counter the advice of the doctor about their health for various reasons, i.e. that the risks they carry out are desired and necessary for their quality of life (Chenitz, Fernando, & Shea, 2014; Frank, Auslander, &

Weissgarten, 2004; Godbold, 2013; Karamanidou, Weinman, & Horne, 2014; Kovac, Patel, Peterson, & Kimmel, 2002; Nabolsi et al., 2015; Rifkin et al., 2010; Vélez-Vélez & Bosch, 2016), these patients are labelled as nonadherent or noncompliant as there is a discordance in the 'normal' power relationship between the doctor and patient. While the healthcare professionals have witnessed the consequences of living at risk, and while the risks the patient is carrying out do not pose an immediate threat to their health, the long-term consequences, usually pre-mature death, are considered unnecessary and undesired for the healthcare team (Croisdale-Appleby, 2011). However, as mentioned in the previous chapter, social workers appear to have a unique perspective from both the patient and other healthcare professionals, as they desire to respect the patient's autonomy, but also wish to protect the patient's health and well-being (Badger et al., 2009; Bransford, 2011; DeWolf Bosek, 2007; Dobrof et al., 2002; Entwistle et al., 2010; Green, 2007; Sasson, 2000). While other healthcare professionals may only focus on medical issues, social workers see the structural issues, the systemic issues, and the overall well-being and quality of life that a dialysis patient who chooses to live at risk experiences. For example, while carrying out my placement in a hemodialysis unit, it was often discussed that dialysis patients were shortening their treatment sessions because they needed to leave to ensure they did not miss their public transportation home or else they would have to wait an additional hour to catch the next bus. While some healthcare professionals saw this as a form of nonadherence since they were not staying for their full treatment, it could be seen as a structural issue: the patients were relying on an inefficient transit system and not deliberately trying to be nonadherent. Although social workers have differing ethical standards to adhere to compared to other healthcare professional (i.e. in that they are to promote the right to self-determination and the respect for autonomy), there is still a disciplinary power relationship between a social worker and a dialysis patient (Gilbert & Powell,

2010). Although the social worker must ethically respect the patient's autonomy, they also have a duty to provide care. The question then remains, where is the line drawn between beneficence and respecting the patient's autonomy?

### **2.3 Biopower and Social Work Values**

There are certain values in social work that allow social workers to use their power and expertise to influence others: the respect for the inherent dignity and worth of persons, the pursuit of social justice, and the service to humanity (CASW, 2005). The respect for inherent dignity and worth of persons can relate to factors such as the best interest of individuals, a respect for their autonomy, protecting the rights of the individuals, promoting self-determination and autonomy, etc. As previously mentioned, sometimes what is an individual's best interest does not respect their autonomy (DeWolf Bosek, 2007). While a social worker can do their best to respect this autonomy, when a patient becomes a danger to themselves or to others, the duty to provide care and beneficence is legally more important than respecting their autonomy. In cases like this, the relationship of power between a social worker and their patient comes into effect and what is in the best interest of the patient becomes the priority. That is why it is important for social workers to carry out advanced care planning with their patients, in order to know the inherent values of the individual so that they can best respect their dignity, even in cases when they cannot respect their autonomy (Roberts, 2014). An example of this would be when dialysis patients experience cognitive impairment; these patients may "attempt to pull out their dialysis needles during treatment, potentially endangering themselves, dialysis center personnel, and other patients" (Allon, Harbert, Bova-Collis, Roberts, & Moss, 2014, p. 804). In cases where advanced care planning is done, a patient can request that if they start pulling at their lines, that they wish to stop dialysis. Since this request was made while they were deemed capable, their request is usually

accepted. However, in cases in which a patient has not made a previous request, patients with cognitive impairments are often deemed incapable of making decisions regarding treatment and a substitute decision maker (SDM) is assigned this task. However, “without explicit advance directives, it is difficult for SDMs to interpret what a patient would want in terms of dialysis” (Ying, Levitt, & Jassal, 2014, p. 974). To make matters more complicated, sometimes family members request that patients with dementia be restrained in order to stop pulling out their lines (Allon et al., 2014; Ying et al., 2014). This is against the autonomy of the patient, and there is consensus among healthcare professionals that “physically restraining and forcing dialysis on such individuals has the potential for harm: emotional distress, infringement on one’s dignity, possible physical harm, and potential demoralization” (Allon et al., 2014, p. 805) even though it would prolong their life.

There are many areas of social work within government institutions that work towards implementing policies as procedures to help assist with the pursuit of social justice. Tangenberg & Kemp (2002) state that some examples of social work practices that facilitate care and control include “monitoring client participation in treatment programs and other interventions, child protective services activity, and work involving residential treatment, involuntary commitments, and incarceration” (p. 14). Furthermore, they state that:

*Social workers know only too well that, directly and indirectly, the body is the primary focus of mechanisms of power, domination, and oppression. Recognition of marginality and privilege inevitably require attention to the body. From acts of physical violence and abuse to more subtle forms of coercion and restriction, such as social expectations regarding treatment compliance, school attendance, and family behavior, the body is fundamentally implicated in mechanisms of domination and control. At the same time, the body is equally central to processes of resistance and rebellion. (ibid.)*

This expectation that dialysis patients will follow their treatment plan is an interesting contrast to their right to live at risk and to use their body as a form of resistance or rebellion. While dialysis patients may not see living at risk as a form of resistance, but rather a matter of quality of life (Frank et al., 2004; Nabolsi et al., 2015), choosing to live at risk contradicts a social norm and as such they are deemed to be noncompliant.

There are laws, policies, and procedures that have been put in place to protect the safety and well-being of the public which is a form of disciplinary power. The need for a disciplinary power or for a set of social norms to be created relates to the social work value of the service to humanity in which social workers have to: “balance individual needs, and rights and freedoms with collective interests in the service of humanity” (CASW, 2005, p. 5). Furthermore, social workers must “place professional service before personal goals or advantage, and use their power and authority in disciplined and responsible ways that serve society” (ibid.). Tangenberg & Kemp (2002) state that these forms of disciplinary power have been manifested in “the practices of ‘normalizing’ institutions and professions—such as medicine, social work, criminal justice, psychiatry, and education—as well as in everyday exchanges and activities” (p. 14). Sawicki (1991) explains that these institutions and professions exert this power not with a threat of violence or force but instead by “creating desires, attaching individuals to specific identities, and establishing norms against which individuals and their behaviors and bodies are judged and against which they police themselves” (p. 68). For dialysis patients who choose to live at risk, they live outside of these norms and do not police their behaviours and bodies according to what the medical institution deems to be acceptable. For healthcare professionals, specifically doctors, their desire is to prolong the life of the patient for as long as possible. However, I have often heard patients and healthcare professionals say that dialysis is a part-time job that no one signed up for. Many patients see

dialysis as a “life-saving and a necessary evil” (Chenitz et al., 2014, p. 367) and many patients experience physical as well as psychological challenges during treatments such as “cramping, lightheadedness, discomfort at the time of cannulation, stress, depression, and frustration” (ibid., p. 368). Besides physical and psychological challenges, dialysis patients often experience difficulties in obtaining transportation to and from dialysis, a lack of motivation to get to dialysis, medication burden, and difficulties following strict limitations on dietary and fluid intake (Chenitz et al., 2014; Frank et al., 2004). As such, the risks that they take are desirable and necessary to improve their quality of life and therefore dialysis patients who choose to live at risk police themselves differently than what is expected of them.

In this chapter I outlined the relationship between power, biopower, and the right to live at risk in regard to dialysis patients. Additionally, I discussed the relationship between biopower and how it relates to social work values. In the next chapter, I will outline the methodology used to explore the role of social workers in working with dialysis patients who choose to live at risk.

### **3. Methodology**

In this chapter, I will outline the methodology used to explore the role of social workers in working with dialysis patients who choose to live at risk. I discuss the methodological approach used, which was grounded theory, as well as the data collection and analytical methods used to interpret the data.

#### **3.1 Grounded Theory**

While there have been attempts to quantify risk using risk assessment tools (Seden, 2016; Stanley, 2005), this is a challenging task since risk is subjective in nature. As previously stated risk appears to exist on a continuum, and as such it is difficult to quantify (MacLeod & Stadnyk, 2015). This is why I chose to use a qualitative methodology for this research study. In order to explore the role of social workers in working with dialysis patients who choose to live at risk, I opted for an approach inspired from grounded theory, since it is a prevalent approach used in similar studies regarding living at risk (Chenitz et al., 2014; MacLeod & Stadnyk, 2015; Warren, 2016).

Charmaz & Bryant (2012) state that the grounded theory method consists of “a set of systematic, but flexible, guidelines for conducting inductive qualitative inquiry aimed toward theory construction [which] focuses squarely on the analytic phases of research” (p. 375). Furthermore, they explain that grounded theory is simultaneously a qualitative method of inquiry as well as the products of that inquiry, as a theory is developed from the method of inquiry. According to Annells (2011), grounded theory aims to create an explanatory theory in regard to common social life patterns; with this, and along with the creation of a new theory, it can then be applied to the social sciences and further research can be used to confirm the theory. Grounded theory is also based on a coding system in order to determine the social life patterns: “grounded

theory begins with very early close coding of collected data. The initial coding aims to ask what is happening in these data and invokes short analytic labels in the form of gerunds to identify specific processes and treat them theoretically” (Charmaz & Bryant, 2012, p. 376).

Charmaz (1990) explains that a grounded theory methodology can be used to analyze chronic illnesses through a social constructionist lens, which assists in studying social and psychological themes present in various chronic illnesses. Engward (2013) states that grounded theory does not “fit neatly within the regular research process because it does not require the researcher to predetermine a research question or means of collecting data (p. 41). Instead, the researcher “should begin the grounded theory research process with an inquisitive and open approach, enabling theories to emerge from the data” (ibid.). Additionally, Engward relates that “grounded theory relies on the collection and analysis of data to formulate theories and hypotheses” (ibid.) and therefore the researcher should not limit themselves to a specific research question. In the case of this project, in order to ensure that the grounded theory approach was effective, it was necessary to not predefine living at risk within a renal context when carrying out the data collection.

### **3.2 Data Collection**

Data collection was completed using semi-structured interviews. A set of one-time interviews, which took place at a local hospital, were carried out with three renal social workers in May 2018. The individual interviews lasted approximately one hour. The social workers were asked twelve open-ended questions ([see Annex 1](#)) to determine what they define as living at risk, why they feel certain dialysis patients choose to live at risk, the ethical implications of working with dialysis patients who choose to live at risk, and the interventions they carry out with these patients. The participants signed a consent form ([see Annex 4](#)) in order for their data to be used.

The interviews were audio-recorded and transcribed in order for a thematic content analysis to be carried out.

### **3.3 Selection Criteria**

The target population for this research study was social workers who work at a local hospital and who have worked with dialysis patients. In order for social workers to be included in the study, they were required to have completed a Master of Social Work degree and had to have worked in a dialysis unit, including a hemodialysis unit, peritoneal dialysis clinic, or a home-hemodialysis clinic, in a hospital setting for a minimum of two years as a social worker. Any social workers who were classified as casual, who did not hold the position of a renal social worker or had not been in the position for two years were excluded from the research study.

### **3.4 Recruitment**

Recruitment of social workers was conducted through a local hospital's Social Work Department beginning in May 2018. An email was sent from the hospital's Social Work Department on behalf of the research team to invite any social worker who met the inclusion criteria to participate in the study ([see Annex 5](#)). In total, three renal social workers were recruited to participate in the study. The semi-structured interviews permitted the exploration of the research question as well as additional questions: the ethical dilemmas faced by social workers between beneficence and respecting patient autonomy, interventions used with dialysis patients who choose to live at risk, patient capacity to understand and appreciate these risks.

### **3.5 Potential Ethical Implications**

In order for this study to be carried out, it had to go through two Research Ethics Boards (see [Annex 2](#) and [3](#)).

A potential risk for the social workers who participated in this research study was that they were required to volunteer professional information regarding interventions used in working with dialysis patients who choose to live at risk. This may have caused them to feel uncertain about previous interventions used with dialysis patients in terms of ethical implications. For these social workers, discussing previous experiences working with individuals who choose to live at risk and the interventions they carried out with them, may have caused them to feel distressed. This could be due a number of potential factors: that they invested significant time and energy in assisting these patients but that their interventions were ineffective; that there were negative consequences towards the social worker and/or the patient; or that the ethical dilemmas caused strife between the patient, social worker, and other healthcare professionals. Abisheva & Assylbekova (2016) state that “social work is a value-based profession and ethical codes have long been fundamental to social work education and practice throughout the world” (p. 7) and that managing and working with individuals who live at risk can raise issues about their personal and professional values.

The benefits to the social workers who participated in this study, along with other renal professionals, is that this study has assisted in expanding the knowledge of what constitutes risk within a renal context and what interventions are carried out in working with dialysis patients who choose to live at risk. It has further developed current research about the right to live at risk, how risks are not always imminent and dangerous, and that positive and desired risks can improve the quality of life of dialysis patients (Chenitz et al., 2014; Frank et al., 2004; Godbold, 2013; Karamanidou et al., 2014; Kimmel & Peterson, 2005; Kovac et al., 2002; Nabolsi et al., 2015; Vélez-Vélez & Bosch, 2016). Furthermore, “social work’s strengths-based, person-in-environment perspective provides the contextual focus necessary for client- and family-centered care and is unique among the health professions” (National Association of Social Workers, 2003,

p. 5), which means that social workers can offer a unique perspective when working with dialysis patients who live at risk since as they are better equipped to understand the motivations behind their choices.

### **3.6 Data Analysis**

A thematic analysis was carried out carry out in order to examine the results of the interviews, as this methods has been used in similar studies (Chenitz et al., 2014; MacLeod & Stadnyk, 2015; Warren, 2016). Each of the interviews were audio recorded and transcribed verbatim in order for the thematic analysis to be carried out. Once the interviews were transcribed, key words were used to form a coding system. As Patton (2002) explains, “because each qualitative study is unique, the analytical approach used will be unique” (p. 433), thus a unique coding system had to be created specifically for this study. The coding led me to interpret the material into four main categories: how do social workers define living at risk; what do social workers perceive as people’s reasons for living at risk; what do social workers think about individuals who live at risk; and what interventions do social workers carry out regarding individuals that live at risk. Each of these categories had sub-themes. Once the interviews were coded, the quotations were placed in an Excel file in order to sort the codes by their themes and sub-themes. After the data was analyzed, the electronic files were transferred onto a USB drive and the physical documents signed by the participants were stored at the local hospital in a locked office in a locked storage cabinet where it will be kept for ten years with only the research team having access to it.

In this chapter, the methodology used in this research study was outlined. It was demonstrated why a qualitative and grounded theory-inspired approach were the best choices for carrying out this research, how the participants were selected and recruited, the potential ethical

implications for the participants, as well as information regarding data analysis. The next chapter will outline the results that emerged from the thematic analysis of the content.

## 4. Results

The semi-structured interviews resulted in four main themes, each with several sub-themes which are outlined in the following table:

Table 1.

Themes	Sub-themes
How do social workers define living at risk?	<ul style="list-style-type: none"><li>• Medical Recommendations</li><li>• Housing</li><li>• Substance Abuse</li><li>• Collateral Damage</li></ul>
What do social workers perceive as people's reasons for living at risk?	<ul style="list-style-type: none"><li>• Barriers</li><li>• Beliefs</li><li>• Lack of Comprehension</li><li>• Choices</li></ul>
What do social workers think about individuals who live at risk?	<ul style="list-style-type: none"><li>• Respect for Autonomy</li><li>• Autonomy versus Beneficence</li><li>• Beneficence</li><li>• Competence</li><li>• Confidentiality</li></ul>
What interventions do social workers carry out with individuals who live at risk?	<ul style="list-style-type: none"><li>• Collaboration</li><li>• Services</li><li>• Support</li></ul>

In this chapter, I present the three participants along with verbatim quotes from the participants to expand on what they feel is their role in working with dialysis patients who choose to live at risk.

### 4.1 Introduction to the Participants

Three individuals participated in this study and were all provided pseudonyms in order to remain anonymous. Sarah received her Master of Social Work (MSW) in the mid 1990s and started working at the local hospital shortly thereafter. She has been a renal social worker since 1997 but

has also worked with women with developmental disabilities, homeless women and abused women and started her own private practice a year and a half ago. Jennifer received her MSW in 2007 and worked in Montreal as a social worker for two years and as a research assistant and coordinator before moving to Ottawa and started working at a local hospital. She has been there for nine years and has worked in various departments: family medicine, cardiology, medicine, and transitional care. Jennifer has worked as a renal social worker intermittently for about three and a half years. Lisa received her MSW about ten years ago and has worked in a hospital setting since graduating. She worked for a while at a local hospital in acute care and tertiary care. She has been a renal social worker for six years but has also worked in inpatient orthopedics, trauma, vascular surgery, and with individuals with multiple sclerosis.

## **4.2 How do social workers define living at risk?**

### **4.2.1 Medical Recommendations**

The interview participants all stated that, to them, living at risk meant not following medical recommendations. They specifically referred to three factors: missing or shortening dialysis sessions, not taking medications, and not following dietary and fluid restrictions. Only Jennifer used the term “medical recommendations”, while Sara used the term “dialysis prescriptions” to describe these recommendations. Both Sara and Lisa used the term “recommendations”. Sara described living at risk as:

*Choosing not to follow the recommendations of the team... so dialysis prescriptions so typically people on hemodialysis come for treatment three times a week that's usually the usual prescription so if they're not coming that would be one thing, not taking medications, choosing not to take medications, not following up with appointments their scheduled for them, not following fluid restrictions or diet recommendations. (lines 6-11)*

Jennifer echoed this by describing living at risk as:

*Not necessarily following the medical recommendations whether that be taking their medication or coming to all of their treatment sessions or not staying for their full treatments [...] just medical recommendations in general so I say medical but that could that could include diet you know any of those things with regards to managing their condition. (lines 5-14)*

Jennifer elaborated by stating that “the ones that are not necessarily following all the medical recommendations tend to be the ones that are choosing to live at risk” (lines 27-28). Lisa also defined living at risk as not coming to treatments, eating foods that are against recommendations, and not taking medications. Yet she also stated that it is the patient’s right to choose to follow these recommendations or not:

*Ultimately, it's about a patient deciding what their treatment is going to be in terms of attending treatment or choosing not to [...] but just whether or not to take a medication or come three times a week or come in four times a week because the doctor thinks that they need the extra run. (lines 5-8)*

Lisa expanded on this further on this by stating that “the biggest one is not showing up for treatment and not taking medication” (line 16) when defining living at risk. The definitions of living at risk provided by the participants focus on the biological and medical aspects of having renal failure.

#### **4.2.2 Housing**

While medical recommendations were identified as the primary aspect of living at risk for dialysis patients, each of the participants also identified housing as another key factor in determining if an individual is living at risk. All three participants stated that patients who live, willingly or not, in an environment that is unsafe, fall under their definition of living at risk. Furthermore, all three participants identified that a patient not being able to adequately care for themselves at home, whether due to physical or cognitive issues, or not having enough support services, is a concern:

*Choosing to live in a place where they're not felt to be safe so if they're having frequent hospital admissions, falls or something and choosing to go back to the place that they're living. (Sara, lines 11-13)*

*People who are quite set on living alone but you know are at high risk for falls or have some kind of cognitive issues that prevent them from, you know, cooking safely, that kind of thing and aren't agreeable to assessments or services coming in. (Lisa, lines 16-19)*

While Jennifer echoed that living at risk in terms of housing meant not living in an adequate environment, such as patients who are "living in an environment that others might see as being questionable" (lines 74-75), she also stated that having stable housing is important:

*Depending on how precarious of a housing situation they have, how well they're able to be caring for themselves... yeah so depends on how stable the housing situation is but it also depends on how well they're managing that. (lines 7-10)*

Jennifer expanded on this by stating that when working with patients living in an unstable or unsafe housing situation, specifically through Ottawa Community Housing (a subsidized program), they are often reluctant to apply to receive more stable and safer housing:

*Often these folks don't want any of those referrals, even if it's something as looking at applying for a change in housing, they often don't want to. They feel it's kind of worthless when there's such a long wait list, they can use that as the excuse to not want to. (lines 66-69)*

Lisa added to this by stating that for the homeless population and people living in shelters, "day to day there's risks there for them and so this dialysis piece is just one more decision they're making" (lines 196-197). While safe and adequate housing may not be immediately obtainable, participants noted that patients who to live in an unsafe environment fall under their definition of living at risk.

### **4.2.3 Substance Abuse**

An additional sub-theme that two of the participants mentioned when defining living at risk was substance abuse. Both Sara and Lisa classified patients who are taking substances, such as drugs or alcohol, under their definition of living at risk:

*Any kind of substance abuse [...] they're taking too much of their pain medication or... drugs, alcohol, yeah any substances.* (Sara, lines 13, 18-19)

*If a person prioritizes [...] wanting to continue to take some substance that is harmful to them knowing it's harmful to them...* (Lisa, lines 274-276)

Sara elaborated by stating that the patient may not be abusing the substances themselves, specifically their prescribed medications, but are abusing their access to these medications:

*I'm thinking of a client who might have been prescribed narcotics and the team has a feeling that they're stashing their narcotics not really using them and they're selling them.* (lines 206-208)

Lisa stated that “obviously the addiction piece comes into it but still they're making a choice” (line 276-277) in relating that some patients she has worked with who have had a substance use problems.

### **4.2.4 Collateral Damage**

While the risks that dialysis patients carry out are not imminent and do not physically harm others, all three participants described an emotional harm that affects family members and friends as well as the healthcare team of dialysis patients who choose to live at risk. This is something I describe as collateral damage, as it is an unintended consequence that impacts individuals in the patient's circle.

When discussing the impact of the patient's decisions on their family and friends, Jennifer stated that "family or close friends are often very concerned that they're not doing what they're

supposed to be doing" (lines 73-74) by not following the medical recommendations of the team. Lisa and Sara used the term "guilt" when describing the collateral damage inflicted upon family members and those close to the patient. This "guilt" takes such forms as not following the medical recommendations, not living in adequate housing, and not being able to affect changes in the patient's behaviour:

*If the [patient] is not following the diet or fluid restriction, the family is trying to help, [...] the family might be in charge of the cooking they feel guilty that the client is continuing to ask the person for foods or is drinking too much and then the family member feels guilty for allowing that to happen or not stopping it. (Sara, lines 95-99)*

*They may have tried every which way to get their loved one to agree to go into a retirement home because they needed help, but the person refused, there was no way to force them and now they maybe feel guilty and you know at fault for having led to this person's you know... death. (Lisa, 93-96)*

*I think it's a lot of times it's working more with the families so providing support to families and so with that just helping families understand that it's the person's choice and that it's not like they might not be able to change the behaviour that it's to alleviate some of their guilt I think. (Sara, lines 120-126)*

On occasions when a patient's family members or friends may be less involved, or the patient may be isolated, their healthcare staff become a support for them. However, they too are affected by the patient's decisions to live at risk, specifically the nursing staff:

*In my experience there's always been somebody somewhere that cares about this person and even if they're really socially isolated the nurses have come to know them [...] and so I think if something happens that leads to them passing away it does affect people, right? (Lisa, lines 87-91)*

*The impact that the clients' decisions have on the team, and in particular the nursing staff, because they're the ones that are that are directly dealing with the consequences of the behaviour and they're the ones that are the most vocal about the issues that are happening with the client. (Sara, lines 430-432)*

Jennifer described a recent incident in which a nurse was not only affected emotionally by the patient's choices, but it also impinged on their ability to provide a patient with proper care:

*I had one yesterday that you know [...] not bathing properly, literally dirt is crusted on and you can tell where the catheter is taped off because that's the only clean part [...] so the nurse's having a hard time because she sees this [...] so it affects them like emotionally but also kind of affects in terms of how they approach their direct care. (Jennifer, lines 83-89)*

While all three participants explained that the other healthcare staff often consults them to speak with patients living at risk, they are not as directly impacted by the consequences of these actions. All three participants stated that the nursing staff are the most impacted by the patient's actions and the social workers are able to detach themselves or walk away from these situations. Sara provided an example of this:

*If the client is, you know, drinking too much fluid in between their dialysis treatments and the nurse is the one that is trying to help the client get that fluid removed during their dialysis treatment and if the nurse is trying to take off too much fluid at that time the client crashes. The nurse is then dealing with the low blood pressure or calling RACE (Rapid Assessment of Critical Events) teams so they're directly impacted more often by the negative behaviour than any of the other team member. (Sara, lines 277-282)*

While the risks carried out by dialysis patients do not impose physical harm on their family members, friends, or healthcare team, Lisa stated that "they're harming others possibly in the sense that you know people are going to be upset, sad, you know if something does happen" (lines 253-255) demonstrating the emotional harm that may result from patients living at risk and thus the collateral damage inflicted on them due to the patient's actions, whether intentional or not.

## 4.3 What do social workers perceive as people's reasons for living at risk?

### 4.3.1 Barriers

All three participants mentioned barriers as one of the reasons that dialysis patients live at risk; however, they explained that many of these reasons for living at risk are unintentional due to obstacles, imposed medical expectations, being overwhelmed and a general loss of control over their health and well-being:

*I think it's hard to follow all the prescriptions that are expected of the patients.*  
(Sara, lines 60-61)

*Sometimes there's someone that just has a lot of obstacles to overcome and at this point they're doing the best they can with what they have so there's kind of a there is a little bit of that kind of distinction.* (Jennifer, lines 28-30)

Jennifer stated that there are many patients that experienced barriers prior to being on dialysis and that their declining health added to the list of problems:

*I think sometimes it's just being overwhelmed it's a lot it's a big life change and they've probably already been struggling with numerous whether it be medical or social along the way so to all of a sudden now have to come to dialysis three times a week on top of everything else it can kind of tip the balance on how well they're doing with all those other things that they were already teetering on not doing well with.* (Jennifer, lines 36-41)

Two of the participants mentioned the barriers imposed by the medical system. Jennifer explained that not all the medications are covered, and that patients often cannot afford to pay for them out of pocket or do not know how to apply to have these medications covered: "not taking medication could be that they can't afford it [...] they don't know how to be applying for the paperwork" (lines 239-240). Lisa emphasized that while the hospital does its best to accommodate dialysis patients, having to come to treatments three times a week limits flexibility and patients can experience a lack of control over their illness:

*I think being on dialysis basically it's that part time job you don't want and there's a lot of people, the medical model being what it is, that dictate to you know you've got to come three days you've got to come at this time because we can't accommodate your schedule although they try to but still like you're kind of locked into the limitations of the system. (Lisa, lines 38-41)*

Participants explained that when they or someone on the healthcare team identifies patients who are encountering barriers, they work with these patients and the team to address these barriers if the patient is agreeable.

### **4.3.2 Beliefs**

Two of the participants stated that beliefs may be a reason dialysis patient might choose to live at risk. Both Sara and Lisa used the term “beliefs” to describe this reason for living at risk:

*I think beliefs sometimes too so again if they have certain beliefs [...] so they might not think that what the team is saying is something that they need to follow through [...] so they just continue on with the things they're doing. (Sara, lines 52-56)*

*I think it's just some people you know might be a belief thing too. (Lisa, lines 45-46)*

Furthermore, both participants noted that these beliefs often cause conflicts between the patient and their healthcare team as the patient's beliefs may not follow the medical model. Lisa used the term “stigma” to denote this conflict:

*You know if their beliefs are that, you know, pharmaceutical companies are just out to make money and these drugs are not actually helpful to my health and you know they go the natural route for instance like there's a lot of stigma around that. (Lisa, 280-282)*

Sara used the term “conflict” to describe these disagreements between a patient's beliefs and the healthcare teams' role in providing them with a medical treatment:

*I think that for some people I think it's hard to know if they're really making a choice or if they just don't understand or if it's a belief that they have that is in conflict with the what the team is recommending to them so I can think of a number*

*of patients like that they have certain beliefs and the team is telling them one thing so they don't really buy into what they team is saying to them. (Sara, lines 30-34)*

The participants stated that it is important for them to respect a patient's beliefs and help the other members of the healthcare team work with these patients.

### **4.3.3 Lack of Comprehension**

All three participants described a lack of comprehension as a reason that patients might be living at risk; in this case, the participants stated that this reason for living at risk tended to be unintentional. All three participants used the term "understand" and two participants used the term "appreciate" to explain that the patient's healthcare team, social workers included, often question whether the patients fully comprehend the implications of their actions:

*I think that for some people I think it's hard to know if they're really making a choice or if they just don't understand [...] they'd have to understand and appreciate when you're really looking at making a choice... you're understanding and appreciating the choice that you're making... so I don't know that all of them do. (Sara, lines 30-40).*

Both Jennifer and Lisa stated that the patient's inability to recognize the consequences of living at risk may be that they do not fully understand or may have a cognitive issue that prevents them from fully comprehending:

*Could be a cognitive thing [...] could be that they don't fully understand necessarily the consequences so it's but not necessarily fully incapable. (Jennifer, lines 42-46)*

*Somebody living at risk may not necessarily have thought ability so I guess I'm thinking of a patient with some kind of cognitive issue right and so they're not really understanding and appreciating generally speaking anything that's discussed with them and so are they making a decision in the right frame of mind? (Lisa, lines 32-35)*

Jennifer expanded on this further by stating that she, as well as the healthcare team, often question if the patient is actively choosing to live at risk or if the patient does not understand the information the team is providing them:

*You're always questioning yourself of did they really understand the implications of their choices? [...] Do they really understand that they're going to die if they don't come regularly? Do they really don't understand that they're going to have another amputation if they don't follow their diet? (lines 287-290)*

Sara also stated she has questioned whether patients fully comprehend the implications of their actions: "I don't know if they always consciously don't realize what they're doing" (lines 130-131). All three participants noted that while they can educate patients, it is still difficult to know if they are able to understand and appreciate the information they provide.

#### **4.3.4 Choices**

While some of the reasons for living at risk are unintentional, the three participants explained that there are times when patients actively decide to live at risk. Two of the participants described this choice to live at risk by explaining that the patient may be accustomed to their lifestyle. Lisa stated that "some people are just used to living a certain way and now they're on dialysis and now people are seeing it and they're being hounded about it" (lines 52-53). Sara used the terms "behaviours" and "desires" to describe these choices:

*It could be just behaviours from the past are just continuing so for example addictions, any kind of addiction issues or any other lifestyle issues [...] so that pattern of whatever was going on before is just continuing for them (lines 44-47).*

She elaborated on the issue surrounding these choices:

*I think sometimes it's when people have certain desires or wants it's hard to stop that those feelings or wanting something and stopping yourself from doing something that feels good or that you want to do and then I think there's also sometimes there's no reinforcement or no negatives consequences of the behaviour. (Sara, lines 61-63)*

Jennifer stated that while patients have the right to choose to live at risk, the healthcare team sometimes does not respect the patient's autonomy:

*For the most part though was that, social work at least, that I've been involved with are ones that they're choosing to live at risk and the team's coming to us with concerns of like "you need to change their mind you need to make this better" and really the patient's just not ready for change. (Jennifer, lines 20-23)*

Lisa echoed this by stating that the patient has the right to make a choice regarding their health:

*I mean I could see that if a person prioritizes not wanting to be in the hospital three times a week [...] they're still making a choice... you know if that's how they want to live their life then yeah who am I to say that that's not a good way to live? (Lisa, lines 274-278)*

Although this reason for living at risk can be contentious as it does not conform to the medical model, the participants reiterated that it is within the patient's right to choose to live at risk.

#### **4.4 What do social workers think about individuals that live at risk?**

##### **4.4.1 Respect for autonomy**

All three participants indicated that patients have the right to choose to live at risk, and while this may cause conflict with the healthcare team, they respect the patient's choices, even if they do not agree with them:

*People do have the right and I think in particular the doctors and the dietitians, you know, they will explain how the client should be following things but then I understand that the client can choose. (Sara, lines 264-266)*

*I have to remind myself sometimes that people choose... I've gotten better at that over the years now that I have so many so many years of experience under my belt that I'm the one reminding the team members that people can choose to live like this [...] but I do sometimes have to remind myself not to work harder than the patient is working to towards change because maybe that's not what they want. (Jennifer, lines 143-147)*

*I think again there it's a matter of open communication reminding people about self determination and autonomy and the right to make decisions about their own body in their own lives. (Lisa, lines 185-187)*

Jennifer and Lisa elaborated by explaining that as long as they ensure the patients have been provided with information about the risks they are taking, they feel they have done their part:

*I think the social work role is to remind people that you do the best you can ensure that the patient is hearing the information that you're giving and beyond that it is of the patient's choosing. (lines 300-302)*

*I'm not so like freaked out by the fact that people might want to make their own decisions and that sometimes those decisions don't line up with mine and may be harmful to them but I guess it's deciding is the person like a risk to themselves or others right? (Lisa, lines 238-240)*

All three participants stated that they advocate for a patient's autonomy and their right to choose, even if it counters their personal beliefs or the medical model of the duty to provide care.

#### **4.4.2 Autonomy versus Beneficence**

All three participants discussed the ethical dilemma between respecting a patient's autonomy and beneficence. Sara provided an example of the necessity to provide care even though a patient chooses to live at risk and the frustration it may cause to the patient's healthcare team:

*When clients miss dialysis treatments regularly and they don't come for regular scheduled appointments and then they show up in emergency it impacts on well it impacts on the whole healthcare system because they come in as an emergency they need to have emergency dialysis so there's huge costs related to that. (lines 379-383)*

Two of the participants discussed how the medical model and the duty to provide care will often take priority for a dialysis patient, but how they need to balance the patient's autonomy and respect their wishes:

*You're always balancing medically what they need because we know that not coming regularly for dialysis not following their diet or not staying their whole time treatment and all these things related to dialysis treatment that that can lead to other complications and can even lead to death. (Jennifer, lines 275-278)*

*We're a healthcare team we want to make people live, like we came up with this dialysis you know, all the medical advances that they're making and all these things, and I think we forget that sometimes people don't want this. (Lisa, lines 262-264)*

Jennifer explained that it is important for them to “only provide care that people consent to except for emergencies” (line 169) in explaining the balance between autonomy and beneficence. However, she described an incident in which there was a struggle between respecting the patient’s autonomy versus exercising beneficence which unfortunately resulted in a patient’s death:

*One patient I was heavily involved with that didn't come regularly, housing was a complete disaster, finances were a disaster, I had finally had her agree that the next time that she came for treatment we would be applying for subsidized housing... and she had a [...worker that] was going to help her kind of gather the documents she needed for the application and unfortunately on the day that the [worker] went in she was on the floor and to be no more... (lines 278-286)*

Lisa echoed this sentiment by explaining that she has questioned her decisions but ultimately decided to respect the right to autonomy:

*I think I've seen staff kind of wonder should we have done more, I've done it you know, I've questioned myself too and then just needed to remind myself that they made a choice. (lines, 91-93)*

The ethical dilemma between beneficence and the respect for autonomy arises often with dialysis patients who choose to live at risk; but the participants all noted that the patients have the right to do so and as such they advocate for other healthcare staff to respect the patient’s autonomy.

#### **4.4.3 Beneficence**

All three participants discussed beneficence as an ethical dilemma they have encountered in working with dialysis patients who choose to live at risk. Two of the participants explained that they often receive requests from other members of the healthcare team to help convince the patient to change their behaviour for their own well-being:

*I think for the nurses in particular they're more directly impacted by the behaviour so that would be more difficult for them so sometimes they're feeling you know a little bit of resentment I think towards some of the other team members maybe but towards the client in particular or anger towards a client more for not kind of following maybe for the team members to for not helping to change the behaviour. (Sara, lines 291-296)*

*How much do you push the patient right? Like how many meetings you have? How times do you go to the bedside and have the same conversation because every time they're here the nurses bring up the same concern because it's not going away? (Jennifer, lines 213-216)*

Jennifer stated that often the team, social workers included, are simply doing what they think is in the best interest of the client without including them in the discussions:

*One of the big struggles is what you think is in the best interest sometimes you get you plow ahead onto that and you forget that sometimes that means you're not being respectful of the person by asking for permission with all best intentions. (Jennifer, lines 181-183)*

Jennifer expanded on this by discussing how the patient's voice and autonomy may unintentionally become an afterthought:

*I think sometimes we forget to ask the patient what's most important to them and we go in and approach what we think is the most important barrier to treatment [...] and we forget to ask the patient what they want to work on because a lot of these patients that are choosing to live at risk have more than one thing that they could maybe use help with. (Jennifer, lines 233-237)*

Lisa explained the question of enforcing beneficence by using the example of patients who regularly miss their dialysis treatments:

*Is it even sort of our... within our purview or within our sort of care circle to actually call the police to find this person to make sure that they're okay you know especially if they're people who miss dialysis regularly and know that missing dialysis could mean they die? (Lisa, lines 221-224)*

While beneficence and the duty to provide care can be challenging when the participants wish to respect the patient's autonomy, Jennifer explained how she deals with treading this line: "I think

part of the ethic too is balancing like the patient's needs my social work responsibilities and the guidelines of what my role is here at the hospital too" (lines 220-222).

#### **4.4.4 Competence**

An ethical dilemma that all three participants have encountered has to do with a patient's ability to understand and appreciate the information they are provided. Sara and Lisa used the term "competence" and both Sara and Jennifer used the term "capable" to describe this concern. Both Jennifer and Lisa stated that a patient's competence is often questioned when they live at risk:

*Sometimes it almost seems like it's easier if a patient is incapable or you can just turn to their decision maker but often these patients are on that teetering on the edge... they're capable, just not making a decision that most of us would make. (Jennifer, lines 210-213)*

*Some people on the medical team have a misunderstanding of just because this person is choosing to live at risk therefore they mustn't be competent. (Lisa, lines 187-189)*

Lisa provided an example of working with an individual with a developmental delay and how this was ethically challenging in terms of determining their level of competence:

*One patient had a bit of a developmental delay and so some decisions she's okay to make and others she may not be but if that's what that person wants then I think that might be a bit more ethically challenging because I think the team, and myself included, would probably feel like we need to protect this person somehow so that's a bit of a grey area I guess because it's not so black and white, it's not so okay they have a developmental delay therefore they can't make any decision, right? (Lisa, lines 225-231)*

Sara provided another example regarding a patient's desire to stop dialysis, including questioning whether a patient fully understands and appreciates the consequences of stopping treatment:

*The issue around stopping dialysis, some of the ethical dilemmas that come up around that has to do with competence, sometimes as well so when there is a client who is either not competent or capable or doesn't speak English or we don't really fully understand and they're voicing discontent about being on dialysis or wanting*

*to stop dialysis and family is saying no continue so there's an ethical dilemma around that. (lines 349-354)*

While the participants are often consulted in such situations to refer to services or to have the patient assessed, Sara discussed the difficulty social workers encounter in trying to assess a patient for competence:

*I mean we can try to assess for competence but it's pretty difficult to do anything about that when someone is living in the community because the client has to pay for formal assessments to be done and nobody's going to do that if they think that the outcome is going to be that they're going to be deemed incapable. (lines 80-83)*

The difficulty in assessing and determining a patient's competence when they choose to live at risk is an ethical dilemma often encountered by the participants.

#### **4.4.5 Confidentiality**

The final ethical dilemma the participants encountered was the issue surrounding confidentiality; all three participants mentioned this as a dilemma in working with partners or agencies in the community outside the "circle of care". Jennifer provided an example of this:

*I got a message from the police about a patient yesterday and yes it's the police, but I'm not going to call them because I don't have the patient's permission so even within the community setting people forget what the boundaries of confidentiality are sometimes. (lines 176-178)*

Jennifer expanded upon this:

*You get a phone call from whoever and without even thinking you start talking to this person on the phone about a patient because they've called so obviously they know you're involved in that person's care so there can be a fine line between how much consent do you need to be working with an existing community partner that clearly is already working with the patient. (Jennifer, lines 187-191)*

Both Sara and Lisa described how the issue of confidentiality arises when patients do not regularly attend their dialysis treatments:

*That would be kind of then impeding on their right to choose and their right to not come versus calling you know whoever their emergency response team is to check on the patient or their emergency contact [...] which could potentially go against the client's wishes to not be contacting people not letting people know (Sara, lines 335-338)*

*When a patient doesn't show up, the nurses call and you know depending on the nurse they may call multiple times, [...] I'm not sure that that's clearly stipulated in any kind of consent form that FYI (for your information) if you miss your treatment we're going to call your son right? Or your daughter or whoever is your primary contact. (Lisa, lines 55-61)*

The participants all explained that maintaining confidentiality, particularly in relation to dialysis patients who choose to live at risk, is an ethical dilemma they often encounter.

## **4.5 What interventions do social workers carry out regarding individuals that live at risk?**

### **4.5.1 Collaboration**

All three participants mentioned the importance of collaboration when working with dialysis patients who choose to live at risk. They all discussed the importance of collaborating with the patient, the healthcare team, and the patient's family members. Jennifer and Lisa discussed collaborating with the patient's family members in order to assist the patient:

*Depending on who their network is then you know you need to be looping in with where they're living... or their family or neighbour type thing. (Jennifer, lines 104-105)*

*If there's family involvement I would probably have some kind of team family meeting assuming the patient is agreeable to this just to discuss the risks and to harness potentially family getting involved. (Lisa, lines 74-77)*

Sara explained that sometimes this collaboration with the team and the patient's family members is to help them understand the patient's choices and to advocate for their autonomy:

*It would just be allowing like just recognizing that or voicing that they can choose to live at risk so if somebody so people can make choices they can choose to follow things or not... so just voicing that with the with the team or families. (Sara, lines 311-313)*

All three participants discussed the importance of collaborating with the patient and their healthcare team. Sara and Jennifer discussed how this collaboration is for the purpose of creating a plan to assist the patient and to ensure that they are better able to support the patient:

*I think it's just as a social worker just talking to the team... working on like a plan with the patient. (Sara, lines 85-86)*

*Facilitating with the team, with the patient, if we're needing any meetings or a larger team meeting approach type thing... as those background discussions that happen would on what are our options for moving forward, what's everyone's opinions. (Jennifer, lines 98-102)*

*Some of what I would do with that as well would be to talk to other colleagues either dialysis colleagues or social work colleagues possibly yeah so either yes social work colleagues or supervisors that kind of thing about difficult situations. (Sara, lines 229-231)*

While all the participants stated that it is important to collaborate with the team and the patients, they also explained that they have limits and ethical responsibilities to uphold:

*A lot of ongoing discussions and it's setting it's actually setting boundaries within the team that reminding them what I can and cannot accomplish. (Jennifer, lines 157-158)*

*Identifying what they feel they (the patients) need help with and not imposing what we think it should be... and yeah a lot of education around with the team so that you know to create that sort of non-judgmental, non-medical model of we're going to impose x, y, and z and that's the way you're... you know there's another way (Lisa, lines 145-148)*

Lisa and Sara both discussed how they often need to remind the team that the patient has the right to live at risk:

*I think it's also a go between the team and the patient so that there's some education but also reminding the team that this individual may have different goals then we do... you know? (Lisa, lines 127-129)*

*Just understanding as much as I can about what their (the patient's) reasons are... where they you know what their past experience have been... just trying to find out a bit more about what their history is to maybe understand a bit more about the issue and sometimes it's bringing some of that back to the team to help them understand. (Sara, line 108-111)*

*I think some education so that it's a bit less sort of a lessen the judgment piece of it around like "look at with this person is dealing with" you know "look at their situation and the fact that they've lost control of their health you know? They may have lived like this forever right?" (Lisa, lines 192-195)*

Lisa elaborated on this by affirming the necessity to advocate for a patient's autonomy:

*Being a voice for the patient right? Ultimately... and making sure that the team knows what their goals are and that we shouldn't be imposing ours just because we think ours are better or safer or you know, the right way. (Lisa, lines 201-204)*

While the participants emphasized the importance of collaborating with the patient, their family members and the patient's healthcare team, they also emphasized the importance of ensuring others understand that the patient has the right to live at risk.

#### **4.5.2 Services**

All the participants discussed the importance of referring patients who live at risk to numerous services, including community resources, additional medical services outside of dialysis, and educating the patient on the risks they're taking. All three participants mentioned that they inform and often refer patients who live at risk to community services:

*I think it's just as a social worker just talking to the team working on like a plan with the patient, making suggestions providing information on community supports. (Sara, lines 85-86)*

*There's the referral piece too, there's liaising with community supports with consent as needed. (Jennifer, lines 115-117)*

*In terms of advocating in the community if the patient's agreeable... I try to get some services in there that might be more in line with you know their situation. (Lisa, lines 206-207)*

Lisa stated that while she ensures the patients are aware of services and resources, she tries to ensure it is a service they would like or need before making a referral:

*Making sure they're aware of whatever resources that can help or would be helpful in their case, or even just you know making sure that you know they're asked about okay well "is there something in particular that you would be open to." (Lisa, lines 121-123)*

Sara stated that she provides patients with resources and services regarding safer housing options:

*Having them assessed for home safety... having services, suggesting services to come into the home to help them, suggesting alternate living arrangements. So, any of the community supports that can be put in to help them be more safe in their home. (Sara, lines 75-77)*

Sara and Jennifer mentioned referring these patients to other services, specifically medical services available to them:

*Getting other people involved so outside of the immediate dialysis team so seeking out other like hospital supports. (Sara, lines 227-228)*

*It could be for other parties to get involved maybe looping back with the family doctor or... other diabetes specialists or whoever depending on maybe we're feeling that we need to have some repeat education for a patient. (Jennifer, lines 58-60)*

All three participants discussed how they, and the team, do their best to educate patients who choose to live at risk by trying to ensure they understand what taking these risks means:

*If they realize they're living at risk, then they have the right to live at risk... and I think it's helping them understand what that risk is or what the consequence of that risk is... letting them know what the consequence of that risk is [...] I think it's supporting, educating, giving information on resources checking out to see if they understand that they're at risk or not and if you can get a sense of that. (Sara, lines 141-143, 146-148)*

*You can't always ensure they're safe when they're choosing to live risk, you can do the best you can to make them aware of what their options are and who's concerned for them and why... they may digest that information, they may not, but you can't always ensure that they're safe, you could try to put referrals in but if they don't agree with that then your hands are tied...* (Jennifer, lines 52-55)

*I make sure that they knew that you know they could be at risk for x, y, and z and if they don't show up for dialysis making sure that the doctor has told them what can happen and has informed them of ways to you know what to look for in case they start feeling a certain way they may want to call 911.* (Lisa, lines 154-157)

While the participants articulated that they provide patients with information regarding resources and services, and are willing to provide a patient referrals, they stated that it is ultimately the patient's choice to accept these services or not.

### **4.5.3 Support**

All the participants stated that in cases where a patient is choosing to live at risk, it is important to provide support to the patient, their family members, as well as to their healthcare team. Lisa and Jennifer described how they try to support patients who live at risk:

*Sometimes it can be that motivational kind of interviewing counseling at the bedside with them trying to work on some of that with some patients depending on again it depends on the reason their living at risk depends on like what exactly they're struggling with it.* (Jennifer, lines 109-111)

*I concentrate on making sure that I build rapport with that patient and some level of trust so that you know they don't feel that my getting involved or giving them resources or ideas of where to go for certain things is encroaching on their independence uh or their decision to live a certain way.* (Lisa, lines 71-76)

Lisa reiterated the importance she feels in creating a rapport with these patients so they feel comfortable approaching her:

*Again, I think it's trust and rapport and non-judgmental sort of attitude so that they feel that they can come to the social worker if, for myself, if they do have you know concerns do come up for them.* (Lisa, lines 119-121)

Sara stated that often it is not the patients who need the support, but rather their family members:

*Providing support to them and their families so in particular, the families I think because the clients don't always need as much support as the families. (Sara, lines 118-120)*

The participants all mentioned that in supporting a patient and their decision to live at risk, it can cause strife with the patient's healthcare team. As Sara stated, "I think it's supporting the team because it can be it is challenging working with that group of clients" (lines 115-116). The participants stated that it is important for them to support the team in working with these patients:

*Letting people express what their concerns are so that they have a place to kind of express what their concerns are and to understand where they're coming from as well [...] just letting them kind of express some of the that, helping them understand maybe where the client is coming from to you. (Sara, lines 299-306)*

*It's a lot of supporting the team while they struggle with seeing the patient especially the nurses like three times three times a week or not three times a week maybe that's the issue. (Jennifer, lines 161-163)*

*I've found myself having to do a lot of education around that right? Around the you know okay "they're able to make their own decisions and we don't like it... you know we may have chosen a different path but this person is doing x and they're allowed to do x even if we think there's harm." (Lisa, lines 110-116)*

The participants emphasized the importance of supporting not only the patient but also their family members and the patient's healthcare team in understanding the right to live at risk and the need to respect a patient's autonomy. In the next chapter, I analyze these findings in relation to the literature review and the theoretical framework, bio-power.

## **5. Discussion**

In this chapter, I provide an interpretation of the results by analyzing the data using the theoretical framework, bio-power, and by putting the results into dialogue with the literature review from Chapter 1, as well as supplementary research.

### **5.1 Defining Living at Risk**

In the previous chapter I presented the participants' definitions of living at risk in regard to dialysis patients, which included three factors: medical recommendations, housing, and substance use. As the participants discussed, medical recommendations referred to patients taking their medication, following their dietary and fluid restrictions, and attending their dialysis sessions; patients who did not follow these recommendations were considered to be living at risk. This follows suit with the definition of risk within a renal context presented in Chapter 3, in which being nonadherent or noncompliant refers to dialysis patients not taking all prescribed medications, not following diet and fluid restrictions, and missing or shortening treatments (Dantas et al., 2013; DeOreo, 1997; Dobrof et al., 2002; Gagnon et al., 2013; Ghimire et al., 2015; Amani A Khalil et al., 2013; Rosenthal Asher et al., 2012; Tohme et al., 2017; Wileman et al., 2015). While this was an expected result, housing and substance use were not present in the initial literature but are particularly relevant in defining living at risk for dialysis patients.

Mikkonen & Raphael (2010) discuss how housing has a considerable influence on an individual's health and that inadequate housing increases the risks to an individual's well-being. Furthermore, they state that "living in poor housing creates stress and unhealthy means of coping such as substance abuse" (ibid., p. 29) and that "the presence of lead and mold, poor heating and draft, inadequate ventilation, vermin, and overcrowding are all determinants of adverse health outcomes" (ibid.). In 2010, the Research Alliance for Canadian Homelessness, Housing and Health

(REACH<sup>3</sup>) published a report of their findings, stating that individuals with inadequate housing encounter the same severe health issues as individuals who are homeless. Additionally, they stated that “people who don’t have a healthy place to live – regardless of whether they’re vulnerably housed or homeless – are at high risk of serious physical and mental health problems, problems accessing the health care they need, hospitalization, assault, and going hungry” (ibid., p. 3). As the participants mentioned, while individuals may choose to live in an unsafe environment which creates further vulnerabilities such as frequent hospital admissions, falls, and an inability to properly care for themselves, there may be extenuating circumstances motivating these patients to remain in those environments. As Jennifer mentioned, there is a long waitlist for individuals seeking subsidized housing. The Social Housing Registry of Ottawa (2018) states that “the time on the waiting list varies but can be 5 years or more” (paragr. 2) and the waitlist to change housing is approximately one to three years. Furthermore, if an individual requires daily assistance, the waitlist to get into long-term care residences can be even longer, with some residences in the region having an almost 12-year waitlist (Ministry of Ontario, 2018). While there are residences that have a much shorter waitlist (only four months) (ibid.), patients have related that these residences tend not to be their first-choice, as they are costly, do not provide adequate support, and/or are of ill repute. As such, it appears that many patients opt to stay at their current residence and wait for the long-term care residence they desire while often putting their health and well-being at further risk.

Substance abuse and renal failure are unfortunately quite common since long-term substance use, particularly cocaine and heroine use, can lead to renal failure (Grubbs, Vittighoff, Grimes, & Johansen, 2016; Levine, 2007; Scott, Taylor, & Dudley, 2018). As such, there exists further complications when working with dialysis patients who abuse substances: “coexisting alcohol and mental health problems, low socio-economic status, contamination of intravenous

dialysis access and chaotic lifestyles” (Scott et al., 2018, p. 270). Levine (2007) states that “due to the convergence of substance abuse, HIV infection, and renal failure, an increasing proportion of the dialysis population in urban centers has a history of substance abuse” (p. 46). As Lisa mentioned in the previous chapter, there are patients (particularly those who abuse substances) who are accustomed to living a certain way but, due to kidney failure, their choices are now under the scrutiny of their healthcare team. For example, when individuals first start dialysis they are often given an intravenous catheter, and eventually patients have surgery in which an artery and vein in the forearm are surgically connected to create a dialysis access site known as a fistula (KFOC, 2015). For individuals who used intravenous drugs, this gives patients easier access for injections (Levine, 2007). However, Scott et al., (2018) relate that “fistula formation is technically challenging in those with venous damage from intravenous drug use. The use of dialysis catheters by patients as a portal for drug abuse risks infection and catheter occlusion” (p. 273). As such, using these sites for drug injection has life-threatening consequences and makes treating dialysis patients with a current or past problem with substance abuse very difficult.

In analyzing this from the biopower perspective, someone who is living at risk, whether intentional or not, is not policing themselves according to what is expected by their healthcare team. As mentioned in Chapter 3, the team’s role is to “optimize [the body’s] capabilities, efficiency, [and] usefulness” (Chambon et al., 1999, p. 132) as well as “to *foster* life or *disallow* it to the point of death” (Foucault, 1978, p. 138); but an individual living at risk by not following medical recommendations is contravening medical advice. Additionally, those living in inadequate housing and/or using substances are contravening the team’s advice for their overall well-being. While the concept of collateral damage was not directly included in the participants’ definitions of living at risk, it does denote that others are affected by the patient’s decisions to live at risk.

Although no physical harm comes to others who care about the patient, the participants stated that others are affected emotionally by the patient's actions: frustration, hopelessness, anger, worry, and guilt. This links back to biopower and power itself as the patient's healthcare team and their family members are attempting to "to *foster* life or *disallow* it to the point of death" (ibid.) and exert power on the patient by trying to ensure the patient follows medical recommendations. While the collateral damage may itself be inflicted on the patient's family members, friends, and their healthcare team, their choice to live at risk can also be a form of collateral damage to themselves. Puar (2017) describes how choosing living at risk and death itself is a form of collateral damage:

*For Foucault, modern biopower, emerging at the end of the eighteenth century, is the management of life—the distribution of risk, possibility, mortality, life chances, health, environment, quality of living—the differential investment of and in the imperative to live. In biopower, propagating death is no longer the central concern of the state; starving off death is. Cultivating life is coextensive with the sovereign right to kill, and death becomes merely reflective, a by-product, a secondary effect of the primary aim and efforts of those cultivating or being cultivated for life. Death is never the primary focus; it is a negative translation of the imperative to live, occurring only through the transit of fostering life. Death becomes a form of collateral damage in the pursuit of life. (p. 32)*

As Puar states, the pursuit of life and good quality of life has collateral damage attached to it, i.e. death; in the case of dialysis patient who choose to live at risk, a premature death (ibid.). As such, collateral damage from this pursuit of life for dialysis patients in turn causes emotional harm to members in the patient's circle.

## **5.2 Reasons for Living at Risk**

Of the four reasons the participants presented as to why a dialysis patient might be living at risk, two appear to be intentional, i.e. beliefs and choices, while the other two appear to be unintentional, i.e. structural barriers and lack of comprehension.

In discussing barriers, the participants explained that many of these reasons for living at risk are unintentional due to obstacles, imposed medical expectations, a feeling of being overwhelmed and a general loss of control over their health and well-being. These barriers can be issues such as: missing dialysis due to inadequate transportation; not taking prescribed medications because of a lack of funds and not knowing how to apply for coverage; not being able to afford homecare services; and having difficulty following a renal diet. When working with individuals who encounter barriers, Karolich & Ford (2010) state that in order to better support an individual in being adherent and predicting any further health complications, “an understanding of what may be impeding a client’s ability to formulate *pathways* to enable them to understand and manage their illness is very important” (p. 32). This relates back to biopower as the healthcare team establishes the medical expectations of the patient. The loss of autonomy or control also relates to biopower in the sense that the patient has lost control of their health; as such, they have lost power over their well-being and often rely on their healthcare team for their knowledge and expertise. Holmes, Perron, & Savoie (2006) state that in such cases, the “patient will thus become ‘subjectified’ to the [team’s] expertise and authority, even when the [team] is unaware of exercising such authority” (p. 9). The participants related that when the team identifies patients who are encountering barriers, they work with them and exercise their authority in order to help them overcome these barriers in order to become more adherent. However, the participants and the team must work in the confines of the medical model which may not provide much room for flexibility.

In addition to structural barriers being an unintentional reason for living at risk, the participants stated that lack of comprehension of the consequences of the risks was also an unintentional reason for living at risk. However, the participants noted that this was more difficult

to identify. The participants discussed how patients living at risk may be doing so due to cognitive disorders or a lack of ability to comprehend the consequences of living at risk. Furthermore, the participants stated that even after explaining and educating patients, there are times when they are unsure if a patient continuing to live at risk is doing so by choice or because of a lack of comprehension. As Sara stated: "I don't know if they always consciously realize what they're doing" (lines 130-131) with Jennifer stating she has questioned herself in determining if a patient "understand[s] the implications of their choices" (line 288). While participants stated that they do their best to ensure patients understand and appreciate the information they provide them, there is no certainty in knowing if they patient truly comprehends the consequences of their actions. Holmes et al., (2006) reinforces this by stating that "the way in which a [healthcare professional] presents a patient with the information [...] will impact this patient's decision" (p. 9), but if a patient is unable to understand and appreciate the way the information is presented, this too will impact the way they behave and police themselves. Therefore, these decisions to live at risk are scrutinized by the patient's healthcare team, family, and friends, and the patient's competence is questioned.

While the participants stated that barriers and a lack of comprehension cause individuals to unintentionally live at risk, participants felt that a patient's beliefs and choices were intentional reasons motivating them to live at risk. In discussing beliefs, Lisa noted that beliefs often cause conflicts between patients and their healthcare team as the patient's beliefs may not follow the medical model. These beliefs, in turn, affect a patient's decisions and choices in terms of policing themselves; as Sara stated, a patient's desires will determine the choices they make. The participants also explained that when a patient experiences a loss of control over their health, the choices they make are a way for them to exert control. As such, the risks they carry out are desired

and necessary for their quality of life and are a way for them to exert control (Chenitz et al., 2014; Frank et al., 2004; Godbold, 2013; Karamanidou et al., 2014; Kovac et al., 2002; Nabolsi et al., 2015; Rifkin et al., 2010; Vélez-Vélez & Bosch, 2016). In terms of exerting this power, Foucault (1978) has stated that “where there is power, there is resistance” (p. 95) which Laidlaw (2013) expands on by stating that “power [has] therefore come preponderantly to take not the negative form of repression but positive techniques for the elicitation of desires” (p. 26). Additionally, as mentioned in Chapter 1, Schulman-Green et al. (2012) state that the “optimal self-management entails the ability to monitor the illness and to develop and use cognitive, behavioral, and emotional strategies to maintain a satisfactory quality of life” (p. 137). The wish to fulfill these desires, whether based on an individual’s beliefs, choices, or the need to exert control, is a form of resistance, not necessarily against their healthcare team, but against their loss of power over their own health (Frank et al., 2004; Nabolsi et al., 2015).

### **5.3 Ethical Dilemmas**

The participants stated that they often encounter ethical dilemmas in working with dialysis patients who choose to live at risk, particularly when it comes to ensuring their autonomy is respected, determining their level of competence, and maintaining a patient’s confidentiality.

The most prevalent ethical dilemma encountered by the participants is the issue of autonomy versus beneficence when working with dialysis patients who choose to live at risk. Since these social workers work in a medical setting, the duty to provide care is often in the foreground, with the right to self determination and the respect for autonomy taking a back seat. The participants discussed how their role is to advocate for and to be the voice of the patient to ensure the team respects the patient’s autonomy, even when the team does not agree with the patient’s choices. What appears conflicting, however, is that when kidney disease became classified as a

chronic illness there was a push for self-management; yet, when individuals do not self-manage or police themselves as expected, they come under the scrutiny of the healthcare team. However, as Bury (2010) states, “patient autonomy is stressed rather than professional autonomy” (p. 175) which tends to place a great deal of pressure on the patient to manage their symptoms and take a more active role in the management of their illness; the purpose of self-management has been to reduce healthcare costs and to keep individuals with chronic illness out of formal care systems. As Sarah mentioned, when patients miss their dialysis treatments and end up coming to the emergency department for treatment, “they need to have emergency dialysis so there’s huge costs related to that” (lines 382-383). As such, patients that self-manage or police themselves properly are considered adherent and thus do not put a strain on the system, but those that do not self-manage or police themselves properly are seen as nonadherent and a burden on the system. While the medical model is pushing for self-management and for patient autonomy, it appears to do so with the expectations that the patient will be adherent, i.e. that they will comply with the medical recommendations set out for them by the healthcare team. While the duty to provide care and beneficence may seem unjust and infringing upon a patient’s right to live at risk, it is, as Pantilat (2008) states, the healthcare provider’s “beneficent duty to look out for the patient’s best interests” (paragr. 8) and they have a legal obligation to the duty of care as they must prolong a patient’s life, and to disallow to the point of death. As Jennifer explained, the healthcare team, social workers included, often struggles with beneficence versus respecting a patient’s autonomy: “one of the big struggles is what you think is in the best interest sometimes you get you plow ahead onto that and you forget that sometimes that means you’re not being respectful of the person” (lines 181-183). As illustrated, it appears that beneficence for dialysis patients who choose to live at risk is not carried out malevolently or with the purpose of exerting power over patients; instead, it is done

with the best intentions to ensure patients' health and well-being. Biopower seems to be an unintended outcome.

When analyzing autonomy through the biopower lens, it appears that the two concepts are contrasting. Foucault (1978) states that biopower is the “numerous and diverse techniques for achieving the subjugation of bodies and the control of populations” (p. 140); however, when self-management for individuals with a chronic illness became essential to cut healthcare costs, it seems that the medical system transferred this power to the patients. The patients then became the ones with the power to self-manage their condition, with some individuals choosing to counter biopower in not choosing to “*foster* life or *disallow* it to the point of death” (ibid., p. 138), but instead opting for quality of life over quantity. In discussing autonomy, Allen (2011) mentions three main factors that relate to dialysis patients who choose to live at risk. First, Allen states that autonomy is “understood as the twin capacities to reflect critically upon the power–knowledge relations that have constituted one’s subjectivity and to engage in practices of self-transformation” (ibid., p. 44). In this sense, dialysis patients are requested to self-manage their illness, but are still “‘subjectified’ to the [team’s] expertise and authority, even when the [team] is unaware of exercising such authority” (Holmes et al., 2006), p. 9). However, patients can take the information received from their healthcare team and choose to use it to engage in self-transformation, thus becoming more compliant, or choose to pursue a better quality of life versus quantity. Second, Allen (2011) states that “for Foucault, autonomy consists not in freely binding oneself to a necessity in the form of the moral law but in freely calling into question that which is presented to us as necessary” (p. 50). For dialysis patients, this means questioning the medical recommendations presented to them by their healthcare team and determining if they feel the prescribed treatment plan is necessary for a decent quality of life and/or their quantity of life. Since patients are requested to self-manage and

have the right to autonomy and self-determination, the patients have the right to decide what is necessary; however, as the participants mentioned, oftentimes when a patient makes a decision that goes against medical recommendations, their competence is often questioned. Last, Allen (2011) discusses that “since there is no outside to power, freedom always involves strategically reworking the power relations to which we are subjected” (ibid., p. 51). In this sense, dialysis patients who choose to live at risk are ‘reworking’ or attempting to alter (whether intentionally or not) the power relationship between themselves and their healthcare team, in order to exert their right to autonomy and self-determination. As the participants mentioned, they advocate to ensure the patient’s autonomy is respected, even when they do not agree with the patient’s decisions or are concerned for their well-being. As Holmes et al., (2006) state, in social work:

*Respect for patient's autonomy (self-determination) is ever present in codes of ethics. It is [their] responsibility to ensure that patients have all the necessary information to make informed decisions [...] this is especially true when such decision will impact the rest of a patient's life, such as is the case in the context of kidney disease. However, through the lens of bio-power, one wonders how one can be ethical and truly endorse a patient's right to self-determination. (p. 9)*

As the participants stated, as long as they ensure the patients have been provided with information about the risks they are taking, they feel they have done their part; as Lisa stated, if the patients are informed then they have “the right to make decisions about their own body in their own lives” (lines 186-187). This is similar to what Junges (2009) states: “the right to health includes elements of autonomy, comprising the freedom to administrate one’s own health [...] free from interference and use of non-consented treatments” (p. 2). Thus, it appears that the right to self-determination and the right to live at risk seeks to “strategically [rework] the power relations to which we are subjected” (Allen, 2011, p. 51) and thus seeks to ‘rework’ biopower and the power relationships between the patient and their healthcare team to ensure that their decisions and rights are respected.

An additional ethical dilemma that the participants discussed was the patient's level of competence to understand and appreciate the information they are provided. While a social worker's code of ethics states that they must respect a patient's "right to self-direction and freedom of choice without interference from others" (CASW, 2005, p. 28), they also "may be obligated to limit self-determination when a client lacks capacity or in order to prevent harm" (ibid.). The participants stated that when a patient is living at risk, their competence is questioned since they are unsure if the patient understands and appreciates the consequences of their actions. As Lisa explained, "some people on the medical team have a misunderstanding of just because this person is choosing to live at risk therefore they mustn't be competent" (lines 187-189). Holmes et al., (2006) summarize the question of competence in relation to biopower:

*In an era of Bio-power, the individual body is the focus of analysis and thus is constructed through the powerful discourses (including practices) of healthcare professionals. Many power techniques are involved in the construction of docile, obedient and compliant bodies. Disabled bodies constitute a target for professional gaze and scrutiny. Whatever the 'impairment', whether physical or psychological, professional interventions are likely to target the individual. (p. 4)*

As Sarah stated, it is difficult to assess for capacity since a patient must pay for this service in the community and "nobody's going to do that if they think that the outcome is going to be that they're going to be deemed incapable" (lines 82-83). The participants also discussed that teams feels some patients may be incapable or have a psychological impairment since the patient may have a developmental delay, a brain injury, or may not understand medical terminology. Additionally, many patients experience cultural barriers in that their first language is neither English nor French; while it is possible to have a family member or friend translate to them, unless a healthcare staff speaks their language, there is no way to ensure the patients are being given the proper information.

The last ethical dilemma discussed by the participants was confidentiality when working with community partners, agencies, and a patient's family members. Confidentiality is a core value to social work and as the CASW (2005) states:

*Social workers protect clients' identity and only disclose confidential information to other parties (including family members) with the informed consent of clients or the clients' legally authorized representatives, or when required by law or court order. This obligation continues indefinitely after the social worker has ceased contact with the client. The general expectation that social workers will keep information confidential does not apply when disclosure is necessary to prevent serious, foreseeable, and imminent harm to a client or others. (p. 6)*

The participants related that there are often extenuating circumstances that occur in which they and the healthcare team encounters dilemmas regarding confidentiality such as in emergencies, when a patient misses their treatments, and when the police are involved. Additionally, Grace (2004) states that maintaining confidentiality is becoming increasingly difficult “because of the number of health professionals involved in a patient's care, insurance company demands, the accessibility of patient chart information, and the advent of electronic record sharing” (p. 33). Furthermore, Grace states that healthcare professionals also encounter complex situations in which they must make tough decisions to determine if they should breach confidentiality or not, especially is there is a potential for harm to the patient or others. For dialysis patients, this can derive from situations in which they have missed one or multiple treatment sessions, when emergency services need to be involved, or even when the police contact the hospital looking for a patient. Grace (2004) also states that “the decision to breach patient confidentiality must be based on an assessment of the nature and severity of the risk to the patient or others” (p. 35). Therefore, when the patient is considered to be a potential harm to themselves or others, the duty to provide care takes priority over a patient's right to self-determination and autonomy. In cases of missing treatments, I feel this relates to biopower, beneficence, and the duty to provide care in that the

healthcare team exerts their power over the patient's body to ensure they attend dialysis; the patient has missed treatment and since this is a life-sustaining treatment, patients must attend to continue to live. Additionally, it appears that the healthcare team is only breaching confidentiality to ensure the patient's well-being and exerting their power over to patient not out of malice, but out of their ethical obligation to the duty of care.

#### **5.4 Interventions with Those Who Live at Risk**

One of the interventions discussed by the participants was their role in collaborating with patients who are living at risk, along with their family members and their healthcare team. The purpose of this collaboration is to help the patient achieve their goals and to help others respect the patient's decisions. In characterizing this type of collaboration, Kim (2015) cites Henneman, Lee, & Cohen (1995) in stating its nine attributes: "joint venture, cooperative endeavor, willing participation, shared planning and decision-making, team approach, contribution of expertise, shared responsibility, nonhierarchical relationships, and shared power based on knowledge and expertise" (p. 164). Perhaps what is most interesting about these attributes is the concept of shared power. While Henneman et al. (1995) state that power is shared and is based on the knowledge and expertise of each member of the healthcare team, they additionally state that "there is clearly a hierarchical approach in which it is assumed that the physician has ultimate power and decision-making ability" (p. 106). However, as previously mentioned, the medical team's disciplinary and authoritative power appears ineffective when a patient chooses to live at risk, thus shifting the power balance in favour of the patient. The patient then holds the ultimate power and they choose to exert control over their health and well-being. While there may be disaccord between the patient's decisions and the healthcare team's wishes (i.e. respecting the medical model and being adherent to their treatment), Berke (2014) states that "the development of genuinely collaborative

relationships, which redefine an adversarial client as one who has the right to self-determination, facilitates discussion and engages the family, health care teams and agencies to support the client's goals" (p. 11). As such, the team and the family's decision to collaborate to support the patient instead of opposing them is far more effective for ensuring the patient's well-being.

An additional intervention mentioned by the participants was their role in referring patients to services, including community resources, additional medical services outside of dialysis, and educating the patient on risks. As the participants mentioned, they provide patients with information regarding resources and services, and are willing to provide patients with referrals, but that it is ultimately the patient's choice to accept these services or not. While the participants related that other members of the healthcare team may request a service for patient, as Lisa stated, it is still important that the patient consent to this service and ensure that it is a service they would like to receive. Karolich & Ford (2010) state that this early identification of a patient's needs "may enable the worker, client, and their significant supports to provide meaningful educational materials at their level of understanding, and encourage their involvement in support groups and ongoing dietary counseling" (p. 34). Additionally, they state that "more active promotion of family education and involvement in clinic support services may increase positive health outcomes." (ibid.). In cases where patients have additional services outside of dialysis, particularly home services to help ensure their living environment is safe, research has shown this helps to minimize some of the risks that patients are taking (Berke, 2014; De Bono & Henry, 2016; Karolich & Ford, 2010; MacLeod & Stadnyk, 2015). Additionally, research demonstrates that dialysis patients are more susceptible to depression which may contribute to their nonadherence (Keskin & Engin, 2011; Amani Anwar Khalil & Frazier, 2010; Kimmel & Peterson, 2005; Nabolsi et al., 2015; Rosenthal Asher et al., 2012). As Khalil & Frazier (2010) explain, identifying patients who are

experiencing depression is important for ensuring they are referred to a mental health professional. Furthermore, Khalil & Frazier state that mental health professionals can provide essential services to “dialysis clinics with comprehensive patient evaluation for those with positive screening results, pharmacological and nonpharmacological management, as well as patient, family, and clinic personnel education about achieving and maintaining mental health” (ibid., p. 329). In analyzing these services through the lens of biopower, it appears that repetitive education and the team’s request for services for a patient is a way to enforce beneficence and ensure that the patient is more adherent. However, as the participants noted, as long as a patient is able to understand and appreciate the consequences of their decisions, they do not feel the need to continually berate the patient when they are consulted to speak with them per the team’s request.

A final intervention discussed by the participants was their supportive role to patients, their family members, and the healthcare team. Much of the current research available regarding nonadherence or noncompliance with dialysis patients focuses on supporting them to become more adherent (Dantas et al., 2013; Ghimire et al., 2015; Gibson, Held, Khawnekar, & Rutherford, 2016; Kammerer, Garry, Hartigan, Carter, & Erlich, 2007; Karolich & Ford, 2010; Khalil et al., 2013; Khalil & Frazier, 2010; Umeukeje et al., 2016), rather than on supporting the patient’s autonomy. In discussing supporting patients and their right to live at risk, Abisheva & Assylbekova (2016) state that “social workers should support people to reach informed decisions about their lives and promote their autonomy and independence, provided this does not conflict with their safety or with the rights of others.” (p. 11). However, as the participants noted, when they support and advocate for the patient’s autonomy, it causes strife with the healthcare team. As such, not only do they support the patient, but also support the team and the patient’s family members in helping them understand that the patient has the right to make these decisions. As Lisa mentioned, she often is

required to educate and remind others about a patient's right to autonomy, stating that patients are "able to make their own decisions [even if] we don't like it" (lines 114-115). However, as the participants stated, having a good relationship and rapport with patients is important so that patients feel comfortable approaching them with any concerns. According to research, patients who have strong social supports and a supportive relationship with their healthcare team are more likely to be adherent than those without those supports (Dantas et al., 2013; Ghimire et al., 2015; Gibson et al., 2016; Kammerer et al., 2007; Karolich & Ford, 2010; Khalil et al., 2013; Khalil & Frazier, 2010; Umeukeje et al., 2016). As Umeukeje et al. (2016) state, "an understanding of self-determination theory leads to the appreciation that autonomy support facilitates positive health outcomes by facilitating autonomous regulation and perceived competence" (p. 1109). In this sense, it appears that when a patient who lives at risk is supported by their family members and healthcare team, it leads to a patient being more adherent.

The responses provided by the participants give insight into the role of social workers in working with dialysis patients who choose to live at risk. As the results and discussion demonstrate, their role is fourfold: they advocate for patients; they collaborate with the patient, team, and others in the circle of care; they provide resources and services to patients; and they provide support to the patient, their family members, and their team. The conclusion discusses the implications of the results, the possibilities for future research, and the limitations of this study.

## **Conclusion**

### **Implications**

The results regarding the definition of living at risk within a renal context corroborate previous research but also add to existing research, as participants stated that housing and substance abuse were included in their definition of living at risk. As presented in the Discussion, housing and substance often feature in definitions of living at risk outside a renal context. As for the reasons for living at risk, the participants stated that some of these reasons are to improve the patient's quality of life or because of a lack of comprehension, which also validates current research. The participants did add to this by stating that patients may also be living at risk due to their personal beliefs or because they encounter structural barriers that prevent them from being more adherent. The participants' answers regarding ethical dilemmas gave insight into the difficulties encountered when working in an interdisciplinary team, especially in regard to the fact that each professional has their own set of ethics, values, and standards. Each of the participants demonstrated that although they are working in a hospital which favours the medical model, beneficence, and paternalism, they are able to advocate for patients in order to ensure their autonomy is respected and to defend their right to self-determination. To me, this demonstrates that social workers are able to put aside their individual opinions and values in order to defend and advocate for the rights of patients. These results corroborate the CASW's Code of Ethics (2005) as well as research regarding social workers' role in treading the line between the duty to provide care and the need to respect a patient's autonomy. Last, the participants were able to discuss what interventions they carry out when working with dialysis patients who choose to live at risk. This part of the results was essential, as current research for social workers or other healthcare professionals who work with dialysis patients who choose to live at risk focuses on how to assist

the patient in becoming more adherent (Christensen et al., 1996; Dantas et al., 2013; Gagnon et al., 2013; Ghimire et al., 2015; Gibson et al., 2016; Kammerer et al., 2007; Amani A Khalil et al., 2013; Nabolsi et al., 2015; Rosenthal Asher et al., 2012; Tohme et al., 2017; Umeukeje et al., 2016; Vélez-Vélez & Bosch, 2016; Wileman et al., 2015). The participants were able to demonstrate that there are alternatives to paternalism and beneficence when working with these patients. To me, this is extremely innovative as there is minimal research on how social workers can support individuals who chooses to live at risk.

### **Limitations**

Due to the time constraints of this project, it was necessary to have a small sample size. While I intended to recruit four participants, I was only able to recruit three. Such a small sample size does not mean that these results are the opinions of the majority of renal social workers. Additionally, all of the participants had to have their Master of Social Work and be employed by the local hospital, which excludes the understanding of social workers without a master's level education and those who work in a non-institutional and/or community setting.

### **Future Research**

This work opens numerous possibilities for future research. First, the current research could be expanded to have a larger sample size to validate the results I obtained during this study. Second, I believe that it would be interesting to perform similar research with dialysis patients to determine how they define living at risk and why they choose to live at risk. Additionally, this could be carried out with other healthcare professionals who work with dialysis patients, or potentially patients' family members and friends, to provide a fuller understanding of the power relationships between dialysis patients, their healthcare teams, their family members, and friends. Third, the concept of the right to live at risk could be another topic for future research as very little

research currently exists on the topic. It could be related to a variety of topics including but not limited to: other chronic illnesses, other medical conditions (i.e. cancer, palliative care, dementia, mental health, etc.), and other populations such as adolescents and older adults. Finally, I feel an extremely relevant topic in regard to the need to “*foster* life or *disallow* it to the point of death” (Foucault, 1978, p. 138) is the right to die by assisted suicide with Medical Assistance In Dying (MAID) programs. MAID programs and assisted suicide in Canada will be an increasingly important research topic within the next several decades as healthcare professionals, the government, and policy makers seek to determine who has the right to die.

## References

- Abisheva, K., & Assylbekova, L. (2016). Risk Management and Ethical Issues in Social Work (pp. 5–15). <https://doi.org/10.15405/epsbs.2016.09.2>
- Adam, B., & van Loon, J. (2000). The risk society and beyond: Critical issues for social theory. In *Introduction: Repositioning risk; the challenge for social theory*. (pp. 1–31). London: SAGE Publications, Inc.
- Adlersberg, M. (2006). Duty to provide care. *Nursing BC*, 38(1), 25.
- Allen, A. (2011). Foucault and the politics of our selves. *History of the Human Sciences*, 24(4), 43–59. <https://doi.org/10.1177/0952695111411623>
- Allon, M., Harbert, G., Bova-Collis, R., Roberts, S. V., & Moss, A. H. (2014). The Demented Patient Who Declines to Be Dialyzed and the Unhappy Armed Police Officer Son: What Should Be Done? *Clinical Journal of the American Society of Nephrology*, 9(4), 804–808. <https://doi.org/10.2215/CJN.08400813>
- Anells, M. (2011). Grounded theory method: Philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research*, 6(3), 379. <https://doi.org/10.1177/104973239600600306>
- Australian Institute of Health and Welfare. (2016). *Australia's Health* (p. 518). Canberra: Government of Australia. Retrieved from <https://www.aihw.gov.au/getmedia/9844cefb-7745-4dd8-9ee2-f4d1c3d6a727/19787-AH16.pdf.aspx?inline=true>
- Badger, J. M., Ladd, R. E., & Adler, P. (2009). Respecting patient autonomy versus protecting the patient's health: A dilemma for healthcare providers. *JONA'S Healthcare Law, Ethics and Regulation*, 11(4), 120–124.
- Baker, K., Campton, T., Gillis, M., Kristjansson, J., & Scott, C. (2007). WHOSE LIFE IS IT, ANYWAY? SUPPORTING CLIENTS TO LIVE AT RISK. *Perspectives (Pre-2012)*, 31(4), 19–24.
- Barsky, A. (2015). Risks of Risk Management. *The New Social Worker*, 22(2), 4–5.
- Beck, U., 1944-2015, author. (1992). *Risk Society: towards a New Modernity*. London: Sage Publications, 1992.
- Beck, U., 1944-2015, author. (2009). *World at risk* (English ed.). Cambridge, UK: Cambridge, UK.

- Berke, R. (2014). Older Adults Living at Risk" Ethical Dilemmas, Risk, Assessment and Interventions to Facilitate Autonomy and Safety. *International Journal of Nursing Student Scholarship*, 1(3), 1–14.
- Bernell, S., & Howard, S. W. (2016). Use Your Words Carefully: What Is a Chronic Disease? *Frontiers in Public Health*, 4(159), 1–3.
- Boholm, Å., & Corvellec, H. (2011). A relational theory of risk. *Journal of Risk Research*, 14(2), 175–190. <https://doi.org/10.1080/13669877.2010.515313>
- Bransford, C. L. (2011). Reconciling paternalism and empowerment in clinical practice: An intersubjective perspective. *Social Work*, 56(1), 33–41.
- British Columbia Renal Agency. (2015). *End Stage Renal Disease and the Discontinuation of Dialysis* (p. 34). Vancouver: British Columbia Renal Agency. Retrieved from <http://www.bcrenalagency.ca/our-research-site/Documents/ESRD%20FamilyPractice.pdf>
- Bury, M. (2010). Chronic Illness, Self-management and the Rhetoric of Empowerment. In *New Directions in the Sociology of Chronic and Disabling Conditions: Assaults of the Lifeworld*. Basingstoke: Palgrave Macmillan.
- Butler, A. M., Olshan, A. F., Kshirsagar, A. V., Edwards, J. K., Nielsen, M. E., Wheeler, S. B., & Brookhart, M. A. (2015). Cancer Incidence Among US Medicare ESRD Patients Receiving Hemodialysis, 1996-2009. *American Journal of Kidney Diseases*, 65(5), 763–772. <https://doi.org/10.1053/j.ajkd.2014.12.013>
- Canadian Association of Social Workers. (2005). *Guidelines for Ethical Practice*. Ottawa: Canadian Association of Social Workers. Retrieved from [https://www.casw-acts.ca/sites/default/files/attachements/casw\\_guidelines\\_for\\_ethical\\_practice.pdf](https://www.casw-acts.ca/sites/default/files/attachements/casw_guidelines_for_ethical_practice.pdf)
- Chambon, A. S., 1949-, Irving, A., & Epstein, L. (1999). *Reading Foucault for social work*. New York: Columbia University Press, c1999.
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine*, 30(11), 1161–1172. [https://doi.org/10.1016/0277-9536\(90\)90256-R](https://doi.org/10.1016/0277-9536(90)90256-R)
- Charmaz, K., & Bryant, A. (2012). *The SAGE Encyclopedia of Qualitative Research Methods*. 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. <https://doi.org/10.4135/9781412963909>
- Chenitz, K. B., Fernando, M., & Shea, J. A. (2014). In-center hemodialysis attendance: Patient perceptions of risks, barriers, and recommendations: Barriers to hemodialysis attendance. *Hemodialysis International*, 18(2), 364–373. <https://doi.org/10.1111/hdi.12139>

- Christensen, A. J., Wiebe, J. S., Benotsch, E. G., & Lawton, W. J. (1996). Perceived health competence, health locus of control, and patient adherence in renal dialysis. *Cognitive Therapy and Research*, 20(4), 411–421.
- Croisdale-Appleby, D. (2011). *Learning to Live with Risks* (p. 32). Leeds: Skills for Care. Retrieved from <https://www.skillsforcare.org.uk/Document-library/Skills/Living-with-risk/Learningtolivewithriskanintroduction.pdf>
- Culpitt, I. (1999). *Social Policy and Risk*. London: SAGE Publications Ltd. <https://doi.org/10.4135/9781446218211>
- Dantas, L. G., Cruz, C., Rocha, M., Moura, J. A., Paschoalin, E., Paschoalin, S., & Marcilio de Souza, C. (2013). Prevalence and Predictors of Nonadherence to Hemodialysis. *Nephron Clinical Practice*, 124(1–2), 67–71. <https://doi.org/10.1159/000355866>
- De Bono, C. E., & Henry, B. (2016). A positive risk approach when clients choose to live at risk: a palliative case discussion. *Current Opinion in Supportive and Palliative Care*, 10(3), 214–220. <https://doi.org/10.1097/SPC.0000000000000223>
- DeOreo, P. B. (1997). Hemodialysis patient-assessed functional health status predicts continued survival, hospitalization, and dialysis-attendance compliance. *American Journal of Kidney Diseases*, 30(2), 204–212.
- DeWolf Bosek, M. S. (2007). When respecting patient autonomy may not be in the patient’s best interest. *JONA’S Healthcare Law, Ethics and Regulation*, 9(2), 46–49.
- Dobrof, J., Dolinko, A., Lichtiger, E., Uribarri, J., & Epstein, I. (2002). Dialysis Patient Characteristics and Outcomes: The Complexity of Social Work Practice with the End Stage Renal Disease Population. *Social Work in Health Care*, 33(3–4), 105–128. [https://doi.org/10.1300/J010v33n03\\_08](https://doi.org/10.1300/J010v33n03_08)
- Douglas, M. (1982). *Risk and culture: an essay on the selection of technical and environmental dangers*. Berkeley: University of California Press, c1982.
- Engward, H. (2013). Understanding grounded theory. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, 28(7), 37. <https://doi.org/10.7748/ns2013.10.28.7.37.e7806>
- Entwistle, V. A., Carter, S. M., Cribb, A., & McCaffery, K. (2010). Supporting Patient Autonomy: The Importance of Clinician-patient Relationships. *Journal of General Internal Medicine*, 25(7), 741–745. <https://doi.org/10.1007/s11606-010-1292-2>
- Foucault, M. (1978). *The History of Sexuality Volume 1: An Introduction*. New York: Pantheon Books.

- Foucault, M. (1979). *Discipline and punish: the birth of the prison*. New York: Vintage Books.
- France, A., Freiberg, K., & Homel, R. (2010). Beyond Risk Factors: Towards a Holistic Prevention Paradigm for Children and Young People. *British Journal of Social Work*, 40(4), 1192–1210. <https://doi.org/10.1093/bjsw/bcq010>
- Frank, A., Auslander, G. K., & Weissgarten, J. (2004). Quality of life of patients with end-stage renal disease at various stages of the illness. *Social Work in Health Care*, 38(2), 1–27.
- Füredi, F., 1947-. (2006). *Culture of fear revisited: risk-taking and the morality of low expectation* (4th ed.). London.
- Gagnon, M., Jacob, J. D., & Guta, A. (2013). Treatment adherence redefined: a critical analysis of technotherapeutics: *Treatment adherence redefined*. *Nursing Inquiry*, 20(1), 60–70. <https://doi.org/10.1111/j.1440-1800.2012.00595.x>
- Ghimire, S., Castelino, R. L., Lioufas, N. M., Peterson, G. M., & Zaidi, S. T. R. (2015). Nonadherence to Medication Therapy in Haemodialysis Patients: A Systematic Review. *PLOS ONE*, 10(12). <https://doi.org/10.1371/journal.pone.0144119>
- Gibson, E. L., Held, I., Khawnekar, D., & Rutherford, P. (2016). Differences in Knowledge, Stress, Sensation Seeking, and Locus of Control Linked to Dietary Adherence in Hemodialysis Patients. *Frontiers in Psychology*, 7. <https://doi.org/10.3389/fpsyg.2016.01864>
- Gilbert, T., & Powell, J. L. (2010). Power and Social Work in the United Kingdom: A Foucauldian Excursion. *Journal of Social Work*, 10(1), 3–22. <https://doi.org/10.1177/1468017309347237>
- Godbold, N. J. (2013). Tensions in compliance for renal patients—how renal discussion groups conceive knowledge and safe care. *Health Sociology Review*, 22(1), 52–64.
- Government of Canada, S. C. (2014, January 27). The 10 leading causes of death, 2011. Retrieved December 16, 2017, from <https://www.statcan.gc.ca/pub/82-625-x/2014001/article/11896-eng.htm>
- Government of Canada, S. C. (2017, February 17). The 10 leading causes of death, 2013. Retrieved December 16, 2017, from <https://www.statcan.gc.ca/pub/82-625-x/2017001/article/14776-eng.htm>
- Grace, P. J. (2004). Patient Safety and the Limits of Confidentiality: Do you know when you shouldn't keep patient information confidential? *AJN, American Journal of Nursing*, 104(11), 33–37. <https://doi.org/10.1097/00000446-200411000-00021>

- Green, D. (2007). Risk and Social Work Practice. *Australian Social Work*, 60(4), 395–409. <https://doi.org/10.1080/03124070701671131>
- Grubbs, V., Vittighoff, E., Grimes, B., & Johansen, K. L. (2016). Mortality and illicit drug dependence among hemodialysis patients in the United States: a retrospective cohort analysis. *BMC Nephrology*, 17(1). <https://doi.org/10.1186/s12882-016-0271-1>
- Heidland, A., Klassen, A., Vienken, J., & Ritz, E. (2012). Heinrich Necheles: Pioneer of Hemodialysis in the Treatment of Experimental Uremia. In *Dialysis: History, Development and Promise* (pp. 51–58).
- Henneman, E. A., Lee, J. L., & Cohen, J. I. (1995). Collaboration: a concept analysis. *Journal of Advanced Nursing*, 21(1), 103–109. <https://doi.org/10.1046/j.1365-2648.1995.21010103.x>
- Holmes, D., Perron, A. M., & Savoie, M. (2006). Governing therapy choices: Power/Knowledge in the treatment of progressive renal failure, *Philosophy, Ethics, and Humanities in Medicine*, 1(2) 1-6.
- Junges, J. R. (2009). Direito à saúde, biopoder e bioética. *Interface - Comunicação, Saúde, Educação*, 13(29), 285–295. <https://doi.org/10.1590/S1414-32832009000200004>
- Kammerer, J., Garry, G., Hartigan, M., Carter, B., & Erlich, L. (2007). Adherence in patients on dialysis: strategies for success. *Nephrology Nursing Journal*, 34(5), 479.
- Karamanidou, C., Weinman, J., & Horne, R. (2014). A qualitative study of treatment burden among haemodialysis recipients. *Journal of Health Psychology*, 19(4), 556–569.
- Karolich, R. L., & Ford, J. P. (2010). Meaning, Comprehension, and Manageability of End-Stage Renal Disease in Older Adults Living with Long-Term Hemodialysis. *Social Work in Health Care*, 49(1), 19–37. <https://doi.org/10.1080/00981380902958601>
- Keskin, G., & Engin, E. (2011). The evaluation of depression, suicidal ideation and coping strategies in haemodialysis patients with renal failure: Depression, suicidal ideation and coping strategies in haemodialysis patients. *Journal of Clinical Nursing*, 20(19–20), 2721–2732. <https://doi.org/10.1111/j.1365-2702.2010.03669.x>
- Khalil, Amani A, Darawad, M., Al Gamal, E., Hamdan-Mansour, A. M., & Abed, M. A. (2013). Predictors of dietary and fluid non-adherence in Jordanian patients with end-stage renal disease receiving haemodialysis: a cross-sectional study: *Dietary and fluid nonadherence and hemodialysis*. *Journal of Clinical Nursing*, 22(1–2), 127–136. <https://doi.org/10.1111/j.1365-2702.2012.04117.x>
- Khalil, Amani Anwar, & Frazier, S. K. (2010). Depressive Symptoms and Dietary Nonadherence in Patients with End-Stage Renal Disease Receiving Hemodialysis: A Review of

- Quantitative Evidence. *Issues in Mental Health Nursing*, 31(5), 324–330.  
<https://doi.org/10.3109/01612840903384008>
- Kim, H. S. (2015). *The Essence of Nursing Practice: Philosophy and Perspective*. New York: Springer Publishing Company. Retrieved from  
<http://ebookcentral.proquest.com/lib/ottawa/detail.action?docID=2166659>
- Kimmel, P. L., & Peterson, R. A. (2005). PSYCHOSOCIAL FACTORS IN PATIENTS WITH CHRONIC KIDNEY DISEASE: Depression in End-Stage Renal Disease Patients Treated With Hemodialysis: Tools, Correlates, Outcomes, and Needs. In *Seminars in Dialysis* (Vol. 18, pp. 91–97). Wiley Online Library.
- Kovac, J. A., Patel, S. S., Peterson, R. A., & Kimmel, P. L. (2002). Patient satisfaction with care and behavioral compliance in end-stage renal disease patients treated with hemodialysis. *American Journal of Kidney Diseases*, 39(6), 1236–1244.  
<https://doi.org/10.1053/ajkd.2002.33397>
- Laidlaw, J. (2013). *The Subject of Virtue An Anthropology of Ethics and Freedom*. Cambridge: Cambridge University Press, 2013.
- Levine, M. I. (2007). Substance Abuse and the Hemodialysis Unit. *Seminars in Dialysis*, 8(1), 45–49. <https://doi.org/10.1111/j.1525-139X.1995.tb00328.x>
- MacLeod, H., & Stadnyk, R. L. (2015). Risk: ‘I know it when I see it’: how health and social practitioners defined and evaluated living at risk among community-dwelling older adults. *Health, Risk & Society*, 17(1), 46–63.  
<https://doi.org/10.1080/13698575.2014.999749>
- Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: the Canadian facts*. Toronto: York University, School of Health Policy and Management. Retrieved from  
<http://www.deslibris.ca/ID/223317>
- Ministry of Ontario. (2018). Long Term Care Wait Time. *Ministry of Ontario*, 3.
- Nabolsi, M. M., Wardam, L., & Al-Halabi, J. O. (2015). Quality of life, depression, adherence to treatment and illness perception of patients on haemodialysis: Quality of life and haemodialysis. *International Journal of Nursing Practice*, 21(1), 1–10.  
<https://doi.org/10.1111/ijn.12205>
- National Advisory Council on Aging. (1993). Rights and Limits to Risk. *Government of Canada - Expressions*, 9(2), 1–9.
- National Association of Social Workers. (2003). *Social Work Practice in Health Care Settings* (p. 52). National Association of Social Workers. Retrieved from

<https://www.socialworkers.org/LinkClick.aspx?fileticket=fFnsRHX-4HE%3D&portalid=0>

- National Institute of Diabetes and Digestive and Kidney Diseases. (2014). Kidney Disease Statistics for the United States. Retrieved July 21, 2018, from <https://www.niddk.nih.gov/health-information/health-statistics/kidney-disease>
- Newfoundland & Labrador Association of Social Workers. (2012). Decision-Specific Capacity Assessments. *Newfoundland & Labrador Association of Social Workers*, 18.
- Obialo, C. I., Hunt, W. C., Bashir, K., & Zager, P. G. (2012). Relationship of missed and shortened hemodialysis treatments to hospitalization and mortality: observations from a US dialysis network. *Clinical Kidney Journal*, 5(4), 315–319. <https://doi.org/10.1093/ckj/sfs071>
- Pantilat, S. (2008). Autonomy vs. Beneficence. Retrieved July 21, 2018, from [http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast\\_fact\\_auton\\_bene.htm](http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_auton_bene.htm)
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks: Sage Publications.
- Poushter, J., & Manevich, D. (2017). Globally, People Point to ISIS and Climate Change as Leading Security Threats, 32.
- Power, M. (1997). *The audit society: rituals of verification*. Oxford [England]: Oxford England.
- Puar, J. K. (2017). *Terrorist Assemblages: Homonationalism in Queer Times* (Vol. Tenth anniversary expanded edition). Durham: Duke University Press Books. Retrieved from <https://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=1691715&site=ehost-live>
- Research Alliance for Canadian Homelessness, Housing and Health. (2010). Housing Vulnerability and Health: Canada's Hidden Emergency, 12.
- Richard, A. A., & Shea, K. (2011). Delineation of Self-Care and Associated Concepts. *Journal of Nursing Scholarship*, 43(3), 255–264.
- Rifkin, D. E., Laws, M. B., Rao, M., Balakrishnan, V. S., Sarnak, M. J., & Wilson, I. B. (2010). Medication Adherence Behavior and Priorities Among Older Adults With CKD: A Semistructured Interview Study. *American Journal of Kidney Diseases*, 56(3), 439–446. <https://doi.org/10.1053/j.ajkd.2010.04.021>
- Roberts, S. (2014). A Quarterly Column About Medical Ethics: Ethics and End-Stage Renal Disease. *The Ochsner Journal*, 14(2), 154.

- Rosenthal Asher, D., Ver Halen, N., & Cukor, D. (2012). Depression and nonadherence predict mortality in hemodialysis treated end-stage renal disease patients: Depression and mortality in HD. *Hemodialysis International*, *16*(3), 387–393.  
<https://doi.org/10.1111/j.1542-4758.2012.00688.x>
- Sasson, S. (2000). Beneficence versus respect for autonomy: An ethical dilemma in social work practice. *Journal of Gerontological Social Work*, *33*(1), 5–16.
- Sawicki, J. (1991). *Disciplining Foucault: feminism, power, and the body*. New York: Routledge.
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., ... Whittemore, R. (2012). Processes of Self-Management in Chronic Illness: Self-Management Processes. *Journal of Nursing Scholarship*, *44*(2), 136–144.  
<https://doi.org/10.1111/j.1547-5069.2012.01444.x>
- Scott, J. K., Taylor, D. M., & Dudley, C. R. K. (2018). Intravenous drug users who require dialysis: causes of renal failure and outcomes. *Clinical Kidney Journal*, *11*(2), 270–274.  
<https://doi.org/10.1093/ckj/sfx090>
- Seden, J. (2016). Social work: risks, needs and balanced assessments. *K216 Readings*.
- Smith, R. (2010). Social Work, Risk, Power. *Sociological Research Online*, *15*(1), 1–10.  
<https://doi.org/10.5153/sro.2101>
- Solomon, R. C., & Sherman, D. (2003). *Blackwell Guide to Continental Philosophy*. Oxford: Oxford Blackwell Publishing Ltd.
- Stanley, T. W. (2005). Making decisions: Social work processes and the construction of risk (s) in child protection work.
- Tangenberg, K. M., & Kemp, S. (2002). Embodied practice: Claiming the body's experience, agency, and knowledge for social work. *Social Work*, *47*(1), 9–18.
- The Kidney Foundation of Canada. (2015). *Book 2: Living with Kidney Failure*. Toronto: The Kidney Foundation of Canada. Retrieved from <https://www.kidney.ca/file/Book2-complete.pdf>
- The Kidney Foundation of Canada. (2017). What is Kidney Disease? Retrieved July 18, 2018, from <https://www.kidney.ca/kidney-disease>
- The Kidney Foundation of Canada. (2018). *Facing the Facts* (p. 2). The Kidney Foundation of Canada. Retrieved from <https://www.kidney.ca/file/Facing-the-Facts-2018.pdf>

- The Social Housing Registry of Ottawa. (2018). The Registry - Centre d'enregistrement - FAQs | Ottawa Community Housing. Retrieved July 11, 2018, from <http://www.housingregistry.ca/faqs/>
- Tohme, F., Mor, M. K., Pena-Polanco, J., Green, J. A., Fine, M. J., Palevsky, P. M., & Weisbord, S. D. (2017). Predictors and outcomes of non-adherence in patients receiving maintenance hemodialysis. *International Urology and Nephrology*, *49*(8), 1471–1479. <https://doi.org/10.1007/s11255-017-1600-4>
- Umeukeje, E. M., Merighi, J. R., Browne, T., Wild, M., Alismaan, H., Umanath, K., ... Cavanaugh, K. L. (2016). Health care providers' support of patients' autonomy, phosphate medication adherence, race and gender in end stage renal disease. *Journal of Behavioral Medicine*, *39*(6), 1104–1114. <https://doi.org/10.1007/s10865-016-9745-7>
- United States Renal Data System. (2016). *2016 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States - Volume 1: CKD in the United States*. Ann Arbor: United States Renal Data System. Retrieved from [https://www.usrds.org/2016/download/v1\\_CKD\\_16.pdf](https://www.usrds.org/2016/download/v1_CKD_16.pdf)
- Van Ness, P. H. (2001). The Concept of Risk in Biomedical Research Involving Human Subjects. *Bioethics*, *15*(4), 364–370. <https://doi.org/10.1111/1467-8519.00244>
- Vélez-Vélez, E., & Bosch, R. J. (2016). Illness perception, coping and adherence to treatment among patients with chronic kidney disease. *Journal of Advanced Nursing*, *72*(4), 849–863. <https://doi.org/10.1111/jan.12873>
- Warner, J., & Sharland, E. (2010). Editorial. *British Journal of Social Work*, *40*(4), 1035–1045. <https://doi.org/10.1093/bjsw/bcq054>
- Warren, M. (2016). Shaping risky choices: Ethics and the effects of organizational decisions. *Healthcare Management Forum*, *29*(4), 165–167. <https://doi.org/10.1177/0840470416644384>
- Washington, T., Zimmerman, S., & Browne, T. (2016). Factors Associated with Chronic Kidney Disease Self-Management. *Social Work in Public Health*, *31*(2), 58–69. <https://doi.org/10.1080/19371918.2015.1087908>
- Webb, S. (2007). Risk. *Social Work & Society*, *4*(2), 379–382.
- Webb, S. A., 1956-. (2006). *Social work in a risk society: social and political perspectives*. Basingstoke [England]: Basingstoke England.
- Wileman, V., Farrington, K., Wellsted, D., Almond, M., Davenport, A., & Chilcot, J. (2015). Medication beliefs are associated with phosphate binder non-adherence in

hyperphosphatemic haemodialysis patients. *British Journal of Health Psychology*, 20(3), 563–578. <https://doi.org/10.1111/bjhp.12116>

Wise, P. (2012). Claude Bernard and the Milieu Intérieur: Origin and Evolution of the Concept. In *Dialysis: History, Development and Promise* (pp. 13–18). World Scientific.

World Health Organization. (2017). WHO | Risk factors. Retrieved July 21, 2018, from [http://www.who.int/topics/risk\\_factors/en/](http://www.who.int/topics/risk_factors/en/)

Ying, I., Levitt, Z., & Jassal, S. V. (2014). Should an Elderly Patient with Stage V CKD and Dementia Be Started on Dialysis? *Clinical Journal of the American Society of Nephrology: CJASN*, 9(5), 971–977. <https://doi.org/10.2215/CJN.05870513>

# Annex 1 – Interview Guide

Version 2 – March 4, 2018

Co-Investigator Holly Pankhurst

---

Questionnaire for Semi-Directed Interviews with Social Workers in the framework on my Memoire: What is the role of social workers in working with dialysis patients who choose to live at risk?

These interview questions will be read aloud to the participants during the interview. They will not have access to them prior to the interview:

- 1) What does it mean to you to live at risk regarding dialysis patients?
- 2) Do you feel there is a difference in living at risk versus choosing to live at risk for dialysis patients?
- 3) Can you explain what you feel are some of the reasons behind why dialysis patients might choose to live at risk?
- 4) How do you ensure that dialysis patients are safe when they choose to live at risk?
- 5) While the type of risk carried out by dialysis patients is not imminent or physically detrimental to others, do you feel there are other consequences that effect the patient's various circles (i.e. family members, friends, healthcare team?)
- 6) What do you feel is your role in working with dialysis patients who choose to live at risk?
- 7) What interventions do you carry out when working with these dialysis patients who choose to live at risk?
- 8) Do you feel that your personal and professional values as a social worker often come into conflict with dialysis patients that choose to live at risk? If yes, then how so? How do you manage these conflicts with these patients?
- 9) Do you feel that your role and your values as a social worker (i.e. respect for autonomy and self-determination) come into conflict with other healthcare staff when discussing a dialysis patient's right to live at risk? If yes, then how do you manage these conflicts?
- 10) How do you advocate for dialysis patients that choose to live at risk?
- 11) What are some of the ethical dilemmas you have encountered in working with dialysis patients who choose to live at risk (i.e. beneficence versus autonomy)?
- 12) What are the ethical implications of working with these patients? Annex 2 – Ethics Approval Letter, The Ottawa Hospital



**Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa**

Civic Box 411 725 Parkdale Avenue, Ottawa, Ontario K1Y 4E9 613-798-5555 ext. 14902 Fax : 613-761-4311  
<http://www.ohri.ca/ohsn-reb>

May 9, 2018

Ms. Michele Holwell  
Ottawa Hospital - General Campus  
Cancer Assessment Clinic  
7NE  
501 Smyth Road  
Ottawa, ON K1H 8L6

Dear Ms. Holwell:

**Re: Protocol # 20180020-01H      The role of social workers in working with dialysis patients who choose to live at risk.**

**Protocol approval valid until - May 8, 2019**

I am pleased to inform you that this protocol underwent delegated review by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is approved for the recruitment of English speaking participants only. No changes, amendments or addenda may be made to the protocol or the consent form without the OHSN-REB's review and approval.

Date of approval: May 9, 2018

PLEASE NOTE: THE APPROVAL OF THIS PROTOCOL IS CONDITIONAL UPON A FULLY-SIGNED STUDY CONTRACT/AGREEMENT BETWEEN THE OTTAWA HOSPITAL RESEARCH INSTITUTE, THE PRINCIPAL INVESTIGATOR AND THE SPONSOR (OR AS OTHERWISE REQUIRED). YOU CANNOT START THE STUDY, OR BEGIN TO RECRUIT RESEARCH PARTICIPANTS INTO THE STUDY UNTIL THE STUDY CONTRACT/AGREEMENT HAS BEEN SIGNED BY ALL PARTIES, AND HAS BEEN RECEIVED BY THE OTTAWA HOSPITAL RESEARCH INSTITUTE'S CONTRACTS OFFICE. FOR FURTHER DETAILS, PLEASE CONTACT CONTRACTS ADMINISTRATION AT [CONTRACTS@OHRI.CA](mailto:CONTRACTS@OHRI.CA) OR AT 613-798-5555 EXT. 19843.

Approval is for the following:

- Protocol dated March 4, 2018
- English Recruitment Email dated March 14, 2018
- English Consent Form dated March 14, 2018
- English Semi-Structured Interview Guide dated March 4, 2018

Your request for a French exemption is approved; the study may proceed in English only.

If the study is to continue beyond the expiry date, a Renewal Form should be submitted to the REB, in hardcopy. All Annual Renewal Reports, regardless of review type (i.e., full board or delegated), must now be submitted according to the full board meeting submission deadlines AND at least 30 days prior to the expiry date of the study to prevent a lapse in approval. If the study is completed by this date, a Termination Report should be submitted.

1/2

2/2

The OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline and the provisions of the Personal Health Information Protection Act 2004.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'FFAS', with a small checkmark at the end.

Francine F-A Sarazin, Ph.D., C.Psych.  
Vice-Chairperson  
Ottawa Health Science Network Research Ethics Board

FFAS/kd

# Annex 3 – Ethics Approval Letter, University of Ottawa

18/05/2018

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



**University of Ottawa**  
Office of Research Ethics and Integrity

## Lettre d'approbation administrative | Letter of administrative approval

<b>Numéro de dossier / Ethics File Number</b>	S-05-18-434
<b>Titre du projet / Project Title</b>	The role of social workers in working with dialysis patients who choose to live at risk.
<b>Type de projet / Project Type</b>	Mémoire de maîtrise / Master's major research paper
<b>CÉR primaire / Primary REB</b>	This research project was approved by The Ottawa Hospital (TOH) and by the Ottawa Hospital Research Institute (OHRI) on DATE
<b>Statut du projet / Project Status</b>	Approuvé / Approved
<b>Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)</b>	18/05/2018
<b>Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)</b>	08/05/2019

### Équipe de recherche / Research Team

<b>Chercheur / Researcher</b>	<b>Affiliation</b>	<b>Role</b>
Holly PANKHURST	École de service social / School of Social Work	Chercheur Principal / Principal Investigator
Marjorie SILVERMAN	École de service social / School of Social Work	Superviseur / Supervisor

**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](mailto:ethique@uOttawa.ca) / [ethics@uOttawa.ca](mailto:ethics@uOttawa.ca)  
[www.recherche.uottawa.ca/deontologie](http://www.recherche.uottawa.ca/deontologie) | [www.recherche.uottawa.ca/ethics](http://www.recherche.uottawa.ca/ethics)

## Annex 4 – Consent Form

Version 2 – March 12, 2018

Co-Investigator Holly Pankhurst



The Ottawa  
Hospital | L'Hôpital  
d'Ottawa  
RESEARCH  
INSTITUTE | INSTITUT DE  
RECHERCHE



uOttawa

### Participant Informed Consent Form

**Title of the study:** The role of social workers in working with dialysis patients who choose to live at risk.

**Principle Investigator:** Michele Holwell, Profession Leader, Social Work Department, The Ottawa Hospital, 613-737-8899, ext. 72134, [mholwell@toh.ca](mailto:mholwell@toh.ca)

**Co-Investigators:**

- Holly Pankhurst, Master of Social Work Candidate, School of Social Work, University of Ottawa, 613-246-6469, [hpank052@uottawa.ca](mailto:hpank052@uottawa.ca)
- Dr. Marjorie Silverman, Assistant Professor, School of Social Work, University of Ottawa, 613-562-5800 x 3456, [marjorie.silverman@uottawa.ca](mailto:marjorie.silverman@uottawa.ca)

**Invitation to Participate:** You are asked to participate in this research study because you are a social worker at The Ottawa Hospital who has at least 2 years experience working with dialysis.

**Purpose of the Study:** The purpose of the study is to determine the interventions used by social workers in working with dialysis patients who choose to live at risk.

**Participation:** Your participation will consist of a one-time 1.5-hour interview session at The Ottawa Hospital. The interview will be audio recorded so it can be transcribed afterwards by the co-investigator.

**Risks:** You will be asked to provide professional information regarding interventions used in working with dialysis patients who choose to live at risk. This may cause you to feel uncertain about previous interventions used with dialysis patients in terms of ethical implications. Every effort will be made to minimize these risks by having a debriefing period after the interview is completed. You do not have to answer any questions that make you feel uncomfortable or that you do not want to answer.

**Benefits:** You may not directly benefit from your participation. Your participation may allow the researchers to expand on the knowledge of what consists risk within a renal context and what interventions are carried out in working with dialysis patients who choose to live at risk.

**Confidentiality**

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you, such as your name, address, etc.
  - The link between your unique study number and your name and contact information will be stored securely and separate from your study records at The University of Ottawa.
  - Audio recordings and coded data will be stored on The Ottawa Hospital server and University of Ottawa server.
  - Audio recordings will be transcribed at The University of Ottawa and all transcriptions will be de-identified.
  - Any documents leaving The University of Ottawa will contain only your unique study number. This includes publications or presentations resulting from this study.
  - Information that identifies you will be released only if it is required by law.
  - For audit purposes only, your original study records may be reviewed under the supervision of Michele Holwell's staff by representatives from:
    - the University of Ottawa,
    - the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
    - and the Ottawa Hospital Research Institute
- Research records will be kept for 10 years, after this time they will be destroyed.

**Compensation:** You will not be paid to participate in this study, nor will there be any cost to you.

**Voluntary Participation:** Your participation in this study is voluntary. If you choose to participate, you can withdraw from the study at any time and/or refuse to answer any questions, without affecting your employment or other services to which you are entitled or are presently receiving at The Ottawa Hospital. If you choose to withdraw, all data gathered until the time of withdrawal will not be used.

**Questions:**

If you have any questions about this study, please contact Holly Pankhurst at 613-246-6469 or, [hpank052@uottawa.ca](mailto:hpank052@uottawa.ca), or Dr. Marjorie Silverman at 613-562-5800 x 3456, or [marjorie.silverman@uottawa.ca](mailto:marjorie.silverman@uottawa.ca).

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) and the University of Ottawa Research Ethics Board have reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson of the OHSN-REB at 613-798-5555, extension 16719, or the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, at (613) 562-5387 or at [ethics@uottawa.ca](mailto:ethics@uottawa.ca)

## **The role of social workers in working with dialysis patients who choose to live at risk.**

### **Consent to Participate in Research**

- I understand that I am being asked to participate in a research study about the roles and interventions carried out by social workers who work with dialysis patients that choose to live at risk.
- This study was explained to me by \_\_\_\_\_.
- I have read, or someone has read to me, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

\_\_\_\_\_  
Participant's Printed Name

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

### **Investigator or Delegate Statement**

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

\_\_\_\_\_  
Investigator/Delegate's Printed Name

\_\_\_\_\_  
Investigator/Delegate's Signature

\_\_\_\_\_  
Date

## Annex 5 – Recruitment Email

Version 2 – March 14, 2018

Co-Investigator Holly Pankhurst



### **Email: Invitation to Participate in a Research Study**

To whom it may concern,

This email is being sent on behalf of Holly Pankhurst, a Master of Social Work Candidate at the University of Ottawa. She is completing her research project on the role of social workers in working with dialysis patients who choose to live at risk. The purpose of the study is to determine the interventions used by social workers in working with dialysis patients who choose to live at risk.

You are being asked to participate in this research study conducted by Holly under the supervision of Michele Holwell, Profession Leader at The Ottawa Hospital and Dr. Marjorie Silverman, Assistant Professor, University of Ottawa. Your participation would consist of a one-time 1.5-hour interview session at The Ottawa Hospital. The interview will be audio recorded so it can be transcribed afterwards. Participation is voluntary.

If you are interested in hearing more, or in participating in this research study, please contact Holly Pankhurst at 613-246-6469, or via email at [hpank052@uottawa.ca](mailto:hpank052@uottawa.ca). You can also contact Dr. Marjorie Silverman, Assistant Professor, School of Social Work, University of Ottawa, 613-562-5800 x 3456, [marjorie.silverman@uottawa.ca](mailto:marjorie.silverman@uottawa.ca) or Michele Holwell, Profession Leader, The Ottawa Hospital, 613-737-8899, ext. 72134, [mholwell@toh.ca](mailto:mholwell@toh.ca).

Best regards,

Patricia deJong  
Secretary to the Professional Practice Manager  
Psychosocial Services, The Ottawa Hospital