Stories of Chronic Kidney Disease: Listening for the Unsayable

by

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B.Sc.N., University of Saskatchewan, 1999
M.N., University of Victoria, 2005

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Supervisory Committee

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Abstract

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Chronic kidney disease (CKD) is frequently described as a chronic illness. It is also a life-threatening illness, although this is rarely discussed. When people with CKD face declining kidney function, they need technological assistance to extend life. Many people receiving treatment will also die within 5 years. The experience of living with CKD is often difficult to articulate, and little is known about the aspects of this illness that are often ineffable, difficult to discuss, or beyond words.

The purpose of this dissertation is to present four papers in which I investigate the concept of the unsayable and illuminate how this concept may be helpful in exploring individuals' stories of living with CKD. Located in social constructionism, this narrative research explores the unsayable aspects of experience for people living with CKD as portrayed through their stories and symbols.

In the first paper, I present a concept analysis of the unsayable and I define the unsayable as that which is not expressed yet alluded to through language and may be conscious or unconscious. Although the unsayable is intertwined with language, it also transcends articulation. In the second paper, I offer a qualitative meta-synthesis and I show how people with kidney failure have experienced restricted freedom that brings

about distant connection, dependent autonomy, abnormal normalcy, and uncertain hope. In the third paper, I present a narrative inquiry using secondary analysis of 46 interviews conducted over 3 years with 14 people living with CKD. Narrative expressions of the unsayable include the following: living with death, embodied experiences that were difficult to language, that which was unthinkable, unknowable mystery, and that which was untold / unheard. Lastly, I offer a narrative visual analysis of symbols that represent living with CKD for 13 participants. Descriptive themes of the symbols include hopes and inspirations, reflections on "who I am," and confrontations of illness. Participants' expressions through symbols are described through stories of memories, emotions, and poetic devices. Consideration of the unsayable may offer insights for nurses who work to support individuals and promote quality of life for those living with this chronic and life-threatening illness.

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Acknowledgments

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Dedication

In memory of my grandma,
Julie Bieber (1914-2009),
and grandpa,
Ted Schick (1913-2010).

In dedication to Leland Makaroff.

Chapter 1. Introduction

Through studying the concept of the unsayable, nurse scholars may gain insights into experiences of people living with chronic kidney disease (CKD) and an understanding of aspects of experience both in and beyond language. A diagnosis of CKD means that there has been a decrease in kidney function or damage to the kidneys for a minimum period of 3 months (Kidney Foundation of Canada, 2011). If CKD progresses, it can result in end-stage renal disease (ESRD), the fifth and final stage of CKD involving the complete, or near complete, failure of kidney function. With ESRD, renal replacement is required for a person to survive. In 2009, 37,744 individuals in Canada were being treated, 21,310 by peritoneal and hemodialysis and another 15,434 were living with a kidney transplant (CIHI, 2011a). Treatment for ESRD extends life, but the disease also threatens life for those facing this illness. Living with CKD presents challenges, some of which are difficult or impossible to articulate, impacting one's daily life as well as quality of life.

I begin this dissertation with a story told by a 64 year-old man who had ESRD. He wished to remain anonymous. He received treatment through hemodialysis for 2 years after a heart transplant, and he died in 1997. I share his story to illuminate the complexity inherent in this disease. He recounted,

> In June of 1991, I had a heart transplant. Ever since, I have been taking immunosuppressant drugs. These have had many effects on my body. They have affected my bones, caused kidney failure, and finally led me to develop lymphoma. The problem is that I have to keep taking these drugs, because

> otherwise my body might reject the new heart. It's a "Catch-22" situation. Almost two years ago, I had to begin dialysis....
>
> Right now, I am walking a very fine line. But I have to keep smiling. If I sit down 24 hours a day feeling sorry for myself, what kind of life will I have? I take things the way they are because I know that if I cry or yell, nothing will come out of it...It's not a pleasant life, but what other alternative do I have?
>
> One thing I wanted very badly was to have a kidney transplant. But because I have lymphoma, this can never happen.
>
> Nothing gives me support. I am sick physically, and not in my head. To me, it's not helpful to just talk and talk. I don't talk to the doctors, I diagnose with them. I ask them many questions. So far, the field of medicine is a very large field, in which many things have not been discovered yet. It's true that the field of surgery has advanced a lot. But there is one thing which I still require from it. When I had a severe heart attack, I received a heart transplant. Now my kidneys are failing, and I need a kidney transplant. How is this going to be possible?...
>
> If anyone with kidney failure thinks that they can survive without dialysis, they are being very foolish. For people whose kidneys aren't working, dialysis is a must. There is no such thing as "maybe" in a case like this. The only choice that people have concerning dialysis is whether to take it or leave it. (Dialysis and Transplant Units, 2000, pp. 161-162)

As this man so poignantly identified, treatment for ESRD extends and significantly changes life, but the disease threatens life. He alluded to this as a "catch-22 situation."

This anonymous individual's issues are similar to many others living with CKD. Like others, he bore the burden of additional disease, in his case, cancer. While his ESRD resulted from cardiac disease, researchers have shown that others living with early ESRD have a significantly increased risk of developing heart disease (Muntner, He, Hamm, Loria & Whelton, 2002). He explained the complexity of trying to navigate his own responses to this illness: decisions to choose to "keep smiling," to not feel sorry for himself, and to adopt the pragmatic view that "nothing will come out of" crying or yelling. His hopes were deferred because, although medicine has come a long way, treatment had not advanced so that he could have a kidney transplant. Dialysis extended his life, but he explained that life was neither easy nor always pleasant.

CKD typically begins slowly and without obvious symptoms; thus, it is frequently undiagnosed in early stages (Molzahn et al., 2008). Progression of CKD takes place over years. Not everyone advances from the first to the fifth stage, but prevention is essential to slowing the deterioration of renal function. Complications of CKD can frequently be deferred or prevented through early identification and treatment. Such complications that need to be treated early in CKD include the following: hypertension (which is also a cause of CKD), anaemia (which has cardiac consequences), protein-energy malnutrition, disorders related to calcium and phosphorous metabolism, metabolic acidosis, neurological disorders, and dyslipidemias (Bargo McCarley, 2006).

Treatment of cardiovascular disease and diabetes is crucial in delaying CKD progression. Diabetes is the most frequent cause of ESRD with 34% of all patients in Canada needing renal replacement due to diabetes. Manuel, Rosella, Tuna and Bennett

(2010) reported that 1.9 million Canadians are expected to develop diabetes by 2017. In other words, 1.9 million people are at risk of developing CKD (KFOC, 2010).

CKD is incurable and the incidence of this chronic and life-threatening illness is on the rise. In 2011, the Canadian Institute of Health Information (CIHI, 2011a) identified that between 2000 and 2009 there was a 12% increase of newly diagnosed cases of patients with ESRD in need of renal replacement. This rise marked a 58% increase compared to the incidence of ESRD in 1990. The prevalence of people being treated with dialysis has increased by 212% between 1990 and 2009.

ESRD (also referred to as kidney failure) means that the kidneys are functioning at or below 15% of normal (KFOC, 2011). People who reach this state are either actively receiving dialysis or may be considered for a kidney transplant. Dialysis is an intensive, ongoing technological intervention to extend a person's life. Dialysis can be provided through peritoneal dialysis or hemodialysis. Peritoneal dialysis entails the insertion of an indwelling catheter so that a person's abdomen (peritoneal cavity) can be filled with a special dialysis fluid and drained periodically to remove both water and toxins from the body. With hemodialysis ("hemo" referring to blood), blood is drawn from a person's body and put through an artificial kidney several times per week in order to remove excess water, toxins, and electrolytes. Hemodialysis can be provided in a home, a hospital, or a community renal clinic. If a person is able to have dialysis at home, a dialysis machine is installed in the house. The person must regularly clean and maintain the dialysis machine. At home, the length of time on dialysis can be adjusted by a physician to tailor to the individual's needs. On average, most people spend 3-5 hours (not including time to set up the machine and clean it afterwards), 3-4 times per week on

dialysis at home. Hemodialysis in a hospital or community clinic typically entails three visits per week for approximately 3-4 hours each time. A person must arrange transportation to and from dialysis. For those living in rural settings, this can entail many hours of commuting to get to the clinic or hospital. A more recent innovation is nocturnal dialysis, or "quotidian" meaning "more frequent dialysis" (Harwood & Leitch, 2006), where a person dialyzes at home or in hospital approximately 8 hours a night, three to four times per week.[1] Treatment of ESRD is complex and involves not only hemodialysis or peritoneal dialysis, but also fluid and dietary restrictions, prescribed medications, and ongoing medical engagements (Thomas-Hawkins, 2006). Those who are not candidates for a transplant have a significantly shortened life expectancy (Moss, 2002; Robert Wood Johnson Foundation, 2003). While long-term survival rates have gradually improved, the 5-year survival rate for individuals on dialysis under 18 years old is 87%, but for people older than 75 years old, the 5-year survival rate drops to 24% (CIHI, 2011a). Since 1999, CIHI has found that the highest incidence of newly diagnosed people with kidney failure is for those who are in the 75 years and older age category. Overall, the unadjusted 5 year survival rate for all people on dialysis is 43.2% (CIHI, 2011a).

Treatment of CKD is costly for the Canadian healthcare system. CIHI (2001b) estimated the cost for hemodialysis treatment (the most common form of dialysis) is approximately $60,000 per person for one year of treatment. This cost is based on an average of three dialysis treatments per week, but does not include physician fees or procedures that occur outside of hospital settings. Zelmer (2007) has identified that although less that 0.1% of Canadians have ESRD, in the year 2000 the total healthcare cost for this disease was $1.9 billion. The costs associated with treating ESRD were

[1] Time spent on dialysis for all of these modalities will depend on the individual's needs.

significantly higher per person than for many other diseases. Zelmer has found that treatment costs in Canada are more than 16 times what was spent on average for each person who received care for all health conditions. While there are significant costs to the healthcare system, there are also staggering personal costs of living with this disease.

Although CKD is a chronic illness, it is clearly life-threatening. As the man quoted at the beginning of this chapter so clearly articulated, treatment for ESRD provides hope through extension of life but the disease also threatens life, creating a "catch-22" for those faced with this serious illness. There is evidence in the literature (Charon, 2006a; Frank, 2002; Hines, Babrow, Badzek, & Moss, 1997) that living with a chronic and life-threatening illness impacts quality of life and raises complex questions about life that are difficult to articulate. People with CKD face questions about life and death, amongst other topics, that can be challenging to discuss. As Molzahn, Bruce, and Sheilds (2008) found, people with CKD live with anxiety and uncertainty and are often unable to ask about and/or articulate their fears. Little is known about the experiences of living with ESRD that are difficult to discuss, ineffable, or beyond words; it is these "unsayables" that are the focus of this study.

The unsayable means, as an adjective, "not able to be said, especially because [it is] considered too controversial or offensive to mention" ("Unsayable", 2011). Etymologically, the roots are 1) "un," meaning not; 2) "say," meaning in Old English *secgan* "to utter, say," from Proto-Indo-European**sokei-*, probably from base **seq-* "point out"; and 3) "able" which expresses ability, capacity, fitness, from the Latin *–ibilis or –abilis* (Harper, 2010). Together the origins and the definition identified here refer to the characteristic of not being expressed through language.

I suggest however, that the unsayable includes language but is not limited to it because experience may transcend articulation. My assumption is that there are aspects of experience that are unsayable.[2] The unsayable has been taken up in diverse health contexts but most often in relation to trauma (Cunningham, 2008; Gentile, 2006; Lieberman & Van Horn, 2009; Rogers 1995, 2006, 2007a, 2007b; Rogers et al., 1999) and horror / torture (Ehrensaft, 2008; Frankl, 1959/1984; Mitchell, 2009; Nye, 2008; Rogers, 2007a). The concept has rarely been used in nursing and healthcare; however, I suggest that when we consider this concept, we access an innovative approach through which to consider the experiences of individuals who are living out the complexities, challenges, and disruptive life events of an evolving chronic illness such as CKD. Within this context, examples of the unsayable may include not speaking of the risk of death related to CKD, choosing not to say something due to the fear of how others may respond, or ineffable aspects of confronting mortality that are hard to articulate and perhaps beyond words.

Purpose and Research Question

The purpose of this dissertation is to develop a comprehensive set of papers intended to explore the concept of the unsayable and to illuminate how this concept may be helpful in exploring individuals' stories of living with CKD. The overarching research question is, "What are the unsayable aspects of experience for people living with CKD as portrayed through their stories and symbols?"[3] I explore this question through a social

[2] Further, I assume that unsayable aspects of experience will be different for each person and storied in nuanced ways. From a social constructionist perspective (described below), meaning of experience for an individual is created iteratively with society and shared in stories in unique ways.

[3] I use the phrase "unsayable aspects of experience" to identify the unsayable in relationship to experience.

constructionist perspective which posits that reality[4] is a socially based *construction* through which multiple interpretations, truths, and realities are possible (Cody, 2002; Kinsella, 2009; Newman, 1992; Paley, 2005; Rodgers, 2005; Schoenhofer, 2002). I explore how experiences of CKD are sustained through the stories that participants tell and the symbols they portray.

In this dissertation, I primarily focus on how unsayable aspects of experience are intertwined with language but I recognize that, 1) the unsayable also lies beyond speech, and that, 2) there are other ways to inquire into experiences that transcend language. I acknowledge that there are other avenues to study the unsayable that I do not take up and they may encompass the arts, literature/fiction, philosophy, embodied experience, or performance. In chapter 5, however, I depart from language and look at symbols[5] as representations of experience. In this study, I focus on narrative inquiry (Riessman, 2008) which provides me with an avenue to study the experiences of individuals who are living within the complexities and disruptive life events of an evolving chronic and life-threatening illness. When individuals are invited to tell stories, they are presented with an opportunity to express experiences that are hard, and perhaps impossible, to language.

In this chapter, I will describe how I became interested in this topic. I will then explicate my position within social constructionism, explain my use of narrative inquiry, identify the significance of this study, and outline the four dissertation papers.

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[4] In *Discourse of modernism*, Reiss (1982) explains that how we consider and discursively express reality is a phenomenon that is created and endorsed through our culture.

[5] Language itself may be considered a symbolic representation of experience (see Peirce's theory of signs in *The collected papers of Charles Sanders Peirce*, edited by Hartshore, Weiss & Burks, 1994). As Saussure (1916/1983) explains, it is through language that signifiers (such as words or images) are linked with that which is signified (such as concepts or ideas). By "symbols," I am referring to aesthetic expressions imbued with meaning (Remen, 2011) that signify experience. I describe symbols more fully in chapter 5.

Background

I have been interested in the unsayable within chronic illness since I began my doctoral studies. In 2005, I completed my Master of Nursing (MN) (Policy and Practice) thesis which focused on chronic illness and disability using qualitative methodology. The unsayable offered me an avenue to consider how nursing knowledge may contribute to quality of life for individuals with persistent illnesses. As my masters program was concluding, I began to work as a research coordinator with a research team focused on ethics (Storch et al., 2009). I gained a further awareness of the moral imperative involved in working alongside people living with ongoing illnesses. After completing my MN, I was able to continue studying chronic illness when I became a research assistant on a national project called *CanPREVENT – Canadian Prevention of Renal and Vascular Endpoints Trial* (Molzahn et al., 2008). Within this research environment, focused on nephrology, I conducted interviews, chart reviews, and data analyses, and I learned of people's diverse experiences of living with CKD. Further, I observed the complexity of CKD, its impact on people's daily lives, and on the quality of lives.

In 2007, I began my doctoral program and concurrently obtained a fellowship within the CIHR-funded project *Re-stor(y)ing Life Within Life-threatening Illness* (Sheilds et al., 2010). In this qualitative narrative study, we inquired into the ways in which individuals storied and re-storied their experiences of living with the uncertainty that accompanies life-threatening illnesses such as cancer, HIV/AIDS, and CKD. Building upon my previous work, and with the support of the *Re-stor(y)ing* research team, I chose to focus on the CKD population. Together, these experiences laid the

groundwork for this dissertation, and I engaged in secondary analysis of data from the *Re-stor(y)ing* project to study unsayable aspects of experience for people with CKD.

As I spoke with participants in the *Re-stor(y)ing* project, I became intrigued with the idea that many struggled to fully language their thoughts, feelings, and experiences. I began to ask questions such as these: Can individuals living with CKD express their experiences, or are there aspects that transcend language? Are there differences between expressions of life as it is lived, experienced, and told; and does this influence how people see the world? (See E. Bruner, 1984.) Rogers et al.'s (1999) articulation of the languages of the unsayable has provided me with greater curiosity about these questions.

The unsayable, according to Rogers et al. (1999), is that which is "difficult to say but may be implied through negation, revision, evasion, or silence" (p. 91). Although Rogers suggests that the unsayable is portrayed through language, she also proposes that it lies beyond speech.[6] Nevertheless, there seems to be an assumption within Rogers' (1995, 2006, 2007b) work that the unsayable must be resolved, and that the unconscious *should* come into consciousness. A similar position is echoed by other authors in the field (Levitt, 2002; Lieberman & Van Horn, 2009; Thomas, 2004) who argue that the unsayable should be articulated. The Western cultural idea that we *can* and perhaps *should* be able to articulate experience or reality is one challenged by Reiss (1982). Influenced by Foucault and the poststructuralist movement, Reiss claims that modern discursive practices (culturally influenced ways of speaking/thinking) have, until recently, not been questioned. Reiss maintains that in the discourse of modernism, a worldview to which many in nursing still adhere, discourse is understood to fully

[6] Rogers' ideas come from linguistics, language, creative writing, feminism, and psychology (particularly Lacan).

represent experience, i.e. words represent thoughts. What is not recognized is how thought is mediated, *shaped* by cultural practice, as in scientism.[7] Therefore, experiences beyond words, experiences that do not fit within the range of modern discursive practices, can only be "alluded to."

Aligning myself with Reiss (1982), I take a different position than Rogers (1995, 2006, 2007b) as I challenge the assumption that we can or should articulate experience. Further, I suggest that unsayable aspects of experience may not always be resolved, may remain unconscious, and may transcend language. In agreement with Peirce (Hartshore et al., 1994), I suggest that consciousness and thoughts are signs that are *sometimes* brought to language or symbols. Other times, the unsayable persists outside expression.

Experience intrinsically changes once we use words to express that which is lived. We possess both ability and inability to represent through language, life as it unfolds through experience. Therefore, I do not advance the position the unsayable should translate into language. I propose that the unsayable encompasses an innate in/ability to language that which surpasses speech. In/ability presents a space to represent capacity, both ability and inability, in our expressions. Although the predominant perspective from psychology focuses on saying the unsayable, I offer an alternative thesis. In keeping with Peirce (Hartshore et al., 1994), I suggest that unsayable aspects of experience cannot and should not always be brought to speech because they rest both within and beyond language.

I would argue, in agreement with Budick and Iser (1989), that the unsayable is an inherent aspect of language and it "speaks for something that is arguably as real as anything else we know, even if it can be located by carving out a void within what is

[7] By scientism, I mean a rationalist view of science that becomes ideology (Reiss, 1982).

being said" (p. xi). Although Budick and Iser assert the unsayable is "real"[8], Rogers (1995, 2006, 2007b) seems to places dominance on language and asserts the unsayable may be resolved through speech or text. Her reliance on language perhaps stems from modernism which asserts that it is through language that we come into being. While Rogers draws on Budick and Iser in her "languages of the unsayable," she does not take up their emphasis on what is beyond language. Awareness of unsayable aspects of experience that coexist in and beyond language may illuminate how to best support people living with CKD.

The concept of the unsayable has not been previously explored in relation to chronic and life-threatening illness or CKD. The term "unsayable" was, however, identified from the beginning of the *Re-stor(y)ing* project. The *Re-stor(y)ing* team members discussed the concept in relation to aspects of illness experiences that are difficult to articulate, thus highlighting unsayable aspects of liminal and metonymic experiences. The concept of the unsayable is particularly poignant as people living with CKD face the complexity of their illness amidst the hope of extending life through multifaceted treatments. The experience of living with such an illness is often difficult to discuss, described by the man quoted at the beginning of this chapter as "walking a fine line." Discussion of the unsayable in nursing may offer insights into individuals' experiences that are challenging to express in a culture that avoids discussions of death (Robert Wood Johnson Foundation, 2003). Furthermore, nursing knowledge may advance as we learn from people living with CKD about the fears or desires that have

[8] Derrida (1989), drawing on Wittgenstein, states that the inexpressible exists and manifests itself in the mystical.

been difficult or impossible to express to healthcare professionals, their loved ones, and perhaps even to themselves.

Philosophical Perspective: Social Constructionism

Social constructionism provides the paradigmatic perspective for this study. Constructivism is defined as "the theory that knowledge is not something we *acquire* but something that we *produce*; that the objects in an area of inquiry are not there to be discovered, but are invented or constructed" (Mautner, 2005, p. 123).[9] Broadly in nursing, constructivism is a paradigm (Kuhn, 1970) at times referred to interchangeably with the terms naturalistic, constructionism, or social constructionism (Paley, 2005; Rodgers, 1991). I choose the latter term because of the recognition of the social influences in individuals' construction of knowledge.

How might this philosophical perspective advance nursing's body of knowledge? Cody (2002) proposed that a constructivist framework offers a unique avenue to engage in theory development and critical thinking within the discipline. In the nursing literature, the constructivist ontology is articulated as that of a relativist, and the epistemological viewpoint is interactive and subjectivist (Schoenhofer, 2002) meaning that "what exists depends on what individuals perceive to exist" (McEwan & Wills, 2011, pp. 8-9). Knowledge does not exist independently of the human mind (Paley, 2005), and our interpretations are based upon our pre-existing knowledge, histories, and traditions. Knowledge is also co-constructed within society (Hollingsworth & Dybdahl, 2007). Thus, an individual's learning unfolds in relation to her or his interactions in society.

In understanding social constructionism, I draw upon multiple scholars (Berger &

[9] Construction comes from the mid 15th century Latin *constructionem*, derived from *construere* meaning to "pile up together, build," from *com-* "together" and *struere* "to pile up" (Harper, 2010). The two words, constructivism and construction, are linked and they both employ the mechanistic metaphor of building.

Luckmann, 1967; Davis & Sumara, 2002; Gergen & Gergen, 1991, 2004[10]; Hacking, 1999). The term "social constructionism" is attributed largely to Berger and Luckmann whose thesis is that people interacting with each other in society form concepts of each other's actions, and these concepts ultimately become habituated into roles enacted by people in relation to one another. Knowledge of reality becomes rooted within the society and in this manner, reality is socially constructed through language.[11] Berger and Luckmann's framework is attractive to researchers who study how social forces inscribe individuals' conceptualizations of health and illness, and how nurses, and by extension the discipline of nursing, undertake knowledge development and practice with people.

Social constructionism provides me with a perspective to focus on a person's articulated and non-articulated aspects of experience as the core empirical datum portrayed in stories and symbols. A person's reality includes all that is experienced relationally, temporally, contextually, and historically, as well as that which is languaged and not languaged. Unsayable aspects of experience are constructed and interwoven within language, and some aspects may transcend language.[12] Emphasis on language, a hallmark feature within social constructionism, considers the meanings generated by people as they collectively depict, explain, and language experiences. Bakhtin (1981) stressed both the immeasurable plurality of experience in language, and *social language*, a discourse specific to a branch of society (i.e. illness groups) within a social system at a

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[10] Gergen & Gergen's view on social constructionism grew from social interactionism. The authors emphasize how language is collectively created, sustained, and abandoned in relationships among people.

[11] Berger & Luckmann's work has guided sociologists, social scientists (Schwandt, 2001; Guba & Lincoln, 2005) and a generation of nurse researchers (Schreiber & Stern, 2001).

[12] Derrida's (1967/1997) famous claim is that "there is nothing outside the text" (p. 158). He later explained that this could be interpreted to mean there is nothing beyond context. He further highlights the importance of taking into account what is excluded, denied or absent; in other words, what is not signified (Derrida, 1989; Trueit, 2005). For Derrida, what is left out is as important as what we affirm or state. I would suggest that one example of what is often left out is the unsayable, and the sayable is what we affirm. In agreement with Derrida, I suggest that our reality is not limited to language.

point in time. Emphasis of language in social constructionism nevertheless falls short from acknowledging that language is but one way to express significance of experience.

Social constructionism complements narrative inquiry and through this lens I suggest that our lives are molded by and folded within narratives in our society. A narrative, told by a narrator, cannot be split from the social context. The researcher, in turn, balances the story told by the individual and the social context of that story (Rogers, 2007b). Incorporating a social constructionist perspective, one necessarily shifts from focusing solely on the individual to viewing the individual recursively within society.

Narrative Inquiry

Social constructionism complements narrative inquiry because our understandings of reality are developed through the stories we tell. Further, it offers a philosophical grounding for narrative inquirers to analyze how people and groups construct and uphold shared understandings through stories (M. Gergen, 2004). From this perspective, narrators construct events through stories as opposed to only referring to events.

I use the terms narrative and story interchangeably, as do other contemporary narrative inquirers (Duffy, 2007; Elliott, 2005; Polkinghorne, 1988; Riessman, 2008; Sandelowski, 1991, 1994). While a simple definition of narrative is not possible (Clandinin & Connelly, 2000; Riessman, 1993, 2008), when I use this term I mean a bounded segment of interview text about an incident (Riessman, 2008).

The approach I use in this dissertation would best be described using Riessman's term, "personal narratives." In personal narratives, inquirers share an interest in the *what* and *how* of storytelling in first-person accounts of specific aspects of people's lives. The story that I present at the beginning of this chapter is a good example of a personal

narrative. Researchers of personal narratives are interested in the following: 1) how individuals narrate meaning via various linguistic practices, 2) how narrators and listeners interact dialogically, 3) how participants make sense of experiences in relation to historical and cultural discourses, and 4) how they incorporate, oppose or alter such discourses to story themselves, their experiences, and their lives (Charon, 2006a; Chase, 2005; Mishler, 1995; Riessman, 2008). A personal narrative methodology often uses stories to explore opposing and variable hegemonic discourses or meta-narratives that we often assume to be stable forces (Chase, 2005; Mehl-Madrona, 2007).

I use personal narratives from a social constructionist perspective, meaning that the focus is not solely on the individual, but rather on the iterative interplay between the individual and the social through which narratives are constructed. Personal narratives offer an avenue to study the experiences of individuals who are living in the complexities, challenges, and disruptive life events of CKD. Further, when individuals living with CKD are invited to tell their stories, they are presented with an opportunity to convey experiences to others that may be otherwise hard to language. I assert, however, that not everything that is unsayable can (or must) be storied into language. Consideration of unsayable elements may illuminate the poly-vocality (Bakhtin, 1981) of experiences that accompany CKD and offer insights for nurses who work to support quality of life for individuals living amid this chronic and life-threatening illness.

In this narrative inquiry, I use reflexivity to become aware of the assumptions I bring to my study. By reflexivity, I refer to a "critical self-awareness about how the research was done and the impact of critical decisions made along the way" (Riessman, 2008, p. 191). Through reflexivity I consider not only my subjective engagement in the

research, but also my subjectivity (Oberg, 2004), my assumptions moulded within society.

The practice of reflexivity in nursing research has perhaps been more widely embraced than narrative inquiry. Although narrative inquiry has not been extensively used in nursing research, it offers an avenue to explore nursing's metaparadigm including human beings, environment, health, and nursing (Fawcett, 2005). Gadow (1995) explains, "narrative inquiry offers nursing an epistemology that is both ethically and aesthetically congruent with its practice of engagement" (p. 211).[13] Narrative invites consideration of a narrative mode of knowing (Bruner, 1986) from many philosophical views.

The practice or art of nursing has tremendous capacity to honour individuals' experiences. On a daily basis, nurses are in a position to honour, witness, and respond to patients' changing health. Unfortunately, stories told by patients in healthcare are frequently seen as a digression and not important (Charon, 2006a). Yet there seems to be a growing acknowledgement that patients' and families' narratives are significant and have a vital role to play in directing their healthcare and offering professionals the opportunity to bear witness to the suffering of others (Bailey & Tilley, 2002; Mehl-Madrona, 2007; Newman, 2008; Sakalys, 2003; Sandelowski, 1994; Tschanz, 2006). Recognition of the importance of narratives in healthcare may be due to a sense that patients' stories are being dominated by technology, business endeavours, and the medical model which depersonalizes experiences of illness (Frank, 2002).

Frank (2002) writes from the perspective of an individual with cancer and he cautions that not all experiences can be narrated. Offering people the time and space to

[13] Narrative inquiry offers a way of knowing through which we offer our experiences to another. "Only by addressing others as subjects, as authors of experience, can we know them in a way that does not reduce them to objects but enlists them in our explorations and joins them in theirs" (Gadow, 1995, p. 213).

articulate their needs will not automatically produce a coherent "packaged" version of experience. Narrative is rarely that simple. One of my assumptions is that people's narratives of living with CKD will not always be tidy, consistent, comprehensible, or complete. Further, I assume that not all experiences can be translated to narratives.

I suggest that narrative inquiry in nursing may not only offer people the opportunity to story their concerns, hopes, and plans, and provide the opportunity to be heard, but also honour people living amid the complexity of health and illness. Further, it may nourish and refresh nurses who practice alongside of those who are ill. If we can offer people what they seek and desire − a space to express their stories and to be heard − we may simultaneously present nurses with what they too pursue and long for: a practice that acknowledges suffering, offers solace, and honours illness narratives (Charon, 2006a; Kleinman, 1988). Both patient and nurse desire connectedness (Sakalys, 2003).

Significance

Narrating experience involves language, what is said and alluded to through the vernacular, but I recognise some experiences cannot be narrated. It is on this latter point that I distinguish my work. I propose that unsayable aspects of experience rest both within and beyond language. Broadly, this dissertation is located in inquiry that attends to language, thought, and experience (Hartshore et al., 1994).

Healthcare professionals may not know what is unsayable for people living with CKD, yet ignoring these unknowns is clearly unhelpful (Frank, 2001). Listening for unsayable aspects of experience pertaining to living with CKD may provide insights into what is important yet challenging or impossible to discuss, and may enrich the quality of nurse-patient relationships. When nurses listen for the unsayable aspects of experience in

practice, but do not necessarily strive to have patients articulate them, they may hear stories as persons choose to tell them. I neither suggest nor argue that nurses should strive towards helping individuals articulate the unsayable aspects of living with CKD. Rather, I propose that listening to the unsayable woven within and beyond language, between the lines of the stories, may illuminate nuanced insights into what is important for people. Charon (2006a) argues there is a moral imperative within an intentional practice that encompasses listening. Frank (1997) further articulates that "listening is hard, but it is also a fundamental moral act" (p. 25).

In narrative, we may listen for sayable and unsayable aspects of experience. As the man quoted anonymously at the beginning of this chapter explains, it is "not helpful to just talk and talk." Here he references the importance of what lies beyond language. His response is to diagnose with his doctors and ask questions. In this manner, he is able to enter into conversations through speech and silence about his own care while centering upon physicians' descriptions and not his own.

I offer the findings from this study for nurses and healthcare professionals who work alongside individuals living with CKD to support them in managing their illness and creating space for them to share their stories and symbols. When we listen for the unsayable, we may have greater awareness that patients can have difficulty and may be unable to express what is most important to them regarding their illness. Such recognition may allow individuals with CKD to feel understood by those who care for them. These endeavors may augment the quality of life for people living with CKD through recognition of suffering and honoring another's experiences of illness. Ultimately, understanding unsayable aspects of CKD may enhance provision of healthcare.

Overview of Manuscripts

I present the results of this study in four papers, each of which have been submitted for publication. Each paper is written for a specific journal. The first two papers (chapters 2 and 3) are sole-authored. The second and third papers (chapters 4 and 5) are co-authored with two members from the *Re-stor(y)ing* team because data from the *Re-stor(y)ing* project is used for the secondary analysis and because the team members contribute substantively to the conceptual development of the papers.

In the first manuscript, I review the literature on the unsayable using Rodgers' (2000) evolutionary concept analysis method. A concept analysis of the unsayable has not been previously conducted in any discipline. For the reasons I previously articulated, I did not want to use Rogers et al.'s (1999) definition of the unsayable and a concept analysis allowed me to create a new definition based on multiple sources.

In the second paper, I present a qualitative meta-synthesis (Sandelowski & Barroso, 2003b, 2007) of nursing research related to the experiences of people living with kidney failure. As more qualitative nursing research has been conducted, researchers are beginning to conduct meta-syntheses of this work so that we may interpret multiple qualitative research findings and examine them for usefulness in practice. The last literature review of the qualitative nursing research was done by Polaschek in 2003. However, no one has yet synthesized the qualitative research findings in the academic literature on the experiences of people living with kidney failure.

Through the use of narrative inquiry, in the third manuscript we explore what 14 people narrate as their unsayable aspects of experience within CKD. To our knowledge, there has not been any other nursing research that has examined unsayable aspects of

experience. We have the luxury of being able to engage in a secondary analysis of 46 interviews from over 3 years, and this data offers rich narratives about living with CKD.[14]

In the fourth manuscript, we describe a narrative visual analysis (Riessman, 2008) of representational symbols that are identified and described by participants living with CKD. We find that symbols provide an alternative avenue to examine the experiences of living with CKD in a manner that does not solely rely on the spoken word.[15]

At the beginning of each chapter, I provide a foreword as an introduction to the paper. I also present a number of footnotes which focus on my own learning. These footnotes demonstrate reflexivity, provide background information, and thread these papers together as a whole. In the last chapter, I synthesize the findings from the four manuscripts and I discuss the significance of this dissertation. I conclude with consideration of the issues and questions I encounter in this research, limitations of this study, and recommendations for future research.

[14] Longitudinal data about the experiences of people living with CKD is rare. One exception is O'Brien's (1983) study, conducted almost 3 decades ago, where she interviewed people three times over 7 years. O'Brien described dialysis as a life career and she found that patients successfully learned to manage the dialysis patient role. This success, though, was fraught with dependency, uncertainty, pain, and stigma.

[15] Each of the four manuscripts is crafted for particular journals and specific audiences. Further, I acknowledge the problematic in that the first paper on concept analysis comes from an "analytico-referential" (Reiss, 1982) discourse, whereas the fourth paper on representation symbols is located in the field of aesthetics.

Chapter 2. The Unsayable: A Concept Analysis

Foreword

In this first manuscript, I report an analysis of the concept of the unsayable. In nursing there is recognition that not all experiences of illness can be fully expressed and therefore may be unsayable. However, in the discipline of nursing, the concept of the unsayable has been used minimally, and a concept analysis has not previously been undertaken to explore the relevance of the concept for nursing practice. The literature search is limited to the past five years (2005-2010), including English, peer-reviewed literature in the databases CINAHL, Web of Science, and PsychINFO. Rodgers' (2000) method of evolutionary concept analysis is used to read and analyse references according to surrogate terms, related concepts, attributes, antecedents, and consequences.

In analysis of the unsayable, I identify three surrogate terms (unsaid, unspeakable, and ineffable), one related concept (unknowable), four attributes (not being expressed through language, being alluded to through language, may be conscious, and may be unconscious), four antecedents (suffering, challenges with communication, communication in relationship, societal influences), and two consequences (responses by others, and responses by self). Based on this analysis, the unsayable seems to refer to what is not expressed yet alluded to through language and may be conscious or unconscious. Although literature on the unsayable has been developed primarily outside the discipline of nursing, exploration of the concept within nursing may assist nurses to consider situations and experiences that are challenging, elusive, and perhaps impossible for patients to language while living amid illness.

Manuscript 1

Understanding the experience of illness is a central focus of nursing and there is a growing awareness that sayable and unsayable[16] aspects of illness co-exist. Within nursing research and practice, attention has been primarily focused on the "sayable" aspects of human experience, those that can be expressed through language. However, people may not fully express their experiences of illness and therefore, certain aspects are unsayable. To date, the concept of the unsayable has been explored primarily in psychology; however, it is critically important to analyze this concept within nursing as this concept may assist nurses in considering persons' experiences that are challenging, perhaps impossible, to express. In this paper I suggest that consideration of the unsayable, which rests both within and beyond language and consciousness, may proffer insights into being with those who are living amid illness.

The aims of this study are to conduct a concept analysis, to examine the current use of the concept of the unsayable, and to identify a definition of the unsayable. Findings from the concept analysis are contextualized within the nursing literature. Further, suggestions are offered of how this concept can be attended to in nursing practice. While the unsayable may not be fully expressible, it is intertwined with language and may attend to elements of illness that are typically overlooked. Rainer Maria Rilke (1903/1986) seems to have articulated this best: **"**Things aren't all so tangible

[16] When I first began to work on this paper, I had written unsayable metonymically as "un-say(able)." Metonymy refers to the space between opposites which are associated, and thus offer possibilities and multiple meanings at the same time (Aoki, 2005; Bruce, Sheilds, & Molzahn, 2011). An example of a metonymy is when a person uses the term "Washington" in reference to the US government. The un-say(able) represents concurrent interpretations including unsayable, sayable, able, unsay, and say. Over time, I felt like the use of brackets and a dash in writing this word seemed to either confuse readers or "put them off." So, I let go of the metonymic format of writing "un-say(able)," but I still believe that the concept of the unsayable can be conceptualized metonymically to encompass multiple interpretations at the same time.

and sayable as people would usually have us believe; most experiences are unsayable, they happen in a space that no word has ever entered" (p. 4).

Background

If we assume that the primary concern of the discipline is the interconnections among human beings, environment, health, and nursing (Fawcett, 2005), then understanding of illness experiences is foundational to nursing knowledge development.[17] Frank (2001) aptly argues that "the problem for ill people is ruling relations' insistence that all can be spoken...but [research] refuses to acknowledge that aspects of suffering remain unspeakable" (p. 358). It is important then for nurses to understand both the sayable and unsayable aspects of human experience of illness. Much of nursing research in this area has focused on broader issues of communication.[18] One assumption is that nurses' communication skills offer therapeutic means to connect with individuals; this assumption is based on the beliefs that listening is helpful and that all patients' illness experiences can be communicated. Within the health care system, patients are expected to express their experiences as clearly as possible[19], and if certain experiences are not put

[17] Disciplinary knowledge in nursing may advance when the unsayable is acknowledged alongside of the sayable experiences of illness which are central to the focus of nursing.

[18] In nursing, there has long been a focus both on communication as well as being with people amid health and illness. It is necessary to clarify and refine the concept of the unsayable and add to the knowledge base of communication within nursing. Communication has been a key component in nursing, taken up internationally within nursing theories, practice settings, and in nurse-person relationships (McGeehin Heilferty, 2009; McGilton et al., 2009). In this way, communication has been conceptualized to articulate how a nurse may care for an individual, gather and/or transfer important information, and assist a person to express questions, concerns or hopes. The discipline of psychology has significantly influenced how communication has been conceptualized within nursing. The focus has been on cognition, behavioural interventions, assessments, and outcomes (see McGilton et al., 2009).

[19] Individuals receiving care for their health are taught that one way to positively self-manage their illnesses is through learning the skills of "good" communication. For example, in Lorig et al.'s (2006) book on self-management of chronic conditions, the authors have provided technical steps for individuals to follow. An example includes "communicating your symptoms accurately" (p. 14) with your doctor, nurse, and other healthcare professionals because they may not be able to help if the problems are not well described. Given Lorig et al.'s international influence on self-management of illnesses and given that self-management groups are being run by lay-leaders world-wide, it is clear that their messages (Lorig, Gonzalez & Laurent, 1999) are meeting a need within the population.

into language, nurses have diagnosed people as having impaired communication, being in a state of denial, or being noncompliant (Doenges, Moorhouse, & Burley, 1995). Thus, if nurses perceive a lack of communication, topics left unsaid may be pathologized in the interests of *explanation*. By narrowly focusing on communication, we fail to recognize that not all experiences of illness can be fully expressed.

In psychology, there is a growing recognition that attention has been on the sayable, on voice and communication (Adams, 2010; Gentile, 2006; Kruger, 2005). This focus dates back to the Enlightenment and the emergence of positivistic perspectives and scholars who argued that the natural world was interpreted through the physical senses in discovery of knowledge (Adams, 2010; Oldnall, 1995). As a result, that which is not voiced is easily overlooked. An unequal binary of the sayable/unsayble has marginalized elements of life that are challenging or perhaps impossible to communicate (Adams, 2010).

Interactions with people regarding their illnesses are of prime importance to nurses; yet, like researchers and practitioners in psychology, we have focused our attention on the sayable. However, in engaging with people experiencing illness, nurses are faced daily with health and illness experiences that are profound and unspoken (birth of a child, pain and anguish of affliction and loss). Nurses have the opportunity to be with, listen, or bear witness as patients hear the unthinkable: "It is cancer; based on statistics, you have one month left." Nurses are with people in the everyday, unsayable moments. To date, however, there has been little if any exploration of the unsayble within

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Although communication is deeply valued in nursing and patients are frequently educated and disciplined (Mills, 2004) to speak of their illness experiences, I would also agree with Lorig et al. (2006) and Siemens (2001) who have articulated that healthcare professionals often feel that they are too busy or important to take the time required to talk with persons. Therefore, individuals' questions or concerns may either not be acknowledged or not voiced.

the nursing literature, a gap that must be attended to if nurses are to advance disciplinary knowledge. The first step in attending to this gap is to conduct an evolutionary concept analysis of the unsayable.

To date, a concept analysis of the unsayable has not been published.[20] There are a number of reasons supporting the need for such an examination and addressing this gap in the literature. First, the concept of the unsayable in nursing is new; thus, there is a need for the concept to be clarified and defined. Second, this analysis expands the range of existing concepts used in nursing research and practice. Third, nurses need concepts to reflect their practice that honour individuals' complex experiences which are not easily voiced and perhaps, unsayable.[21]

Concept Analysis

Within nursing there is a well-developed body of knowledge on concept analyses (Hupcey & Penrod, 2005; Rew et al., 2005; Risjord, 2009; Rodgers, 2000; Walker & Avant, 2005). Rodgers' evolutionary concept analysis method was selected for this examination of the concept of the unsayable because it is inductive and incorporates multiple perspectives and contexts related to a concept. Further, Rodgers' method acknowledges that concepts are not static.

Concepts are expressed through words to communicate and share meanings (Rodgers, 2000; Walker & Avant, 2005). In Rodgers (2000) view, concepts are dynamic, context-dependent, and open to change.[22] Therefore, I am not approaching this analysis with the intention of demarcating what the unsayable *is* or *is not*. Rather I will describe

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[20] This paper offers the first report of a concept analysis of the unsayable.

[21] My bias is that not everything that is important for persons can be (easily) communicated, nor should nurses expect that persons will always be able to do so.

[22] While concepts are individual in nature, our society significantly influences our processes of abstraction and association with other types of expression (Rodgers, 2000).

a context rich in diversity and breadth which spans a number of disciplines. Further, in light of Risjord's (2009) forms of concept analysis, in this paper, I consider the unsayable from a theoretical perspective in order to "make explicit both the theoretical role of the concepts and its relationship to observation or practice" (p. 689) as represented in scientific literature.[23]

The methods used in this analysis are based on Rodgers' (2000) evolutionary method involving six main activities (with the exception of an exemplar):

1) identify the concept (including surrogate terms);
2) select and identify the sample for data collection;
3) gather data to identify the related concepts, attributes, antecedents, and consequences incorporating contextual influences;
4) analyze data;
5) develop an exemplar of the concept (if appropriate);
6) identify implications for future development of the concept.

Data Sources

This concept analysis of the unsayable is based on a systematic review of the literature using the terms: unsayable, unsaid, unspeakable, and ineffable within CINAHL, Web of Science, and PsychINFO data bases conducted between October, 2009 and October, 2010. I documented each reference, keeping an audit trail of decisions made during the extensive literature search. I found 60 references through CINAHL, 680

[23] Theoretical analysis of a concept may also add to theory development as conceptual terms are illuminated and theorists may incorporate such innovations in future work (Risjord, 2009).

references in Web of Science, and 407 references in PsychINFO.[24] All 1147 articles were filtered and screened according to the following inclusion criteria:

- articles written in English;
- peer-reviewed literature;
- research articles/books/dissertations;
- book reviews (to consider the referenced book for inclusion);
- literature published between 2005 and 2010; and
- texts from the disciplines of nursing, medicine, and psychology.

Exclusion criteria were:

- studies without available abstracts; and
- editorials/opinion pieces/commentaries.

Thirty-five articles/book chapters and three books fit the inclusion criteria, and each was reviewed. With further examination, I determined that three articles and two books were not relevant due to their focus or content. One additional book (Frankl, 1959/1985) and one article (Rogers et al., 1999) were added as landmark pieces (Rodgers, 2000) because they were repeatedly referenced. In total, 35 references met the inclusion criteria. References were grouped according to the discipline of the first author: 28 texts were written by psychologists, five by physicians, and two by nurses.

Findings

A summary of the findings are presented in Table 1. Key elements including surrogate terms, related concepts, attributes, a definition of the concept[25], antecedents, and consequences are described below in greater detail.

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[24] Rodgers (2000) identified that researchers may reduce a sample to attain a manageable data set by "constricting the time frame, choice of disciplines, or choice or literature sources" (p. 90).

Table 1. Summary of Analysis

Surrogate terms
Unsaid
Unspeakable
Ineffable
Related concepts
Unknowable
Attributes
Not being expressed through language
Being alluded to through language
May be conscious
May be unconscious
Definition
The unsayable is that which is not expressed yet alluded to through language and may be conscious or unconscious
Antecedents
Suffering
Challenges with communication
Communication in relationship
Societal and cultural influences
Consequences
Responses by others
Responses by self

Surrogate Terms

Surrogate terms discussed in the literature included the unsaid, unspeakable, and ineffable. (See Table 2 for the supporting literature.) Throughout the literature, the unsayable and the three surrogate terms were consistently used interchangeably by the majority of authors, with the exception of Rogers et al. (1999). Given that these terms were used interchangeably, all surrogate terms were used as search terms with the databases.

[25] I had specifically chosen not to use Rogers et al.'s (1999) definition of the unsayable and one of the benefits of engaging in a concept analysis was that I could create a new definition of the unsayable.

Table 2. Literature Support for Surrogate Terms

Attributes	Authors
Unsaid	Koppe, 2010; Parks & Strohman, 2005; Rubin & Winrob, 2010; Schwappach, 2008; Shoham, 2009; Todorova, 2007; von Hippell & Gonsalkorale, 2007
Unspeakable	Adams, 2010; Allphin, 2007; Ehrensaft, 2008; Gentile, 2006; Hill, 2007; Kruger, 2005; Livingston, 2006; Märtsin, 2010; Mitchell, 2009; Nye, 2008
Ineffable	Cunningham, 2008; Downing, 2007; Flegel & Anderson, 2008; Graffigna & Olson, 2009; Harrell, 2005; Horner, 2006; Klein, 2005; Mather, 2008; Ready, 2010; Rominger, 2010; Rykov, 2008; Vivona, 2006

Related Concepts

Concepts are never merely black or white; rather, their boundaries are arbitrary, blurred and they bump up against related concepts. In the review of the literature, one related term, the unknowable, did not share the same attributes. The unknowable is broader than the unsayable, focusing on "what is known and what is not known" (Mitchell, 2009, p. 115). It is a related concept because it emphasizes the mystery of that which is not expressed through language. The unknowable locates the unsayable contextually within a broader base of knowledge (Rodgers, 2000).

Attributes

Related to the unsayable I identified four attributes: 1) not being expressed through language; 2) being alluded to through language; 3) may be conscious; and 4) may be unconscious. In Table 3, I provide the references for each attribute, thereby creating an audit trail of the analysis. I identified attributes through two questions posed by Rodgers (2000): "What are the characteristics of (the concept)? What is this "thing" the writer is discussing?" (p. 91).

Table 3. Summary of Literature Support for Attributes

Attributes	Authors
1.Not being expressed through language	
Not said/named or missing	Allphin, 2007; Frankl, 1959/1985; Kruger, 2005; Livingston, 2006; Rogers et al., 1999; Rominger, 2010; Rubin & Winrob, 2010; Rykov, 2008; Schwappach, 2008
Beyond words/too great for words	Cunningham, 2008; Ehrensaft, 2008; Flegel & Anderson, 2008; Horner, 2006; Klein, 2005; Mather, 2008; Mitchell, 2009; Ready, 2010; Rogers, 2007a; Rykov, 2008; Shoham, 2008; Vivona, 2006
Difficult to say	Downing, 2007; Flegel & Anderson, 2008; Graffigna & Olson, 2009; Klein, 2005; Rogers, 2007a; Rogers et al., 1999
A private experience that is a part of being human	Harrell, 2005; Ready, 2010; Vivona, 2006
Not said due to being socially inappropriate	Graffigna & Olson, 2009; von Hippell & Gonsalkorale, 2007
Others don't want to hear about it	Graffigna & Olson, 2009; Rykov, 2008
Knowledge too dangerous to discuss	Allphin, 2007; Lieberman & Van Horn, 2009; Rogers et al., 1999
A part of our functional multi-voicedness	Adams, 2010
Memories of having said something that you have not said	Parks & Strohman, 2005
2. Being alluded to through language	
Relies on an interconnection with the said	Flegel & Anderson, 2008; Rogers, 2007a, 2007b; Rogers et al., 1999; Rominger, 2010; Rykov, 2008; Rubin & Winrob, 2010; Schick Makaroff et al., 2010; Todorova, 2007; Vivona, 2006; von Hippell & Gonsalkorale, 2007
Paradoxically connected with communication (and non-communication)	Adams, 2010; Ehrensaft, 2008; Schwappach, 2008; Shoham, 2009
Moves towards speech and away from speech at the same time	Rogers, 2007a
A distinctive form of language	Rogers, 2007b
An implicit part of everyday functioning	Märtsin, 2010
Space between words	Todorova, 2007

3. May be conscious	
Connected with consciousness	Livingston, 2006; Märtsin, 2010; Nye, 2008; Rogers, 2007a, 2007b; Rogers et al., 1999; Todorova, 2007
4. May be unconscious	
Associated with unconsciousness	Allphin, 2007; Ehrensaft, 2008; Horner, 2006; Livingston, 2006; Märtsin, 2010; Parks & Stroham, 2005; Rogers, 2007a, 2007b; Rogers et al., 1999; Todorova, 2007
A non-narratable dimension of the psyche	Adams, 2010
Due to social reasons	Livingston, 2006

The first attribute of the unsayable is "not being expressed through language". In a range of ways, the unsayable is characterized as inexpressible. For example, experiences are not named/said, but are missing (Allphin, 2007; Frankl, 1959/1985; Kruger, 2005; Livingston, 2006; Rogers et al., 1999; Rominger, 2010; Rubin & Winrob, 2010; Rykov, 2008; Schwappach, 2008) or difficult to express (Downing, 2007; Flegel & Anderson, 2008; Graffigna & Olson, 2009; Klein, 2005; Rogers, 2007a; Rogers et al., 1999). Individuals may also have "memories of having spoken when they have not" (Parks & Strohman, 2005, p. 120). The unsayable also inherently extends beyond language or may be too great for words (Cunningham, 2008; Ehrensaft, 2008; Flegel & Anderson, 2008; Horner, 2006; Klein, 2005; Mather, 2008; Mitchell, 2009; Ready, 2010; Rogers, 2007a; Rykov, 2008; Shoham, 2008; Vivona, 2006). The unsayable is an intrinsic aspect of being human (Harrell, 2005; Ready, 2010; Vivona, 2006), a part of our "functional multi-voicedness" (Adams, 2010, p. 358). Further, there is a relational context to the unsayable in the understanding that others may not or cannot hear of our experiences (Graffigna & Olson, 2009; Rykov, 2008), or they may interpret that expression is "socially inappropriate" (von Hippell & Gonsalkorale, 2007, p. 499) or "socially taboo" (Graffigna & Olson, 2009, p. 793). Such unsayable knowledge is at

times considered too dangerous to talk about with others (Allphin, 2007; Lieberman & Van Horn, 2009; Rogers et al., 1999).

The second attribute is "being alluded to through language". This attribute paradoxically highlights the unsayable as being interconnected with the sayable (Flegel & Anderson, 2008; Rogers, 2007a, 2007b; Rogers et al., 1999; Rominger, 2010; Rykov, 2008; Rubin & Winrob, 2010; Schick Makaroff et al., 2010; Todorova, 2007; Vivona, 2006; von Hippell & Gonsalkorale, 2007) and with communication (Adams, 2010; Ehrensaft, 2008; Schwappach, 2008; Shoham, 2009). There is simultaneous movement "towards and away from speech" (Rogers, 2007a, p. 57). The concept is alluded to as "a distinctive form of language" (Rogers, 2007b, p. 99), but one that is not directly expressed. Such articulation is a part of "our everyday functioning" (Märtsin, 2010, p. 436), referencing the "spaces between" (Todorova, 2007, p. 230) the words we say or write.

The third attribute of the concept includes aspects which may be conscious (Livingston, 2006; Märtsin, 2010; Nye, 2008; Rogers, 2007a, 2007b; Rogers et al., 1999; Todorova, 2007). Given that the majority of the authors writing about the unsayable are from the discipline of psychology, it is understandable that many would link the unsayable with consciousness, a focal point of study within that discipline. However, there are challenges to defining consciousness. Within the new discipline of "consciousness studies," many have agreed that neural processes within the brain also unfold *without* our awareness (Frith & Rees, 2007; Schneider & Velmans, 2007), and some of our mental states are inherently conscious (Tye, 2007). For the authors who attribute consciousness to the unsayable, many reference consciousness in numerous

ways; yet most (Livingston, 2006; Märtsin, 2010; Rogers, 2007a, 2007b; Rogers et al., 1999; Todorova, 2007) also paradoxically attend to unconsciousness.

Therefore, the fourth attribute of the unsayable includes aspects which may be unconscious (Allphin, 2007; Ehrensaft, 2008; Horner, 2006; Livingston, 2006; Märtsin, 2010; Parks & Stroham, 2005; Rogers, 2007a, 2007b; Rogers et al., 1999; Todorova, 2007). Unconsciousness is a state of being mentally unaware of something. For example, an element of the psyche may not be able to be expressed because it is "non-narratable" (Adams, 2010, p. 353). While the unconscious works at a personal level, it also unfolds within transpersonal and collective levels. Livingston (2006) further explained that societal influences may also constrict that which a person does not allow to enter her/his consciousness. Based on these attributes, a definition of the unsayable may be posited.

Definition of Unsayable

In the references reviewed, the unsayable was rarely explicitly defined. The concept was also used interchangeably with the surrogate terms previously identified. Based on this concept analysis and my understanding of the attributes, I suggest the following definition: The unsayable is that which is not expressed yet alluded to through language and may be conscious or unconscious.

Antecedents

Antecedents refer to "what happens before" (Rodgers, 2000, p, 91) the concept of the unsayable. Due to the philosophical perspective in Rodgers' evolutionary method of concepts as dynamic, I found that I could not always identify a linear progression "from before to after" in analysis of the concept. However, many authors did identify such

transition. Antecedents identified in the literature included suffering, challenges with communication, communication in relationship, and societal influences (see Table 4).

Table 4. Literature Support for Antecedents

Antecedents	Authors
1. Suffering	
Trauma	Cunningham, 2008; Gentile, 2006; Lieberman & Van Horn, 2009; Rogers, 2007a; Rogers et al., 1999
Horror/torture	Ehrensaft, 2008; Frankl, 1959/1984; Mitchell, 2009; Nye, 2008; Rogers, 2007a
Illness	Ready, 2010; Rykov, 2008
Pain and suffering	Kruger, 2005; Mitchell, 2009
Near-death experience	Rominger, 2010
An undesirable or unsafe event	Schwappach, 2008
2. Challenges with communication	
Speech fails	Rogers, 2007a; Shoham, 2009
Lack of discussion and information	Rubin & Winrob, 2010
Lack of moral space to discuss concerns	Schick Makaroff et al., 2010
Characterized by non-communication	Schwappach, 2008; Shoham, 2009; Vivona, 2006
Avoiding a sensitive topic	Koppe, 2010
3. Communication in relationship	
Language/communication between people	Allphin, 2007; Harrell, 2005; Mather, 2008; Rogers, 2007a, 2007b
An aim towards verbalization	Hill, 2007; Märtsin, 2010
Non-verbal responses	Livingston, 2006; von Hippell & Gonsalkorale, 2007
4. Societal and cultural influences	
Societal privileging of language/speech	Adams, 2010; Gentile, 2006; Horner, 2006; Kruger, 2005; Rogers et al., 1999; Rykov, 2008; Vivona, 2006
Social discourses of what is and is not acceptable	Klein, 2005; Rominger, 2010; Rubin & Winrob, 2010; Todorova, 2007
Socially taboo topics	Graffigna & Olson, 2009; Schwappach, 2008
Social interactions	von Hippell & Gonsalkorale, 2007

The first category of antecedents is suffering. A broad range of diverse forms of suffering is discussed in the literature, the most severe including trauma (Cunningham,

2008; Gentile, 2006; Lieberman & Van Horn, 2009; Rogers, 2007a; Rogers et al., 1999), horror, and torture (Ehrensaft, 2008; Frankl, 1959/1984; Mitchell, 2009; Nye, 2008; Rogers, 2007a). Suffering frequently seen in healthcare includes illness (Ready, 2010; Rykov, 2008), pain (Kruger, 2005; Mitchell, 2009), "near-death experiences" (Rominger, 2010, p. 18), and "undesirable" (Schwappach, 2008, p. 2) or unsafe events in hospitals.

The second grouping of antecedents is challenges with communication. The need for communication comes from a "lack of discussion and lack of information" (Rubin & Winrob, 2010, p. 738) or "a lack of moral space to discuss concerns" (Schick Makaroff et al., 2010, p. 570). Challenges arise where "speech fails" (Rogers, 2007a, p. 8), when one "cannot say what it really is" (Shoham, 2009, p. 521), or where there is non-communication (Schwappach, 2008; Shoham, 2009; Vivona, 2006). The tendency to avoid a "sensitive" topic (Koppe, 2010, p. 329) also gives rise to the unsayable.

The third antecedent also refers to communication but specifically as it arises in relationships (Allphin, 2007; Harrell, 2005; Mather, 2008; Rogers, 2007a, 2007b). Even when someone may be striving to verbalize (Hill, 2007; Märtsin, 2010), the unsayable may follow. Communication between people that encompasses "non verbal responses" (Livingston, 2006, p. 316; von Hippell & Gonsalkorale, 2007, p. 498) also presents the context for the unsayable.

The fourth antecedent acknowledges the larger societal and cultural influences that come into play regarding what is deemed unsayable. The most widely discussed aspect is a societal privileging of language/speech (Adams, 2010; Gentile, 2006; Horner, 2006; Kruger, 2005; Rogers et al., 1999; Rykov, 2008; Vivona, 2006). Discourses established by our society also deem what is and is not acceptable to discuss (Klein,

2005; Rominger, 2010; Rubin & Winrob, 2010; Todorova, 2007), as well as what may be considered socially "taboo" (Graffigna & Olson, 2009, p. 793; Schwappach, 2008, p. 8). Broad social interactions with others, framed within culturally acceptable norms of what is "socially appropriate behaviour" (von Hippell & Gonsalkorale, 2007, p. 497), also determine what is regarded as unsayable.

Consequences

The unsayable has two main consequences: responses by others and responses by self. Yet each of these consequences is multifaceted. First, others respond to the unsayable in multiple ways, both supportive and unsupportive. Others may come alongside and bear witness (Frankl, 1959/1985; Hill, 2007; Mitchell, 2009) to another's unsayable aspects of experiences. They may also be present with another (Cunningham, 2008; Mather, 2008; Mitchell, 2009; Rogers, 2007a, 2007b; Vivona, 2006) and provide the opportunity to listen (Gentile, 2006; Mitchell, 2009; Rogers, 2007a) even amidst silence. Conversely, others may turn away and not be present when confronted with the unsayable (Mitchell, 2009; Rogers, 2007a; Rogers et al., 1999). Given that we are surrounded by relationships, incidents of the unsayable often unfold alongside others and impact how we respond to the unsayable.

The second consequence is one's own response. There are three potential responses that may arise for people. First, in light of encountering the unsayable, an individual may engage in personal introspection, "self-reflection" (Livingston, 2006, p. 321), self-examination (Allphin, 2007), or search for meaning (Frankl, 1959/1985; Nye, 2008). A person's response to the unsayable may have individual qualities because what is unsayable to one person may not be unsayable to another. Further, the unsayable has a

significant impact on one's "outlook on life" (Rominger, 2010, p. 21); thus, it has personal significance.

Second, alternative representations of the unsayable are demonstrated through verbal articulation and complementary manifestations. In response, we struggle to express the unsayable in speech (Adams, 2010; Hill, 2007; Horner, 2006; Klein, 2005; Koppe, 2010; Lieberman & Van Horn, 2009; Livingston, 2006; Märtsin, 2010; Rogers, 2007a; Mitchell, 2009; Rominger, 2010; Rubin & Winrob, 2010; Todorova, 2007; Vivona, 2006). In verbalization of the unsayable, we may invoke negation (or the opposite such as "not-" or "un-") (Rogers, 2007a, 2007b; Rogers et al., 1999; Shoham, 2009; Todorova, 2007; Vivona, 2006) or revision to speech (Rogers, 2007a, 2007b; Rogers et al., 1999; Todorova, 2007). "Smokescreens" are also used to divert attention to a safer place (Ehrensaft, 2008; Graffigna & Olson, 2008; Kruger, 2005; Rogers, 2007a, 2007b; Rogers et al., 1999; Shoham, 2009 Todorova, 2007). The unsayable may also be expressed through the use of narrative or story (Adams, 2010; Downing, 2007; Kruger, 2005; Mitchell, 2009; Rogers 2007a, 2007b; Todorova, 2007).

Additional response by the individual may also surface in a complementary fashion to verbal articulation. Examples include expression through play (Lieberman & Van Horn, 2009; Rogers, 2007a), physical manifestation (Ehrensaft, 2008; Gentile, 2006; Kruger, 2005; Lieberman & Van Horn, 2009; Livingston, 2006; Rogers, 2007a; Rominger, 2010; Todorova, 2007), metaphor (Harrell, 2005; Mitchell, 2009; Rogers et al., 1999; Vivona, 2006), poetry/creative writing (Harrell, 2005), music (Ready, 2010; Rogers, 2007a; Rykov, 2008), and art (Cunningham, 2008; Downing, 2007; Rominger, 2010; Rogers, 2007a).

Third, one's response to the unsayable may alternatively remain inexplicable. An individual may respond through silence (Adams, 2010; Cunningham, 2008; Koppe, 2010; Kruger, 2005; Rogers, 2007a, 2007b; Rogers et al., 1999; Schick Makaroff et al., 2010; Schwappach, 2008; Todorova, 2007). Reactions may also include "questioning whether to tell" (Rominger, 2010, p. 21), or choosing not to speak (Schwappach, 2008; von Hippell & Gonsalkorale, 2007). A person may also be denied the opportunity to speak (Hill, 2007). The unsayable may remain inexplicable because it is impossible to articulate (Kruger, 2005; Märtsin, 2010; Mather, 2008; Rogers, 2007a; Rykov, 2008; Shoham, 2009; Todorova, 2007; Vivona, 2006), unthinkable (Allphin, 2007; Graffigna & Olson, 2009), or not possible to put into words (Märtsin, 2010; Schwappach, 2008). When it remains unnamed, a person "may not be able to create meaning at all" (Kruger, 2005, p. 18). If the unsayable remains inexplicable, it does not mean that it cannot be expressed through alternative representations.

Consequentially, when the unsayable remains inexplicable, in some circumstances there is emotional wounding. Experiences range from feeling no control (Ehrensaft, 2008), "misunderstood" (Hill, 2007, p. 13), pain, anger, or hurt (Allphin, 2007; Rogers 2007a), "rendered mute" (Gentile, 2006, p. 311), lost, alone, unheard, or shame (Livingston, 2006; Rykov, 2008), forced to speak too early (Ehrensaft, 2008; Kruger, 2005; Rogers, 2007a), "dread" (Livingston, 2006, p. 321), or fear (Graffigna & Olson, 2009; Rominger, 2010; Schwappach, 2008). Overall, the consequences of the unsayable surface in personal responses, as well as in the responses of others, and highlight the importance for nurses to acknowledge experiences that are challenging, elusive, and perhaps impossible for individuals to language while living amid illness and suffering.

Limitations

The analysis was limited by focusing on research from the disciplines of nursing, medicine, and psychology. Inclusion of research prior to 2005 from the previously mentioned disciplines, along with additional disciplines, would broaden the analysis. There is also the potential that not all sources which fit the inclusion criteria were located. In an effort to minimize this limitation, a resource librarian was consulted to ensure that the databases were used efficiently. Further, due to the subjective nature of inductive interpretation, audit trails for decision-making and analysis were maintained.

Rigor

Use of Rodgers' (2000) evolutionary method provides a framework for synthesizing literature. Although Rogers views concepts as dynamic, an undercurrent of linearity may be perceived. As previously noted, I reviewed texts where authors did not consistently identify a linear progression from antecedents to consequences of the unsayable. The findings from this concept analysis are not advanced in a linear model but rather as open to change (Rodgers, 2000).

Discussion

As a result of this concept analysis, the unsayable is defined as that which is not expressed yet alluded to through language and may be conscious or unconscious. This definition is based on literature primarily from psychology, with fewer texts from medicine and nursing. Disciplinary influences from psychology have clearly influenced the use and development of the concept. Therefore, it is imperative to acknowledge two assumptions from psychology intrinsic in this definition in order to consider how nurses

may respond to the unsayable in practice. In this discussion I will further the notion of the unsayable in the context of nursing.

The first assumption in psychology is that we may identify evidence of the unsayable, even if it is only signified by a void in language, or alluded to through language. This evidence may or may not be perceived within our consciousness. In other words, we are not always conscious of what is unsayable. While psychologists focus on analyzing the unsayable, this is not the focus in nursing. Rather, what is important is for nurses to listen and be aware of the significations that represent the unsayable, i.e. presence or absence of the unsayable. Recognition of the antecedents and attributes of the unsayable may alert nurses to recognize when this may be unfolding for patients. There may be times for nurses to talk with individuals about the unsayable, but this will depend on multiple factors including individuals' willingness, timing, or opportunity. Consequently, when nurses are attuned to this concept, they may purposefully consider how they respond to aspects of illness and suffering[26] that are unsayable.

Given that this first assumption is not of central importance to nursing, an alternative postulation is that nurses may respond through being present with patients during their unsayable aspects of experiences of illness.[27] "Being with" versus "bringing into consciousness" shifts the assumption from a state of "doing" to "being". The concept of presence or being with others in their experiences of illness has long been acknowledged within nursing. Finfgeld-Connett (2006) conducted a meta-synthesis on

[26] Unsayable aspects of suffering may not be within the societal discourses of what is acceptable to discuss; thus, they are outside of the societal privileging of speech.

[27] Nurses may be present for patients during their unsayable aspects of experiences pertaining to illness and their presence may include communication, but it does not presume to be the sole focus.

the concept of presence and found that the attributes of presence include "an interpersonal process that is characterized by sensitivity, holism, intimacy, vulnerability and adaption to unique circumstances" (p. 710). Presence is also a component of several nursing theories. For example, in the Humanistic Nursing theory, presence is "the gift of one's self [that] cannot be seized or called forth by demand, it can only be given freely and be invoked or evoked" (Patterson & Zderad, 1988, p. 16). In the theory Health as Expanding Consciousness[28], presence is a "process-oriented intersubjectivity [focusing] on a deep exploration of relationship" (Newman, 2008, p. 54). In the Theory of Humanbecoming, true presence "is a special way of "being with" in which the nurse bears witness to the person's or family's own living of value priorities" (Parse, 1992, p. 40). Mitchell (2009) further proposes that the practice of true presence is an example of the unspeakable, a surrogate concept of the unsayable, which attends to nurse-person relationships.[29]

The second assumption is that the unsayable *should* be resolved through language or other forms of expression. In the psychology literature, there is a consistent incorporation of communication as behavioural, psychotherapeutic endeavours (Rogers, 1985) to integrate the unsayable with the sayable and express the unconscious. If it is not expressed and remains inexplicable, the consequences include emotional wounding and harm. While psychology focuses on psychotherapeutic expression of the unconscious to avoid wounding, it is not of central importance for nurses to assist patients to seek

[28] Newman's theory draws upon the work of de Quincey who purported that an avenue to knowing all levels of consciousness is through a non-sensory, non-linguistic connection via presence and meaning. Presence as distinct from linguistic action is reminiscent of the attribute of the unsayable, which is, not being expressed through language.

[29] I use the word "presence" here in reference to being with another and witnessing an individual's experiences within health and illness and not in reference to critiques of Western epistemology such as those raised by Derrida or Heidgger. These two authors examined presence as "what is," the relationship between presence and absence, or presence as transcending binaries (Heidegger, 1977; Trueit, 2005).

resolution of the unsayable, nor to avoid harmful consequences that may ensue. From a nursing perspective, an alternative supposition is that profound unsayable aspects of experiences (such as birth, anguish, or death) are inherent within life and do not always require resolution. Further, whether expressed or not, the unsayable does not always result in harm. Rather, what is vital is that, first, nurses recognise that the unsayable exists for patients within their experiences of illness and suffering and that, second, as nurses, they may witness this unfolding. Nurses have openings to bear witness to patients at such times in life. The act of witnessing acknowledges that the unsayable exists, and nurses need not necessarily seek resolution. At this time, we do not know what best practice might look like in attending to the unsayable in nursing practice, and further research in this area is warranted.

Nursing literature addresses how to bear witness to the unsayable. Bearing witness means to offer one's presence and, in so doing, risk experiencing suffering oneself (Cody, 2007).[30] Cody describes bearing witness as a paradoxical experience present alongside of a choice to not bear witness: a turning away from suffering, thus devaluing relational connectedness. Nurses have an option to ask (or not ask), tell (or not tell), and in this manner, bearing witness offers a way to create space in practice which attends to the unsayable. In Tschanz's (2006) study, nurses in palliative care spoke of

[30] A social, contextual element fostering the unsayable in practice may be that people do not perceive willingness from nurses to listen. Thus one aspect of the unsayable may be left unsaid as missing information if people do not perceive that nurses will listen or bear witness to their experiences. Josselson (2007) addressed a similar issue in research: "My experience is that the student who reports that the participant "didn't want" to talk about something is usually reporting what he/she was unable to hear. Most participants will talk about whatever they think can be heard. We listen people into speech" (p. 547).

Josselson identified that, through listening, the unsayable has the potential to become articulated. However, there may be other aspects of the unsayable. I would suggest that not all experiences can be fully expressed; neither may it be desirable to express all aspects of the unsayable. As the concept analysis findings show, the unsayable is discernable in both a lack of expression and through allusions in language. What has not been widely discussed in nursing is the recognition that not all experiences of illness and suffering can be fully expressed.

telling, questioning, reminiscing, and sharing medical information but also of being silent, watching, and listening to persons who were living their dying. Nurses have the unique opportunity, privilege, and ethical responsibility to bear witness "to the most profound and intimate human experiences, to the joys, sorrows, wonders, and mysteries of life" (Drought, 2001, p. 238). Speech cannot fully encompass that to which we bear witness.

Why is the unsayable important for nurses and nursing care? This question is significant in that "it is necessary to address activities surrounding the unspeakable and unknowable because they represent the realities of nurses when they are with persons who are typically living through situations that transform life" (Mitchell, 2009, p. 106). Like Mitchell, I would suggest that nurses are involved in activities with people that are beyond words, indescribable, and may never be fully resolved through language. Acknowledging the unsayable allows nurses not only to understand the complexities inherent in the lives of people living with illness and suffering, but also to seek to support them during these times of uncertainty. Given that the unsayable will not always be resolved through speech, nurses may respond through other avenues of expression including listening to stories, bearing witness, and being present. Nurses must remember that they have a choice whether they will attend to or turn away from people who are experiencing unsayable suffering. With greater appreciation of the unsayable aspects of illness, nurses may restrain from quickly labelling people's expressions, or lack thereof, according to nursing diagnoses. It is further significant to note that people in the healthcare system have been "disciplined" (Mills, 2004) to share specific aspects of their

experiences with healthcare professionals, and they may perceive that other details of their suffering should not be expressed to nurses.

Aspects of illness also arise in everyday nursing practice through narrative communication, also referred to as illness narratives, through which individuals navigate the terrains of illness (Frank, 2002; Kleinman, 1998; Mattingly, 2007).[31] Individuals often welcome opportunities to tell their stories to nurses, yet not everything can always be expressed, and may be unsayable within suffering and illness. As Frank (2009) explains, "ill people need stories to express as much as they can about these inexpressible, mysterious bodies, which have been the often unnoticed source of life, and then become the all too inescapable locus of dying.…Narrative also allows the unsayable just to be, in its silence" (p. 167). Inviting individuals to tell stories in practice may create an avenue of expression for experiences that are otherwise hard to language.

Attending to the unsayable in practice may provide re-conceptualization of nurse-person interactions through listening to stories, bearing witness, and being present.[32] As such, nurses may be assisted to acknowledge that facets of suffering may be both sayable and unsayable and that these seeming contradictions coexist within illness. With these understandings of the unsayable, which rest both within and beyond language and consciousness, disciplinary knowledge of experiences of illness and suffering may advance.

Experiences of illness and suffering inherently possess both sayable and unsayable aspects. Understanding and responding to unsayable elements of illness

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[31] The term "illness narrative" provides insight into how an individual, family or social group understands, responds, and experiences illness.

[32] Such a re-conceptualization of nurse-person interactions shifts away from a focus on behavioural interventions towards honouring another person and perhaps towards the shared human experience of suffering.

experiences in nursing practice has not been widely discussed. The aim of this paper was to conduct a concept analysis of the unsayable, examine the current use of the concept, and identify a definition. Based on this concept analysis, I propose the following definition: The unsayable is that which is not expressed yet alluded to through language and may be conscious or unconscious. From an evolutionary perspective (Rodgers, 2000), concepts change over time and this may certainly be true for the unsayable. Exploration of the concept within nursing is critical so that nurses may consider experiences that are challenging, elusive, and perhaps impossible for patients to language while living amid illness. While the unsayable may not be fully expressible, it is intertwined with language and understanding it more fully may help nurses attend to elements of illness and suffering that are typically overlooked.

Chapter 3. Experiences of Kidney Failure:[33] A Qualitative Meta-synthesis

Foreword

The purpose of this manuscript is to provide a qualitative meta-synthesis on the experiences of kidney failure in the nursing literature. I am specifically interested not only in studying what other researchers have found regarding the experiences of kidney failure, but also in synthesizing these results. The database searches are not limited by date; yet only 13 texts meet the inclusion criteria. Meta-synthesis of the texts suggests that people with kidney failure have experiences of paradoxical nature including occurrences of restricted freedom which bring about distant connection, dependent autonomy, abnormal normalcy, and uncertain hope. When nurses are attuned to the seemingly contradictory nature of experiences of people living with kidney failure they may be better able to develop strategies which will increase quality of life.

Manuscript Two

There has been a steady increase in international consideration of the experiences of kidney failure as a chronic and life-threatening illness. Broadly, research has shifted from an "outside" to an "inside" look at the experiences of those living with chronic illnesses (Thorne & Paterson, 1998). With this shift, qualitative nursing research exploring the experiences of living with kidney failure has also grown. However, to date, no one has undertaken a qualitative meta-synthesis (QMS) to systematically examine the growing number of research texts specifically related to kidney failure. The purpose of this paper is to provide a report of a QMS on the experiences of kidney failure in nursing literature. This QMS suggests that people with kidney failure have experiences of paradoxical nature including a restricted freedom which bring about experiences of

[33] I had originally used the term "end-stage renal disease" but the journal preferred the term "kidney failure."

distant connection, dependent autonomy, abnormal normalcy, and uncertain hope. The implications of the findings are linked to practice, providing suggestions for nurses who support and care for individuals living with kidney failure.

Kidney failure or end-stage renal disease is the fifth and final stage of chronic kidney disease (CKD) involving the complete, or near complete, failure of kidney function. In this stage of CKD, the kidneys are at 15% or less of normal renal function (Kidney Foundation of Canada, 2010). People who reach this state are usually in the process of deciding about dialysis, or are already actively receiving dialysis and may be considered for a kidney transplant. Treatment of kidney failure is complex and involves hemodialysis or peritoneal dialysis, fluid and dietary restrictions, prescribed medications, and numerous medical engagements (Thomas-Hawkins, 2006). Those who are not candidates for a renal transplant have a significantly shortened life-expectancy due to comorbid conditions and decreased survival rates on peritoneal and hemodialysis (Moss, 2002; Robert Wood Johnson Foundation, 2003).

In 2009, 21,310 individuals in Canada were being treated by peritoneal and hemodialysis (CIHI, 2011a). Overall, in Canada the unadjusted five year survival rates for individuals on peritoneal dialysis are 51% and 41.4% for people on hemodialysis (CIHI, 2011a). According to the United States Renal Data System (2009), the five year survival rates for individuals on peritoneal dialysis are 33.5% and 33.9% for people on hemodialysis. These statistics clearly show that while kidney failure is a chronic illness, it is also life-threatening; however, the conventional focus has been on successful treatment using advanced technology within “a culture of death denial” (Robert Wood Johnson Foundation, 2003, p. 61). In addition, there is evidence in the literature (Charon,

2006a; Frank, 2002; Hines, Babrow, Badzek, & Moss, 1997) that living with chronic and life-threatening illness impacts quality of life. In the past decade, the experiences of people living with kidney failure have become the focal point of increasing qualitative nursing research in an attempt to understand the experiences of living with kidney failure. To date, however, a QMS has not been conducted on this topic.

With qualitative research on the rise, one might wonder why a QMS has not yet been conducted on the experience of kidney failure. There may be a few reasons for this gap. First, QMS is still a relatively new methodology within nursing and healthcare.[34] Although QMS continues to gain exposure in healthcare, only a handful of qualitative meta-syntheses have been conducted relating to chronic illness in general (Paterson, 2001; Paterson, Canam, Joachim & Thorne, 2003; Thorne & Paterson, 1998), specific chronic illnesses (Larun & Malterud, 2007), or chronic illness in specific populations (Coffey, 2006; Sandelowski & Barroso, 2003a). Second, while chronic illness is not a new concept within healthcare, the historical emergence of personal narratives of chronic illness became evident in the literature between the late 1960s and the 1980s as researchers began to turn from the dominant positivist tradition of thought.[35] Although qualitative inquiry emerged almost five decades ago, explicit qualitative research on the subjective accounts of kidney failure appears in literature only in the past two decades.[36]

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[34] Nurse researchers Stern and Harris (1985) were the original authors to use the phrase "qualitative meta-analysis" in reference to gathering data from similar qualitative studies.

[35] Early authors from multiple disciplines began to explore experiences of illness. Kleinman (1973) examined illness narratives and identified medicine as one of the first sciences that attends to human-related activities, experiences, and constructs. Giorgi (1969) also began to explore psychology as a human science. And Kuhn (1970) broadly explicated this turn in worldviews as a "paradigm shift."

[36] While qualitative research has been around for over 5 decades, the dominant view in healthcare still seems to reside within an empiricist tradition and focuses on objectivity, causality, predictability, and realism. From this perspective, subjective experience is not highly valued. Yet the tides of inquiry have started to shift to incorporate mixed methods, and interpretive modes have been gaining acceptance within the prevailing standpoint.

Given these shifts in research methodologies and ways of knowing, there is a need for an integration of research on the experiences of chronic and life-threatening illnesses, including kidney failure.

Over the past two decades, qualitative research in kidney failure has gained increasing credibility and exposure, growing in tandem with the proliferation of qualitative research as a whole. The increasing volume of qualitative research presents an opportunity and need for meta-synthesis. Polaschek (2003) addressed the need for synthesis by critically examining eight qualitative studies in a literature review. However, other than Polaschek's work, there has been no attempt to synthesize multiple qualitative research findings within the academic literature. The benefit of QMS is that it offers the opportunity for interpretation of multiple qualitative research findings that can then be examined for usefulness in practice. Thus, research synthesis offers well-founded knowledge, increasing our understanding of the collective and unique experiences of people living with kidney failure which may ultimately enhance our capacity to provide effective care and improve quality of life.

Purpose and Research Question

The purpose of this study was to examine the qualitative nursing research focused on people's experiences of kidney failure and to document the essential interpretation of this phenomenon. The research question was, "What are the experiences of people living with kidney failure?"

Study Design

QMS focuses on research integration by combining findings from qualitative studies on a similar topic. In essence, it is an inquiry aimed at developing broad

assertions achieved through interpretation and analysis of findings from extant, qualitative research which are then woven together and synthesized (Sandelowski & Barroso, 2003b, 2007; Walsh & Downe, 2005). The goal is to "create larger interpretive renderings of all of the studies examined in a target domain that remain faithful to the interpretive rendering in each particular study" (Barroso et al., 2003, p. 154). Thus, it offers a new, yet reminiscent, reading of the data.

There are several technical and methodological approaches for QMS (Sandelowski & Barroso, 2003b, 2007). In the present study, the approach employed is *reciprocal translation and synthesis of in vivo and imported concepts* as described by Sandelowski and Barroso (2007). In reciprocal translation, the reviewer engages in consistent comparison of in-study, conceptual synthesis, or the reviewer may import concepts from other studies to incorporate results. In this study, concepts from other studies were not imported to integrate the QMS findings. Rather, conceptual analyses of the included studies were constantly compared to synthesize and weave together the findings.

Search Methods

A systematic search of peer-reviewed literature, guided by Barroso et al.'s (2003) approach, was conducted using the terms "kidney disease" or "end stage renal disease" combined with the term "qualitative nursing research." The databases CINAHL, Social Science Index, Web of Science, and ProQuest (dissertations and theses) were searched from November to December, 2010. References of articles were further checked to avoid missing texts omitted by database filters. The literature search was not limited by date.

An audit trail was kept of each reference reviewed and of decisions made during the extensive literature search.

Inclusion criteria included the following: articles in English, studies that were explicitly described as qualitative nursing research, research with participants who had kidney failure, and texts that considered the subjective experiences of living with kidney failure as expressed from the viewpoint of persons living with the illness. Included texts were from nursing, meaning that they were assessed based on the discipline of the authors, due to the lack of a previous QMS on qualitative studies conducted by nurses. Exclusion criteria included the following: studies without available texts, texts by authors who studied the subjective experiences of peer-support workers or nurses/spouses/families caring for those with kidney failure, and articles that used mixed methods but either did not distinguish between qualitative and quantitative results, or used open-ended questions at the end of primarily quantitative survey designs.

Search Outcome

From the search of the databases, 153 manuscripts were identified. Figure 1 summarizes the search strategy. Seventeen papers were rejected either because they did not solely focus on people with kidney failure or they were not within the domain of nursing research. Papers were appraised based upon Sandelowski and Barroso's (2003b, 2007) typology of findings. According to this typology, only studies with findings which are considered to have "conceptual/thematic descriptions" or "interpretive explanations" (described below) are included. In reviewing the results of the search, an additional 12

studies[37] were excluded on the basis of not meeting Sandelowski and Barroso's criteria. Thirteen articles met the final inclusion criteria.

Figure 1: Search Strategy

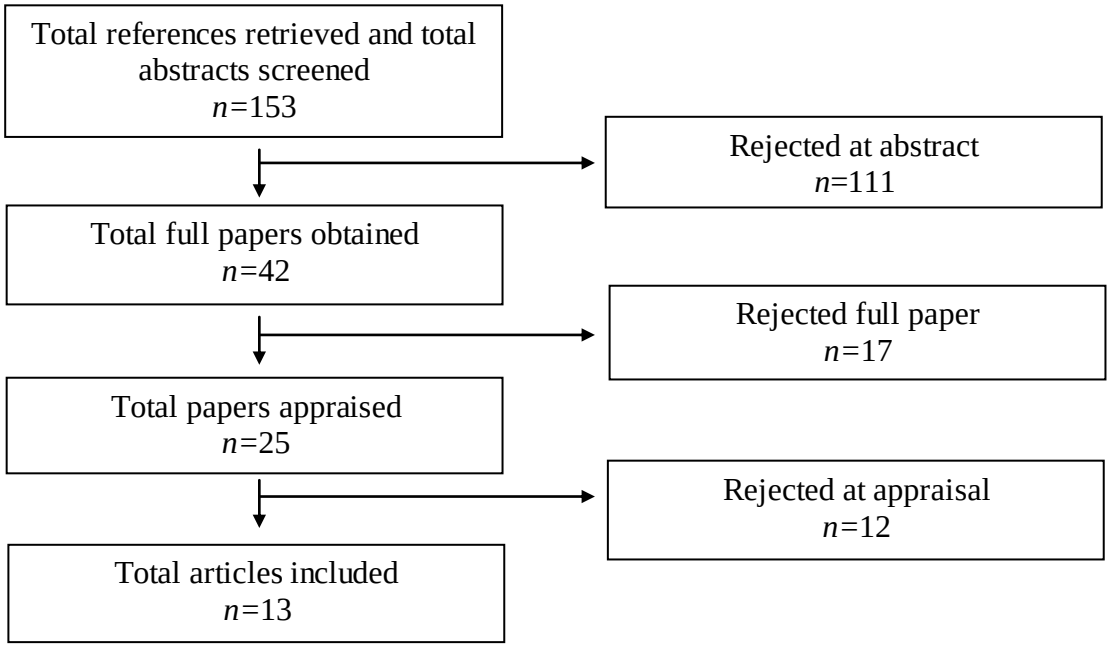

Table 5 identifies the included studies. The research was undertaken between 1990 and 2010 in Australia (1), Canada (3), Hong Kong (1), Ireland (1), Sweden (2), and the United States of America (5). In total, 252 people participated in the 13 studies. Participants from Curtin & Mapes (2001) and Curtin, Mapes, Petillo, and Oberley's (2002) articles were only counted once because the two articles were based on the same research data.

[37] The 12 excluded studies included eight that presented findings as "thematic surveys" (Charuwanno, 2005; Gibson, 1995; Kidner, 1999; Martin-McDonald & Biernoff, 2002; Molzahn, 1991; Murray, 1989; Weil, 2000; Yu & Petrini, 2010), and four as "topical surveys" (Hoothay, DeStefano, Leary, & Foley-Hartel, 1990; Landreneau & Ward-Smith, 2007; O'Brien, 1990; Stevenson, 1984).

Table 5 – Included Studies

Author(s), Year, Country	Purpose	Sample, Sampling, Methodology	Data Collection, Analysis	Typology of Findings
Clarkson & Robinson (2010), USA	Explore lived experience of patients with ESRD and determine if they had adequate education to avoid complications	10 adults; Convenience; Qualitative methodology	Interviews; Thematic analysis	Conceptual/thematic description
Curtin & Mapes (2001), USA	Describe self-management strategies of long-term survivors	18 adults; Purposive and "snowballing"; Exploratory-descriptive	Interviews; Content analysis	Conceptual/thematic description
Curtin et al. (2002), USA	Examine the processes involved in some kidney patients' ability to live long and well on dialysis	18 adults'; Purposive and "snowballing"; Exploratory-descriptive	Interviews; Content analysis	Conceptual/thematic description
Hagren et al. (2001), Sweden	Describe and characterize patients' experiences of suffering from ESRD	15 adults; Purposive; Interpretive qualitative design	Interviews; Interpretive content analysis	Conceptual/thematic description
Hagren et al. (2005), Sweden	Examine how patients suffering from CKD on hemodialysis experience their life situation	41 adults; Purposive; Qualitative methodology	Interviews; Content analysis	Conceptual/thematic description
Leung & Shiu (2007), Hong Kong	Describe experiences of Hong Kong patients awaiting transplant in China	12 adults; Purposive; Exploratory	Interviews; Content analysis	Conceptual/thematic description
Maxwell (1990), Canada	Explore factors that enhance and inhibit adaptation to hemodialysis when transplantation is	8 adult women; Purposive; Phenomenology	Interviews; Coliazzi's phenomenological analysis	Conceptual/thematic description

	not an option			
Molzahn, Bruce & Sheilds (2008), Canada	Explore how individuals with kidney failure story experiences of liminality	100 stories of living with kidney failure; Secondary data; Narrative inquiry	Narratives; Temporality, sociality, and place	Conceptual/thematic description
Moran, Scott & Darbyshire (2009), Ireland	Explore the experiences of people with ESRD undergoing hospital-based hemodialysis	16 adults; Purposive; Heideggerian phenomenology	Interviews; Qualitative interpretive approach	Conceptual/thematic description
Nagle (1998), Canada	Understand the experience and meaning of technology for people receiving hemodialysis	11 adults; Purposive; Gadamerian hermeneutics	Interviews; Hermeneutic analysis	Conceptual/thematic description
Namiki, Rowe & Cooke (2010), Australia	Understand challenges for older adults with home hemodialysis	4 adults between 60-75 years old; Purposive; Exploratory	Interviews; Thematic analysis approach	Conceptual/thematic description
Rittman et al. (1993), USA	Discover and describe the experiences of patients with chronic renal failure	6 adults; Purposive; Heideggerian phenomenology	Interviews; Hermeneutic analysis	Interpretive explanation
Walton (2002), USA	Discover what spirituality means for people on hemodialysis and how it influences their lives	11 adults; Purposive; Grounded theory	Interviews; Constant comparative analysis	Interpretive explanation

Quality Appraisal

The debate surrounding assessment of the quality of research incorporated in QMS is varied and unresolved (Sandelowski & Barroso 2003b, 2007; Walsh & Downe, 2005). In the current study, I used Sandelowski and Barroso's (2003b, 2007) typology of qualitative findings to classify the literature. Their typology involves measurement on an ordinal scale for a continuum identifying categories of data transformation, moving from

findings which are closest to the data to farthest to the data. "Conceptual/thematic description" and "interpretive explanation" are the two categories farthest from the data and include studies with findings with the greatest levels of transformation and integration. The typology is not to be used as a guide for critiquing the scholarly merits of research.

Data Abstraction

The goal of QMS is interpretive incorporation of research findings, as opposed to comparison, contrast, or evaluation of results. Sandelowski and Barroso (2007) offer a guide for data abstraction which includes aim/purpose, sample, sampling method, data collection, analysis, and findings. All details of the included studies (except findings) are summarized in Table 5. Findings are incorporated within the results of the QMS presented below.

Synthesis

Qualitative meta-syntheses encompass a merging of findings, in essence, the QMS creates a whole that is greater than the sum of its parts (Walsh & Downe, 2005). Analysis began with a close study of each text. I analyzed the findings from each research article, focusing on the key concepts and themes. After I completed this step for each article, I considered this data across the studies and visually mapped out the findings from the 13 studies. I re-read the literature as I began to explore in vivo concepts that translated and encompassed the findings of each study, all the while maintaining differences (McCormick, Rodney & Varcoe, 2003). As I considered a potential theme, I noted where and how it was evident in each study. Although I have described this process of analysis as a sequential method for simplicity, the actual process was recursive

as I returned again and again, re-reading the literature, comparing, looking for differences, similarities, correlation with themes, and new possibilities.

Each study was equally considered in articulation of the findings. However, only one study by Leung and Shiu (2007) provided support for the central theme and each of the sub-themes described below. While some studies (Curtin et al., 2002; Maxwell, 1990; Molzahn, Sheilds, & Bruce, 2008; Namiki, Rowe, & Cooke, 2010) supported four of the sub/themes, other reports (Curtin & Mapes, 2001; Moran, Scott, & Darbyshire, 2009) were focused within the sub-theme of dependent autonomy. As a result, the studies were not drawn upon equally and I synthesized the 13 studies in a range of ways in selecting the QMS findings.

Rigor

Due to the nature of the study, member checks could not be conducted with original study participants. In the interests of rigor, and cognizant of the subjective nature of the analysis, documentation of the QMS search strategy is clearly outlined not only for transparency but also with the hope that subsequent researchers might build upon these findings and possibly provide new insights. Included articles had previously undergone the process of peer review. Readers may also review these originally published texts included in this QMS to confirm the findings.

Ethical Consideration

Ethical approval by an Institutional Review Board (IRB) was not required because this is a meta-synthesis of previously published work. All reviewed studies attained IRB approval as necessary and protected the confidentiality and anonymity of all participants.

Findings

Interpreting all of the articles as a whole, I identified one main theme and four subthemes to compose the meta-synthesis. Together, the themes are expressed to affirm that experiences of kidney failure highlight the occurrences of restricted freedom which brings distant connection, dependent autonomy, abnormal normalcy, and uncertain hope. A number of authors (Curtin et al., 2002; Hagren, Pettersen, Severinsson, Lützén, & Clyne, 2001, 2005; Maxwell, 1990; Molzahn et al., 2008; Nagle, 1998) identified ambiguous and paradoxical experiences where participants simultaneously held seemingly contradictory experiences or lived in between the contradictions. The QMS themes are written in a similar fashion, and I discuss each theme below in detail. Further, the themes are expressed through the use of in vivo concepts which were used by authors in the reviewed studies. It is important to note that in vivo concepts constitute the researcher's (not the participants') representations of the data (Sandelowski and Barroso, 2003a). Although each theme is discussed in isolation for heuristic purposes, in essence, all themes coexist and are interrelated across the data.

Restricted Freedom

The most predominant theme across the literature focuses on the duality of living with the restrictions and freedoms that accompany kidney failure. The restrictions primarily focused upon the necessity of the dialysis machine, time consumed in care, restricted diet and fluids, dependence on caregivers, inability to travel or possibly work, medical costs, and reduced income. People felt restricted when, for example, their plans were put on hold, energy and strength failed with fatigue, activities and social contact decreased, and freedom was lost. Yet freedom was concurrently present because many of

these same restrictions sustained life, offered transformation, and provided hope for a transplant. Hagren et al. (2001) wrote specifically of the hemodialysis machine as a lifeline which prevented death at the cost of "restricted freedom." Molzahn et al. (2008) also identified the liminal, in-between space of "restrictions/freedom." Namiki et al. (2010) found that accommodating hemodialysis at home inherently held constraints alongside of benefits and freedom. Curtin et al. (2002) had two themes on coming to terms with "dialysis itself" and "repeated setbacks" which identified the intrusiveness of dialysis, as well as the frequent and potentially serious morbidity events that restrict and accompany kidney failure. Maxwell (1990) also wrote of the process of initially "resisting dialysis" within a process of adaptation. Dialysis was also reframed from a burden to a treatment that sustained life (Walton, 2002).

Technology played a central role as it brought both freedom and restrictions. Nagle (1998) articulated that people with kidney failure struggled to remain embodied amidst being transformed by a reluctant partnership with dialysis technology. In coming to terms with limitations and loss, people accommodated restrictions and actively sought to sustain wholeness. Loss of personhood was transformed and reconstituted because of an alliance with technology. Nagle's theme of "abiding with technology" echoed Rittman, Northsea, Hausauer, Green, and Swanson's (1993) theme "dwelling in dialysis." Both themes speak to the intimacy of being comfortable or "at home" with dialysis, despite the dependence on the technology. Like Nagle, Rittman et al. recognized that an objectification of bodily experiences accompanies a loss of personhood. But in dwelling in dialysis, individuals discovered existential meaning that extended beyond psychological attachment to technology as they became constituted in the context of their

world, and this offered a counterbalance to the dehumanizing objectification that comes with dependence on technology.

Restrictions were apparent within the desire for the freedom of a "normal" life. Normal life was curtailed by decision-making in an effort to maintain quality of life amid restrictions (Leung & Shiu, 2007). Despite constraints and restrictions to roles, Curtin et al. (2002) found that participants still recognized their intrinsic worth, which the authors expressed through the theme "self-worth: 'I'm still valuable'". Limitations and a "restricted life" (Clarkson & Robinson, 2010) accompanied a diagnosis of kidney failure and ongoing dialysis treatment. While Hagren et al. (2005) interpreted that participants spoke of "not finding a space for living" (p. 296), people living with kidney failure simultaneously attempted to manage these restrictions in their lives as they struggled in the pursuit to live a normal life (Hagren et al., 2005; Nagle, 1998).

Distant Connection

Distant connection refers to the coexistence of isolation and closeness within relationships as well as emotions that arise from living with kidney failure. For example, partnerships with spouses and healthcare professionals helped people maintain connection and freedom, but they also preserved distance through professional partnerships which "helped maintain their independence" (Namiki et al., 2010, p. 551). The theme of "connectedness" was articulated by Maxwell (1990) as being on a continuum with "being disconnected". The theme of "alone/connected" was discerned by Molzahn et al. (2008) to address participants' experiences of being alone within their supports from others. Leung and Shiu (2007) found that family relationships influenced decision-making for participants in Hong Kong. While family members witnessed

participants' suffering, the participants also felt they were a burden or in debt because they were being financially supported by family members.

Some authors focused on one aspect of disconnection or connection. For example, Hagren et al. (2005) wrote of the feelings evoked within care, specifically a sense of "emotional distance" in relationships with caregivers. An existential struggle related to the person's very existence ensued and the authors purported that this struggle revolved around the life-threatening nature of their illness and coinciding restrictions and reliance on the dialysis machine to extend life. Alternatively, Leung and Shiu (2007) noted participants' connections with and support from peers which were beneficial when people were making decisions. Walton (2002) also discovered that individuals living with renal failure identified a category of spirituality as "presence" which represented others, God, community, and nature. While the physical presence of other people was supportive, she found that a metaphysical or transcendent presence offered "an intimate connection, a sense of awe, love, and acceptance" (p. 452). Similarly, Clarkson and Robinson (2010) found that people's attitudes and strengths provided motivation, and this arose within supports from family, friends, God, prayer, church, and support groups. Connection and distance coexisted within the experiences of kidney failure and often closely relate to both restrictions and freedom.

Dependent Autonomy

Due to the requirements of consistent treatment for kidney failure, people must repetitively interact with the healthcare system.[38] Dependent autonomy primarily refers to this interaction. Nagle's concept (1998), "enduring the treatment environment,"

[38] Based on the narratives of kidney failure as expressed by people living with the illness, I have a great appreciation of the "balancing act" required as individuals balance the restrictions and freedoms associated with navigating in(dependence) in the healthcare system.

emphasized a restricted freedom and dependence on healthcare professionals to provide patients with the care that literally keeps them alive. Authors' themes reflected people's dependence on healthcare professionals to provide them with information or education so they could make informed decisions (Clarkson & Robinson, 2010; Leung & Shiu, 2007; Nagle, 1998). Further, participants desired that health care professionals provide early treatment and detection for themselves and others in the future (Clarkson & Robinson, 2010). In Hagren et al.'s (2001) subtheme, "dependence on the caregiver" was coupled with the desire to still be seen as a unique individual. This concept was also noted by other scholars (Curtin et al., 2002; Curtin & Mapes, 2001; Nagle 1998).

Experiences of kidney failure emphasized dependence on communication with healthcare professionals. Moran et al.'s (2009) major concept, "communicating with nurses: reality versus myth" (p. 23) identified that relationships rarely progressed beyond a superficial, clinical level. This same finding was echoed in studies by Clarkson and Robinson (2010), Leung and Shiu (2007), and Nagle (1998). Authors noted that shallow relationships left people with unmet expectations, disappointment, frustration, anger, and lack of satisfaction. As people felt unsupported by healthcare providers while being dependent upon them, their relationships further speak to the "emotional distance" that Hagren et al. (2005) identified in participants' relationships with caregivers. Leung and Shiu, as well as Moran et al., provided analyses which brought attention to the depersonalization that people with kidney failure experience when concerns of illness or anxiety are avoided, neither acknowledged nor addressed.

Autonomy within dependence on the healthcare system was significant in many studies. Hagren et al. (2001) expressed the sub-theme "achieving a personal sense of

autonomy" under the overarching theme "alleviation of suffering." Nagle (1998) also wrote of "wanting to have a say" in decisions of care, a comment repeated by other researchers (Curtin & Mapes, 2001; Hagren et al., 2001; Leung & Shiu, 2007). Autonomy brought about freedom within restrictions by the healthcare system. Self-management of care was also presented in themes within studies by Clarkson and Robinson (2010), Curtin et al. (2002), and Curtin and Mapes. Autonomous self-management was pursued to promote good care, retain responsibility and control, transform as long-term survivors, and engage in self-advocacy. It is not surprising that self-management was present in this literature because of the international movement within chronic illness management of individuals as self-care decision-makers (Lorig et al., 2006; Thorne, 2008; Townsend, Wyke & Hunt, 2006). What this synthesis acknowledges is that autonomy within self-care management is also dependent upon interactions with healthcare professionals and the larger healthcare system.

Abnormal Normalcy

Abnormal normalcy represents a search for "normal life" while confronting changes and restrictions that are not normal. Molzahn et al.'s (2008) theme "not normal/normal" was written with a slash to represent that both "not normal" and "normal" coexisted at the same time. Some people in Molzahn et al.'s study did not believe that they were normal because of their kidney failure. The pursuit of normal life was expressed by Maxwell (1990) as "fighting-to-live" and this experience included both positive and negative factors within this "adaptation as a process". One of Leung and Shiu's (2007) findings acknowledged that people who live in Hong Kong may travel to China for a transplant because they are in search of a normal life. In this study, "normal"

referred to life without kidney-related challenges, even though this was no longer possible. In other studies, normalcy included things that many people without kidney failure would not consider normal, such as accommodating hemodialysis within one's home (Namiki et al., 2010) or adjusting to ongoing dialysis (Walton, 2002).

In essence, a new normal was being created. Rittman et al.'s (1993) theme "taking on a new understanding of being" reflected taking the good with the bad. Participants in Rittman et al.'s study fashioned a new normal as they created a way of being in spite of their restrictions. Namiki et al. (2010) also articulate a theme related to sense of self and presented it as "in the present, living with ups and downs" (p. 551). Similarly, in Curtin et al.'s (2002) theme "coming to terms: life constraints", participants redefined restrictions as a "new normal". While people living with kidney failure acknowledged the abnormal or negative aspects of there being no cure for kidney failure, they concurrently accepted this, got on with life, and even felt lucky.

Uncertain Hope

Experiences of kidney failure revolved around the uncertainty that accompanies this chronic and life-threatening illness, mingled with hope. Namiki et al.'s (2010) theme, "the future, hope and uncertainty", related to participants' views that the future was full of uncertainty, but hope facilitated a positive view of life. Nagle (1998), too, saw the relief, freedom, and gratitude that participants in her study felt about dialysis technology, but these feelings coexisted with uncertainty. She wrote of this under a theme entitled "surviving amid uncertainty." In Curtin et al.'s (2002) theme "coming to terms: risk of death/uncertain future", the authors explained that participants were aware of the uncertainty of their future, but "this information served to motivate rather than

paralyze" (p. 618). Maxwell (1990) wrote of "adaptation as a process" which included phases of "accepting" and "facing" dialysis. However, this process was intertwined with times of "losing hold" of the strength to meet the demands of dialysis and conceptualizing of the possibility of "giving up". Although not discussed as a theme per se, uncertainty was recognized by Molzahn et al. (2008) as an overarching experience in-between risk of death and success of dialysis.

The uncertainty associated with the "waiting time" for a potential transplant influenced the decision-making of the participants in Leung and Shiu's (2007) study. Hagren et al. (2001) wrote of "gaining a sense of existential optimism" as participants hoped for a transplant and accepted dependence on hemodialysis for the rest of their lives. This optimism was comingled with the uncertainty that they might not receive a transplant, that their hemodialysis would stop working, or that they might die. Rittman et al. (1993) similarly wrote of "maintaining hope" which sustained people as they lived with disability and pain. While hope offered freedom, uncertainty inherently held restrictions.

Discussion

It is clear from the thirteen studies with 252 participants that the experiences of kidney failure bring to light the coupling of both restrictions and freedom that accompany this chronic and life-threatening illness. Yet what is interesting is the absence of broad recognition within these 13 studies of the life-limiting nature of kidney failure. While recognition of life-threat was at times discussed during early stages of beginning dialysis, focus clearly shifted to living and sustaining life. Further, only three researchers had themes which reflected the life-threatening nature of kidney failure. First, Walton's

(2002) theme, "confronting mortality" was discussed as a powerful spiritual experience. While some people confronted their mortality, others were in denial. Second, Molzahn et al.'s (2008) theme "living/not living" recognized the fine line between living and not living. This fine line related to the diagnosis of kidney failure and the ensuing treatments within the context of mortality. Third, Curtin et al.'s (2002) themes "self preservation: 'I want to live'" and "coming to terms: risk of death/uncertain future" both acknowledged the threat to life. Curtin et al. further explained that "even as patients were affirming their will to live, they were concomitantly accepting the fact that renal replacement therapy would always delimit their ability to continue living" (p. 615). However, experiences of kidney failure focused on the chronic aspects, but not life-threatening nature of the illness. Perhaps "a culture of death denial" (Robert Wood Johnson Foundation, 2003, p. 61) has directed attention on treatment, the use of technology, and sustaining life. Participants in the reviewed studies may not have consistently acknowledged the possibility of an early death. Or perhaps they did, but researchers did not perceive this due to the fact that they too were immersed within the same culture of denying death.

One might ask why these findings might be important for nurses and nursing care? Within the sub-theme of dependent autonomy, researchers identified the superficial relationships that participants perceived in their interactions with nurses and other healthcare professionals (Clarkson & Robinson, 2010; Hagren et al., 2005; Leung & Shiu, 2007; Moran et al., 2009; Nagle, 1998). The findings clearly reflect that individuals are dependent on communication and information from healthcare professionals so that they may participate autonomously in their care. However, the previously mentioned authors also recognized that patients wanted a closer connection

with the nurses who provided their care. For example, in Moran et al.'s research, the researchers noted that participants often thought nurses were too busy to talk to them unless there were technological or physiological complications related to their dialysis. While nurses clearly have many demands on their time, acknowledging each person's individuality and showing interest in what might be of importance to each individual may significantly impact the quality of life for persons living with kidney failure. Nurses may need to take a bit more time to listen to each person's story, be present, and respond to an individual's concerns that are particularly difficult to articulate or address.

Acknowledging the patient's multiple restrictions and freedoms may allow nurses to become aware of the nuances associated with kidney failure.[39] As nurses are aware of the restrictions that go along with kidney failure, they may be in a position to support people who, at times, are experiencing contradictory perceptions such as uncertainty and hope or dependence and autonomy. Nursing support may range from accepting people's struggles for normalcy while on dialysis to asking individuals if there is any information that they need. In this way, patients may find that they are welcome to participate in their own care and that what is important to them will be respected and acknowledged by the healthcare team. The QMS findings identify that experiences of kidney failure are diverse and multifaceted; therefore, nurses cannot predict responses or needs by individuals at specific stages in the illness trajectory.

Limitations

It is important to note that this QMS of research findings is my construction of other researchers' interpretations of the data, constructed from research interviews,

[39] As nurses become aware of patients' restrictions and freedoms, my hope is that nurses may further support patients as they navigate these complexities.

attained from research participants.[40] As Sandelowski and Barroso (2003c) explain, "the best access anyone has to experience-as-lived is via experience-as-told, and qualitative metasyntheses are at least three times removed from the lived experiences they are meant to faithfully represent" (p. 478). In other words, a researcher conducting a QMS does not look at original data; thus, the synthesis is based upon other researchers' analysis. While it is important to acknowledge this methodological caveat, it does not discredit the findings. Further, the findings from this research integration may have theoretical generalizability and may be utilized by nurses who perceive that these findings characterize situations in their practices.

Suggestions for Future Research

Although qualitative nursing research on the experiences of kidney failure began over two decades ago, it is surprising to note that there are relatively few publications in the nursing literature. Because there are numerous studies using qualitative nursing research related to other chronic illnesses, I expected to find in this QMS at least double or triple the number of studies which currently exist. Clearly there is room for additional qualitative research into specific phenomena of concern related to kidney failure. Future research syntheses may consider looking at the literature on lay caregivers' and children's experiences of living with kidney failure, or the literature from disciplines outside of nursing. In light of the findings from this study, it would also be interesting to see how these findings differ from experiences of people living with early CKD. Another area for future research would be to conduct a meta-synthesis and examine nurses' experiences of

[40] These findings could be read as a narrative production that reveals more about myself and the authors of the literature reviewed than any "truth" of the experiences by people living with kidney failure.

caring for people with kidney failure so that we may have greater understanding of how to provide optimal care for persons living with the restricted freedoms of kidney failure.

In conclusion, these findings offer the first QMS of the experiences of people living with kidney failure. In this study, all the qualitative nursing research on the experiences of kidney failure was synthesized to draw attention to restricted freedom which brings distant connection, dependent autonomy, abnormal normalcy, and uncertain hope. Consideration of this synthesis may provide insights for nurses supporting individuals living with the chronic and life-threatening illness of kidney failure.

Chapter 4. Stories of Chronic Kidney Disease: Listening for the Unsayable

Foreword

CKD is considered to be a chronic condition, meaning that it is ongoing and it gets progressively more serious over time, but it is also life-threatening. Many receiving treatment will also die within the first five years. A prevailing denial of death in our society means that we rarely discuss CKD as a life limiting disease. Sometimes people with CKD ask difficult questions about life, death, and other topics that can be challenging and perhaps impossible to discuss. These "unsayables" are the focus of this study. At this time, little is known about the experiences of living with CKD that are difficult to discuss and, for a variety of reasons, beyond words. Recognition that the unsayable resides within and beyond language may help us acknowledge that stories of illness may contain both sayable and unsayable aspects of experience.

The overarching research question of this study is, "What do people story or narrate as their unsayable aspects of experience in CKD?" By "unsayable," we[41] refer to that which is not expressed yet alluded to through language, and may be conscious or unconscious. We conduct a narrative inquiry using secondary data from the project entitled *Re-stor(y)ing Life Within Life-threatening Illness*. This research explores people's stories of facing serious illnesses and how these experiences affect their understandings of health. Fourteen individuals with CKD participated in four in-depth interviews. The participants had a mean age of 66, ten were male and four female, and

[41] This manuscript was co-authored with Drs. Laurene Sheilds and Anita Molzahn. Dr. Sheilds was the principal investigator on the *Re-stor(y)ing* research project and Dr. Molzahn was a co-investigator. Both contributed substantively to the intellectual development of this paper. My role was to review all pertinent literature for the paper, code all the data, develop the case-centered themes, draft themes across all narratives, write the first draft of the paper, and make appropriate revisions.

time from diagnosis ranged from 1 to 50 years. Five participants also had cancer and one had HIV.

In answering our research question through narrative thematic analysis, we identify that the unsayable includes the following: living with death, embodied experiences that were difficult to language, that which was unthinkable, unknowable mystery, and that which was untold / unheard. From these findings, we offer suggestions for healthcare professionals working to enhance the quality of life for these individuals.

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The unsayable aspects of our lives may be embedded within and beyond our language and the stories that we tell. By unsayable, we refer to that which is not expressed yet alluded to through language, and may be conscious or unconscious (Schick Makaroff, 2011a). We know the unsayable is present through allusions to it in language. E. Bruner stated that "irony arises in the open space between what is said and what is experienced" (1984, p. 14). The unsayable resides in this open space. There is evidence in the literature (Charon, 2006a; Frank, 2002) that living with a chronic and life-threatening illness impacts quality of life (QOL), raises difficult questions about life, and is challenging to articulate. In this article, we explore individuals' stories of living with chronic kidney disease (CKD), particularly unsayable aspects of experience.

In 2009, the incidence of treatment by peritoneal and hemodialysis was 159.3 per million in the population (CIHI, 2011a). The unadjusted 5-year survival rates are 51% and 41% for people on peritoneal dialysis and hemodialysis respectively (CIHI, 2011a). Little is known about the experiences of living with CKD that are difficult to discuss, ineffable, and beyond words.

We write this paper for those who are interested in both learning of the lived experiences of people with CKD and promoting QOL, and for narrative scholars who study the interconnections between sayable and unsayable elements within stories. In this paper, we provide background on the concept of the unsayable, briefly describe CKD, and outline the methods and findings from our narrative thematic analysis.

The Unsayable

The unsayable resides alongside the sayable. While our focus in narrative inquiry is on stories, it is easy to forget that not all experiences can be fully expressed in language. Rilke (1903/1986) reminds us that **"**things aren't all so tangible and sayable as people would usually have us believe; most experiences are unsayable, they happen in a space that no word has ever entered" (p. 4). In our use of the unsayable we are not referring to those with physical challenges who cannot speak, but rather that which is alluded to through language and stories.

There is a small yet growing body of literature pertaining to the concept of the unsayable (Lieberman & Van Horn, 2009; Rogers, 2007a, 2007b; Schick Makaroff, 2011a; Schick Makaroff, Storch, Newton, Fulton & Stevenson, 2010). Perhaps the most widely referenced author on the topic is Rogers (1991, 2006, 2007a, 2007b; Rogers et al., 1999), a Lacanian psychoanalyst and professor in clinical psychology, who proposed a textual method of *interpretive poetics* used in narrative inquiry to examine the concept (Rogers, 1991; Rogers et al., 1999). The unsayable, according to Rogers et al. (1999), is that which is "difficult to say but may be implied through negation, revision, evasion, or silence" (p. 91). Although the unsayable is portrayed through language (Rogers, 2007b), we build on Rogers and suggest that it also transcends language.

In her work, Rogers drew upon Budick and Iser (1989) who are editors of a collection of essays that examine the unsayable in literature. They examined the "negative gestures that seem to be implicit in virtually all poetic, philosophical, and even historical language" (p. xi). They asserted that negativity is a necessary part of all writing and speaking, revealing tacit dimensions in each text that contains a doubling of language. Rogers also drew upon Lacan (1977) who attended to notions of the unsayable without labelling it as: "An enunciation that denounces itself, a statement that renounces itself, ignorance that dissipates itself, an opportunity that loses itself, what remains here if not the trace of what *must* be in order to fall from being?" (p. 300). Lacan posited that we are born into language. As can be seen in this quotation, Lacan also suggested something that was alluded to, a falling away, through language.

While some may believe that there is no lived experience absolutely devoid of language, we cannot postulate that language fully represents experience (E. Bruner, 1984; Lacan, 1977). Charon (2006b) acknowledged that our very human condition tries to express unreachable meanings but falls short, running out of language. Languaging life is poignantly described by E. Bruner who distinguished between life as lived, experienced, and told. *Life as lived* refers to what unfolds for the individual. *Life as experienced* encompasses thoughts, feelings, desires, images, and meanings as understood by the person living the experience. While others may interpret or infer, they may never know with certainty what another knows directly. *Life as told* is a narrative informed by the cultural context, social constructions of storying, and the audience with whom the life is shared. However, one's narrative may never fully language life as lived or experienced. In consideration of E. Bruner's three distinctions, we find it interesting that in the modern

Western discourse (Reiss, 1982) we place the most weight upon the telling, but only a partial story is conveyed when the focus is solely on what is spoken (Rogers et al., 1999). In this study, we examined the unsayable for individuals living with CKD.

Chronic Kidney Disease (CKD)

CKD is defined as a decrease in kidney function or damage to the kidneys for a minimum period of 3 months (Kidney Foundation of Canada, 2011). CKD typically begins slowly, without obvious symptoms, and progresses over years. End-stage renal disease is the fifth and final stage of chronic kidney disease when the kidneys have less than 15% of normal function (Kidney Foundation of Canada, 2011). People who reach this state will require dialysis and they may be considered for a kidney transplant. Treatment of end-stage renal disease is complex and involves fluid and dietary restrictions, medications, and dialysis, either hemodialysis (where blood is drawn from the body and cleaned through an artificial kidney several times per week) or peritoneal dialysis (where the inside of a person's abdomen is filled with a special dialysis fluid and drained periodically to remove water and toxins). Those who are not candidates for a renal transplant have a significantly shortened life expectancy (Moss, 2002; Robert Wood Johnson Foundation, 2003). Thus, CKD is both a chronic and life-threatening illness, and when diagnosed, individuals face an altered QOL (Finkelstein et al., 2009; Fukuhara et al., 2007; Mapes et al., 2003; Molzahn, 2006).

Purpose and Research Question

The purpose of this research was to explore individuals' stories of living with CKD, particularly aspects of experience that are unsayable. The guiding research

question was, "What do people story or narrate as their unsayable aspects of experience in CKD?"

Methods

Design: Narrative Inquiry

We conducted a secondary analysis of the project entitled *Re-stor(y)ing Life Within Life-threatening Illness* (Sheilds et al., 2011) that explored people's stories of facing life-threatening illnesses within the context of cancer, CKD, and HIV/AIDS. In the current study, we analyzed 46 interviews conducted over three 3 years with 14 people living with CKD to look for narrative expressions of the unsayable. The in-depth nature of the interviews, which were conducted over time, provided rich data for us to examine what was within and beyond language.

Narrative inquiry, located within a social constructionist framework, guided this secondary analysis. From a social constructionist view, stories are generated by people as they collectively create depictions and explanations in language. Through stories we construct meaning from our world; however, we are also constructed or inscribed by our world (Crotty, 1998; Lather, 1991). If we agree that experience is partially expressed in language through narratives, then (within research) stories are jointly produced inter-relationally, co-authored either in dialogic engagement during interviews, or through concepts, methods, transcription, and analysis (Riessman, 2008). Narratives are bound according to temporality, context, and emplotment[42] (Polkinghorne, 1991; Riessman, 2008).

[42] Polkinghorne (1991) explained that "emplotment transforms a list or sequence of disconnected events into a unified story with a point or theme. Through the operation of emplotment, particular actions take on meaning as a contribution to the unfolding plot of the story" (p. 141). A speaker can assimilate complicated parts or events into one story with a beginning, middle, and end through the means of

Participants

Participants were recruited through purposeful and snowball sampling using advertisements in strategic community places. Fourteen individuals with CKD participated in four in-depth interviews over 3 years.[43] All interviews were audio-recorded and transcribed verbatim. The participants were diverse in age (43-83 years; mean=66), gender (10 male, 4 female), time from diagnosis (1-50 yrs), treatment (conservative management, dialysis, and 3 kidney transplants), and dual-diagnosis (five had cancer and one had HIV). All participants resided in a mid-size urban area in Canada. Table 6 provides additional participant information. Inclusion criteria were: ability to speak English, at least 12 months experience with CKD, and willingness to share experiences of their illness and its impact on their lives.

Ethical Considerations

We attained ethical approval by a University Human Research and Ethics Board (HREB) for this secondary analysis. Confidentiality of all participants was protected. In this paper, pseudonyms are used.

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emplotment, thus bringing disjointed elements together into an ordered, contextual whole in a similar way that a plot structures a story.

[43] As a doctoral fellow, I had the opportunity to conduct approximately one half of the interviews with these participants over 3 years.

Table 6: Participant Demographics

Demographics	Number of Participants
Gender	
Male	10
Female	4
Number of Interviews	
Participated in all 4 interviews	9
Participated in 3 interviews (due to declining health)	1
Participated in 2 interviews (passed away)	3
Participated in 1 interview (withdrew from study)	1
Dual-diagnosis	
Cancer	5
HIV and AIDS	1
N/A	8
Years Since Diagnosis	
1-5 years	9
6-15 years	3
16-25 years	1
26-50 years	1
Treatment Modality	
Pre-dialysis	2
Hemodialysis	6
Home hemodialysis	2
Transplant	1
Peritoneal dialysis, then hemodialysis	1
Home hemodialysis, then transplant	1
Hemodialysis, then transplant	1

Analysis

We were guided by Riessman's (2008) approach to narrative thematic analysis.[44] Through this approach and in close readings of the transcripts, our attention was on the

[44] While many qualitative researchers use thematic analysis, there are a few distinguishing factors when used within narrative inquiry. The key element is that narrative researchers have a case-centered commitment, meaning that they "keep a story 'intact' by theorizing from the case rather than from component themes (categories) across cases" (Riessman, 2008, p. 53). In other words, sequences are preserved and rich detail is provided from longer quotations. In contrast, other approaches to thematic analysis code across segments of data. In narrative thematic analysis, scholars also "attend to time and place of narration and, by historicizing a narrative account, reject the idea of generic explanation" (Riessman, p. 74).

content, or "what" was being expressed through language, rather than "how" the content was communicated (Riessman, 2008). Our unit of analysis was unsayable aspects of experience as expressed in personal narratives. The unsayable was not always clearly evident in the data due to the subjective and highly interpretive nature of the concept. Indicators of the unsayable included a quick change of topics, incomplete sentences, paradoxes, seeming contradictions, counter points, tensions, and double meanings. NVIVO was used in data management and coding. Analysis began with case-centered thematic analysis of each participant's interviews.[45] Themes were then created for each case, after which we began to look across narrative cases.

We acknowledge that in narrative analysis, researchers are also narrators, not just receivers of participants' stories.[46] As narrators in this inquiry, we attended to truth claims and rigor.[47] Given that we engaged in secondary analysis, we could not return to participants. Instead, we kept audit trails of coding, sub-coding, case-centered analysis, and narrative thematic analysis so that another researcher could examine and verify our decision-making and interpretation of findings. Conversations among researchers throughout the analysis were also beneficial in evaluation of results. Early findings were also presented to a kidney stakeholder group for discussion and feedback. Reflexivity was a key component of our analysis. We engaged reflexively in our analysis through memos in NVIVO, journaling during analysis, and discussing analytic decisions and questions with each other.

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[45] After completing the case-centered analysis, I had 61 pages, single-spaced, that outlined the themes for each participant with supporting narrative quotations. After the case-centered analysis, we looked across narratives.

[46] Ontologically the researcher is intimately involved in any phenomena under study and he or she is perceived to influence the inquiry.

[47] Narrative knowledge and truth are considered to be temporal, subjective, contextual, and not presumed to be generalizable. It is from such a perspective that validity of narrative inquiry must be evaluated (Riessman, 2008), and we undertook this pursuit in multiple ways.

Findings

Five themes display the breadth of unsayable aspects of experience: living with death, embodied experiences that were difficult to language, that which was unthinkable, unknowable mystery, and that which was untold / unheard. Whereas the first four themes attend to that which is unsayable *for* people living with CKD, the last theme acknowledges that which is unsayable *to* people living with CKD. Although each theme is isolated from each other theme for heuristic purposes, in essence, they coexist and are interrelated across the data. While the themes pervade the 46 interviews, narratives are presented below as case-centered to keep the stories intact (Riessman, 2008).[48]

Living with Death: "We're not looking at what's coming"

Narratives of living yet confronting death and facing one's mortality permeated the interviews, even though interviewers did not directly ask participants about this topic. Participants chose not to focus on death. Rather, their attention was on living and this was described in numerous phrases such as "keep on going," "I plan to survive," "take one day at a time," "I'm still here," and "you've got to fight it." Despite a focus on living, the uncertainty and unpredictability of death was present in participants' narratives explicitly in the words of participants, but more often alluded to through language, unsayable in text.

Three cases are presented to illustrate how living with death was unsayable. Rick, on home hemodialysis, addressed having a "do not resuscitate" (DNR) order.

[48] We had dozens and dozens of narratives to choose from. We choose to present narratives from different participants to show the breadth of experiences, and we choose stories that clearly (and succinctly) attended to the unsayable.

> We both agreed that if the end comes and there's some kind of a problem we have a 'no resuscitation' order. Poor doctor has to ask us that every six months or whatever it is.
>
> Interviewer: Oh really – to make sure that you still –
>
> Rick: Understand, yeah. Which is you know both of us are you know, why? Why would you want to live with somebody who's a vegetable or in some kind of horrible agony for years when you don't have to? We're not looking at that's going to happen but you never know.

Rick seemed to sympathize with his doctor and by calling him "poor doctor," he implied that the topic was difficult for his doctor.[49] On multiple occasions, Rick spoke about not giving attention to death. He said, "We're not looking at what's coming – you're going to die sometime."[50] Death was unsayable for Rick and his gaze was focused on living.

Brian, an 80 year old man, provided another example of living yet confronting death.

> When you get to be 80 and more and more of your friends have gone you do have to say, more like, when am I going – rather than where am I going. That's what I think comes to my mind more than as I just said, how, how much longer will this kidney disease or whatever medicine I'm getting, keep me alive you know?...I don't have anybody [at the renal unit] that I talk to intimately….
>
> Interviewer: So you don't get to talk to anyone about this question of 'when?'

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[49] Rick also had questions about death, wondering about whether he would have agony in death or if the DNR order would be followed so that he would not be a "vegetable." Rick's phrase, "you never know," draws attention to the unexpected or uncertain possibilities in living with death.

[50] Rick's quotation illustrated how he used language to hint at the unsayable uncertainty of living with death. While he had discussed his DNR order every 6 months, and knew he would "die sometime," his focus was to "keep on going." Rick's response to living in a perpetual state that lacked resolution can also be interpreted from a social perspective which acknowledges that we may normalize death by saying that everyone will die sometime.

> Brian: I don't think it's ever come up. Never. And I don't think I've ever talked to my family about it.

Over the course of the interviews, Brian shared that he had written his obituary and chosen which photo he would like displayed at his funeral. Although he had planned for his death, he had not spoken about it with his family or with anyone in the dialysis unit. In the third interview, he shared that he asked a nurse about "when" he might die.

> I even asked the nurse the other day, what are the signs from your point of view – the medical point of view – that life is coming to an end for me? Cause I'm seeing people going out forever and she said "uh, oh, we see signs" and I said, "well that's not good enough. What do you see?" She says, "well your blood tests, which have been very good lately."

The nurse initially tried to skirt Brian's question but he persisted. First, she directed his attention to numerical blood values, and second, she implied that these values did not show that he was nearing death. The answer he received was distant (referring to blood work) and avoidant. While death had been unsayable for Brian, it was also unsayable for his nurse.

Over the course of four interviews, Carmella frequently spoke of her own mortality. When the interviewer asked if it was important for her to talk about dying, she replied, "I don't really know, I just know that it's helpful and you know you feel better. In fact you feel like you might live longer – which I can't imagine why you do." However, Carmella did not explicitly discuss dying with any family members, friends, or

healthcare professionals.[51] She believed that talking about death would allow her to live longer, which was her ultimate goal.

Difficult to Language Embodied Experiences: "I just can't put words to it"

There were numerous embodied aspects of living with CKD which narrators identified as difficult to put into language. By "embodied," we mean "an inalienable form that experience takes" (Gadow, 2000a, p. 89). The first example relates to the difficulty of articulating a physical experience. Rachel explained what she felt like before she began dialysis, which she tried to delay as long as she could. She said,

> I never felt bad. I never felt sick. I never felt ill. I mean, yes, I had associated symptoms like joint pain. There were times I couldn't get out of a chair, the pain was bad (said in a whisper). I feel fine. I'm doing OK. I wasn't doing OK. It was real denial. You can look back and say that.

Rachel's embodied experiences were unsayable in that they were challenging to language, expressed in counter points and what she called "denial." She transitioned from alluding to not feeling ill to whispering of having so much pain she could not get out of a chair. Her example draws attention to our embodied experiences which are experienced in our bodies but may not necessarily be expressed through language.

Ryan described not speaking with others of his embodied experiences. Ryan has coexisting morbidities and received a lung transplant over 10 years ago. However, his immunosuppressive drugs damaged his kidneys. Early in the first interview when discussing his illness, he said, "I never really talked about this before." In the third

[51] Apart from the interviewer, she had not yet found someone to talk to about death, particularly because this topic was upsetting for her family. In this manner, the interviews were also therapeutic for her, filling a void so she could discuss confronting her mortality.

interview, he told a story about aspects of his illness experience that are difficult to language.

> Interviewer: Do you tell a lot of people your story and your experience?
>
> Ryan: No. If it comes up….I just say ah I got some rare disease that ruined my lungs and I avoid saying the medication caused my kidneys to fail cause if someone's thinking about not donating kidneys or organs and if they hear a story like that then it could tip the balance the wrong way so I, I avoid it.[52]

In the following story, Ian identified the challenges of trying to language a near-death experience.

> It was kind of like on some of those spacey shows they show the swirls and stuff in it – kind of like that except it was dark and at the end there was a really bright light and all I saw was the light and some shadows, personable shadows….Well I got before I came back, I had a feeling of euphoria y'know, peacefulness, calmness, right. I was healthy... I've, I've thought long and hard about it. I just can't put words to it. It just happened.

Ian's account of his near-death experience extends beyond language, beyond what is sayable. He alluded to "those spacey shows" because that was the closest thing he could compare to the experience. Ian's feelings afterwards were also hard to express and he related it to euphoria, peacefulness, calmness, and being healthy, yet his statement that he "just can't put words to it" further identifies that some experiences cannot be fully expressed through words; language fails in some instances. He went on to say that it was

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[52] For Ryan, while he did not typically talk about his transplants with people, when it did come up he was conscious of what he said. His motivation was a larger social issue, not wanting to discourage others from considering organ donation. He knew of the importance of organ donation because it extended his life twice.

"not my time yet" and he hoped for a transplant and a long life ahead. Ian shared this experience 14 months before he passed away.

Unthinkable: "I really don't think about it"

The participants in this study alluded to unsayable aspects of experience in their stories when referencing that which they did not or could not think about. Three narratives are shared below to provide examples of the unthinkable nature of the unsayable.

Ronald had been on dialysis for 2 years. He also had congestive heart failure and he had been cardioverted three times. Both times he had asked for a priest to visit him in hospital and pray the Sacrament of the Living in case he should die. While Ronald had previously thought that he might die, he didn't think about death being close in relation to living with CKD. Ronald said,

> I don't like that word "end stage."
>
> Interviewer: What term do you use?
>
> Ronald: I just say "renal disease," yeah.
>
> Interviewer: Renal disease.
>
> Ronald: I don't like to use the word "failure."
>
> Interviewer: Just renal disease.
>
> Ronald: Yeah.
>
> Interviewer: Because "end" means "the end"?
>
> Ronald: Well yeah I don't really think of it that way but I just think there should be a better term because I mean people are on dialysis for 20 years so "end" is very deceiving.

Ronald chose to "look on the bright side," a phrase he often used, and focus on the years that were ahead of him.[53]

Living with CKD was also unthinkable. For example, Rachel repeatedly said, "I really don't think about it on a daily basis. I live with it." Rachel had been living with CKD since she developed nephritis when she was 10 years old. After marriage, she decided to get pregnant even though she knew it may further damage her kidneys. She became very ill before giving birth and explained: "I did survive, just. Um…it was, um… iffy for a while. The baby was fine in the end." After pregnancy, her kidneys failed and she began dialysis.

> Interviewer: Maybe I shouldn't say it, but you, in a sense, risked your life to have [your son].
>
> Rachel: No, I've never gone there. No. No can't go there. That wasn't his choice. At all. No never go there. That was my choice. You couldn't ever say that to a child. Ever. And never even think, I never even think it because it's not appropriate. We've never thought that, no. Never. It's never even crossed my mind.

Like Rachel, Ryan repeatedly said, "I don't want to think about it," referencing CKD and dialysis.[54] Ryan had received a kidney transplant, but the new kidney was not

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[53] We can see this social construction echoed in Ronald's reference to his illness not as "end-stage renal disease," but just "renal disease." The emphasis for Ronald was not on "end stage," and not on "failure"; these conceptualizations were unthinkable. Rather Ronald had actively re-constructed and re-named his illness as "renal disease" to remove references to the unthinkable possibility that he may die from this illness.

[54] Notions of risking her life were unthinkable, and the risks were unsayable, particularly to her son. In the above quotation we can also see that the unsayable nature of the topic extends beyond the participant; the interviewer also wonders aloud if she should even ask Rachel about risking her life to have a child. Perhaps there is a social, hegemonic discourse that underpins this topic: that mothers, including those who are ill, are expected to lay down their lives for their children, whatever the cost. Alternative thoughts outside of this hegemony are unthinkable.

working after the operation. In the following quotation he discusses what happened in the weeks after his transplant.

> I wasn't worried. I knew it wasn't right but I thought well it's an older kidney, you know, just allowed for it. But two weeks later all of a sudden they wanted to do a biopsy. Now all of a sudden it clicked and I went, oh my god, they're thinking rejection. And I refused to even go there, I hadn't even thought rejection. Like I know about rejection. I've had a few friends that had it with lungs. But I hadn't gone there, I wasn't going to. It was subconscious. And I can't believe that I actually blocked that out. But as soon as the doctor said "rejection, it's not a rejection," I went, good. Because I hadn't thought of that, didn't want to. But anyway uh it was just you know it was just verified at that point that it was a sleeper so – uh (pause) it was (pause) I didn't, I didn't feel good until I got out of the hospital.

The unsayable is evident in Ryan's response to not think about rejection and keep it "subconscious."

Unknowable Mystery: "No one can say for sure"

Participants spoke of faith, spiritual beliefs, existential questions, and large life questions alluding to the unknowable aspects of life. Within these conversations, people raised questions recognizing the mystery in life and in living with a life-threatening illness. Three examples are provided below.

Ian had been on hemodialysis for 2 years. When he was asked if he identified with a faith tradition, he said, "I don't believe, I don't disbelieve, but I don't believe, but I consider myself to be a Christian." The interviewer then asked him,

> How has that influenced your experiences um with your diagnosis at all?
>
> Ian: Mmmmmm not really. I do find myself - talking to somebody – to myself really but in prayer form, sometimes. But like I say I don't know whether it's an ultimate being or you know or when we die do we go join this energy force or what the scoop is. No one knows and no one can say for sure.

Ian's comment "I don't believe, I don't disbelieve" highlights a seeming contradiction but also the mystery that he acknowledged in that "no one can say for sure" what happens when we die.

Ryan also spoke of not believing, yet believing. He had received a kidney transplant but it was termed "a sleeper," only working at 20%. The interviewer said to him:

> So there's nothing you can do with this, this kidney. You can't talk to it, massage it, love it up.
>
> Ryan: No, my wife was somewhere and there was a stone that says it's, it's good for kidney health or something like that so we don't believe in that stuff but we stuck it on my key chain anyway, yeah.

Ryan's words said that he didn't believe but his actions implied he might believe.

Mike's story provides another example of unknowable mystery as unsayable. Mike was 55 years old when he entered the study and he died in the second year of the study. Mike described what happened during one hospitalization while being treated for a wound.

> I was lying in bed and I do my own little prayer kind of thing and I just looked at the sky outside and I went, "you're pissing me off - so show me something you

> know like, hit me on the head or rattle the door or something like that you know" and uh nothing happened but it's funny because about three or four days later the plastics came in with the intern and all of a sudden they're looking at this wound and I hear, "holy shit, whoa, oh my god." And I'm thinking, what is going – what they got like a, what are they finding back there you know? And all of a sudden they're going, he says, "what are you doing?" I said, "me?" He says, "what are you doing?"…And I'm thinking, oh shit, because I was doing things where – I'm not into – I call it the bug and bunny stuff – I've got – I do believe that there's a physician heal thyself. I don't know if you're religious or you have spiritual things but where you have that laying of hands and stuff? I really think that if enough people get together and concentrate, this energy, and keep coming and put their hands on my leg and concentrate, just not even mumbling or chanting or anything like that, like just thinking, healing, healing, healing.

Mike explained that he had a dramatic healing of his wound that he attributed to his prayer and healing thoughts.[55] The mystery of Mike's beliefs, and his healing, were unsayable.

Untold / unheard: "They never told you"

In this last theme, participants spoke candidly about aspects of their care that they believe they were "never told" or information that they did not hear. Interactions were primarily with healthcare professionals, and we provide three narratives as examples.

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[55] He had not been praying out loud but had been thinking "healing, healing, healing" and had been laying his own hands on his leg. While Mike said he wasn't into "the bug and bunny stuff," he did believe "physician, heal thyself." I attribute the latter reference to the Bible in Luke 4:23, New International Version, where "Jesus said to them, 'surely you will quote this proverb to me: 'Physician, heal yourself! Do here in your hometown what we have heard that you did in Capernaum.'" The moral of the proverb is that we should take care of our own problems before criticizing the problems of others.

In this first story, Paula described information that she did not hear. Paula had a university degree in allied health and she gave many examples of times when healthcare practitioners did not talk with her or did not listen to her about specific things related to her care. Paula told a story of having very poor pain control after her kidney transplant.

> [The acute pain doctor] referred me to the chronic pain team so I don't know, I don't think he mentioned that he was signing off but someone else was signing on. So it's just those little details that somehow care professionals leave out that you know again I think they assume that we know or they use language, they use the medical terms for things which I can understand but most people wouldn't be able to. You know they need to sort of get down to the patient's level and talk more human-like instead of - standing at the foot of your bed, towering over you and saying oh this and this and this.

Paula identified that her training allowed her to understand "medical terms" that other patients would not comprehend. But Paula also did not always know the "little details" like when a physician was "signing off," no longer acting as her doctor. These were examples of information that she didn't hear. Paula believed that healthcare professionals should use lay language or "talk more human-like." When healthcare professionals use language that patients don't understand, Paula likened this to "standing at the foot of your bed, towering over you."[56]

In the next two stories, participants identified that they were never told of aspects of their care. The second story is by Carmella who was 68 years old and began hemodialysis six years prior to the study. At one point she became anorexic. She explained:

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[56] Paula elucidates that language can be foreign, missing, and used to dominate others.

> I just didn't want to have anything to eat anymore. I didn't want anything – anything, anything at all. And I went to this doctor, this heart specialist, and he told my daughter, "oh take her home and bring her back in six months and I'll look at her then." Well, we now realize what he was saying: go home and let her die because I would have been dead in six months. I don't know why he didn't tell us that. But he didn't.

In this narrative, Carmella had interpreted the information that she believed the specialist left out: that she was going to die in six months.

Ernie found that he needed to get information from his friends when he could not get it from his doctor. Ernie's kidney function was declining and his doctors anticipated that he would soon need to begin dialysis. Ernie said:

> [The doctor] told me you can live with one kidney. What he didn't tell me: that life is not going to be the same eventually. (pause) And then I met kidney patients [on] dialysis also in the swimming pool. I know from them it's not the same thing as having two good kidneys.

Ernie's story is similar to Carmella's in that we can't know if their doctors addressed specific information, but even if the doctors had, Ernie and Carmella did not hear the information. Their interpretations were that they had not been told.

Discussion

Recognising that the unsayable resides alongside the sayable can help us acknowledge that stories of living with illness may contain both sayable and unsayable aspects of experience. In this study, we found that the unsayable included living with death, embodied experiences that were difficult to language, that which was unthinkable,

unknowable mystery, and that which was untold/unheard. In this discussion, we consider each of these five themes and what they add to the literature. In addition, we discuss the implications of our findings for healthcare practice.

First, confronting death was unsayable while participants focused on living. CKD is life-limiting and most participants acknowledged this in some way, yet a "culture of death denial" (Robert Wood Johnson Foundation, 2003, p. 61) prevailed. In treatment of CKD, the conventional focus has been on successful intervention within a medical tradition that denies death (Robert Wood Johnson Foundation, 2003). For example, on the Kidney Foundation of Canada (2011) website, one finds the following statement: "It is important to remember that end-stage refers to the end of your kidney function (your kidneys are working at less than 15% of normal), not the end of your life." The larger societal construction of focusing on life is echoed in participants' narratives of living with CKD. Such a discourse may deem what is and is not acceptable to discuss (Klein, 2005; Rominger, 2010; Rubin & Winrob, 2010; Todorova, 2007), as well as what may be considered socially taboo (Graffigna & Olson, 2009; Schwappach, 2008). Our findings show that participants have taken up the broader social narratives focusing on life, yet they could not help but consider their own mortality. We would propose that the unsayable aspect of living with death has been largely influenced by the societal narratives which deny death in the larger renal context.

Second, in our study, we found that embodied experiences were challenging for participants to put into language. Some described a conscious choice about whether they

discussed embodied experiences. They portrayed a sense of agency[57] as they navigated such decisions related to their health. Even the language used to narrate embodied experiences can be seen as an act of agency (Gadow, 2000b) for these individuals living with CKD. Other embodied experiences that were difficult to language were linked to suffering, such as physical pain or near-death experiences. In the literature on the unsayable, suffering can be seen as an antecedent to this phenomenon of the unsayable (Schick Makaroff, 2011a). Similarly, other authors have found the unsayable in illness (Ready, 2010; Rykov, 2008), pain (Kruger, 2005; Mitchell, 2009), and near-death experiences (Rominger, 2010). However, other diverse forms of suffering have also been found to be interconnected with the unsayable. For example, scholars have identified trauma (Lieberman & Van Horn, 2009; Rogers, 2007a; Rogers et al., 1999), horror, torture (Ehrensaft, 2008; Frankl, 1959/1984; Mitchell, 2009; Rogers, 2007a), and even undesirable or unsafe events in hospitals (Schwappach, 2008) as examples of suffering which precede unsayable aspects of experience. What our findings uniquely add is specific to the body of literature on CKD which has not previously explicated that visceral or embodied experiences of living with this illness may be difficult to language.

Third, we found that the unsayable included that which was unthinkable. Topics that participants did not or could not think about ranged from the very idea of living with CKD to the possibility that this illness may hasten death. Participants actively re-constructed or re-named aspects of illness to remove references to unthinkable aspects of CKD. Frank (2002), a cancer survivor, wrote, "the questions I want to ask about my life are not allowed, not speakable, not even thinkable" (p. 13). While other researchers from

[57] Riessman (1993) has identified that narrative inquiry offers prominence to human agency because it is through our agency that we decide what is included and excluded in narratives, how plots are constructed, and what meaning is ascribed to our stories.

both psychology (Allphin, 2007) and nursing (Graffigna & Olson, 2009) have discussed unthinkable aspects of the unsayable, the unthinkable nature of living with a chronic and life-threatening illness has not previously been identified in the research on the experiences of living with CKD (Schick Makaroff, 2011b).

Fourth, for the 14 participants in our study, living with CKD raised difficult questions about life and was challenging to articulate. Some of these difficult questions simply could not be answered and they related to existential questions, spiritual values, and notions of faith. In our findings, we have identified that unknowable mystery was unsayable. By this we mean that some existential beliefs and large life questions may not be expressible for the person living with CKD through oral or written language. These findings have long been acknowledged within theology (Sells, 1994), but more recently in psychology (Horner, 2006; Klein, 2005; Mather, 2008; Rykov, 2008; Vivona, 2006) and nursing (Bruce, Sheilds, & Molzahn, 2011; Graffigna & Olson, 2009).

Fifth, we have found that that which is unsayable *for* people is distinct from that which is unsayable *to* people living with CKD, and this finding has not been previously discussed in either the psychology literature on the unsayable or the nursing literature on living with CKD. While participants shared about topics that they were not told by healthcare practitioners, we often wondered if certain information had been shared but perhaps in a manner that was inaccessible to or unheard by participants.[58] The findings in this study draw our attention to the need to re-visit health information repeatedly with

[58] One thing that I learned from the stories of that which was untold / unheard is that healthcare practitioners must be aware that the information that they are providing may not always be "hearable" by patients. Communication involves interplay of language and understanding. But what do we do if our communication is unhearable? Mismatch of communication and receptivity may leave people feeling like they were not told important information related to their health. Re-visiting information may be an important part of communication about a highly complex illness.

patients so that such communication is adaptive, frequent, and repetitive. Like other scholars, we see the unsayable interconnected with communication (Adams, 2010; Ehrensaft, 2008; Schwappach, 2008; Shoham, 2009), at times specifically with challenges in communication. The unsayable may arise from an area where communication is wanting, where there is a "lack of discussion and lack of information" (Rubin & Winrob, 2010, p. 738) or "a lack of moral space to discuss concerns" (Schick Makaroff et al., 2010, p. 570). Challenges may develop for others when "speech fails" (Rogers, 2007a, p. 8), or when they "cannot say what it really is" (Shoham, 2009, p. 521). The tendency to avoid a sensitive topic (Koppe, 2010) may create discomfort for others.

In light of these findings, we see implications for healthcare practice when we consider the unsayable as both resolvable and irresolvable. Findings from this study have shown us that some complex experiences may be resolvable through expression, as Rogers (1991, 2006, 2007a; Rogers et al., 1999) suggests. We found that the unsayable may be resolvable through the act of storytelling. Mattingly (2007) explains that "telling stories can offer a way to make meaning of what is otherwise unthinkable, uninterpretable" (p. 408). Co-construction of storying offers a potential opening for articulation of unsayable aspects of experience. Stories may be used to serve a purpose, namely to language that which is challenging to articulate. In resolving the unsayable, we see how stories provided a conduit through which the unsayable could be expressed (Frank, 2009; Kruger, 2005; Mitchell, 2009; Rogers 2007a, 2007b; Todorova, 2007).[59]

While some unsayable aspects of experience are resolvable, some unsayable elements remained irresolvable. We asked ourselves if full articulation of the unsayable

[59] Other references included Adams (2010) and Downing (2007). I found many instances where not all references could be included in the third or fourth paper due to page limits. I had to pick and choose which references were the most appropriate and which ones I could use multiple times in the paper.

is always possible or even desirable and we found that our answer was "no." We saw irreconcilable expressions of the unsayable in paradoxes, seeming contradictions, tensions, incomplete sentences, counter points, and double meanings. At some point, language seems to fall short (Charon, 2006b) of expressing the totality of our experiences, leaving some experiences unsayable. Language fails to encompass those experiences that may not be fully expressed yet alluded to in language, consciously or unconsciously. This understanding is significant not only for healthcare practitioners but also for narrative scholars. Both groups can be prone to assume that what is important *can* be expressed through stories or language. When we assume that the unsayable is alluded to and thus embedded and beyond language, our expectations shift, and we no longer practice from a position where we believe that all things are entirely sayable.

If some unsayable aspects of experience are irresolvable, as healthcare practitioners we must ask ourselves, are there aspects of individuals' stories that we are either uncomfortable with or we do not want to hear? Are we willing to engage in conversations with patients that may not be resolvable? Can we enter into "unknown" territory where we do not have answers, such as how long it might be before a person might die?[60] Individuals may desire a frank discussion of death if and when they want to discuss dying. A "palliative approach" prepares healthcare workers to open discussions and begin early conversations of needs, comfort measures, or information about death long before a prognosis (Katz & Peace, 2003; Palliative Care Australia, 2005). Such practitioners may benefit from acknowledging that certain aspects of living with death

[60] Remen (2011) has suggested that healthcare professionals have difficulty in situations where we cannot "fix or resolve a problem" because this is how we have learned to define the effectiveness of our work.

may remain unsayable and irresolvable for patients, and possibly for healthcare providers, even if discussions begin early in their health trajectory.

In healthcare practice and narrative research, how may we attend to aspects of the unsayable that are either resolvable or irresolvable? Though it may seem a simple response, we suggest that we offer ourselves to listen generously (Remen, 2011) and witness people's expressions, through narrative or otherwise. Through listening and bearing witness we may create an environment that fosters a sense of openness and respect so that we can explore these issues at the volition of individuals living with CKD. As Charon (2006a, 2006b) has identified, such witnessing is a skill that requires training because it does not come naturally for many. As a listener, the easy response when hearing of another's pain is often to change the subject. Scholars in nursing have addressed the need for nurses and other healthcare practitioners to practice being present (Mitchell, 2009; Newman, 2008; Patterson & Zderad, 1988) and bearing witness (Cody, 2007; Eifried, 2003; Tschanz, 2006) to others in need of care. What is important is that healthcare practitioners and narrative researchers have a greater understanding that what is significant cannot necessarily be expressed.

In summary, we found that participants storied their unsayable aspects of experience in living with death, embodied experiences that are difficult to language, that which is unthinkable, unknowable mystery, and that which was untold / unheard. Attending to the unsayable, as it is interwoven with the sayable in language and stories, may illuminate and provide insight for healthcare professionals into how to best support people and to promote QOL for those living with CKD.

Chapter 5. What did you expect? Symbolic Representations of Living with Chronic Kidney Disease

Foreword

In qualitative research, we often rely predominantly upon the spoken and written word for communication and dissemination. By incorporating visual data, we offer an alternative expression of that which is not elucidated. As we[61] work in the interface between photographs of symbolic representation and participants' narratives of living with chronic kidney disease, we confront our familiar reliance upon spoken discourse in qualitative inquiry. In this paper, we share some of our expectations and learning about narrative visual analysis of symbols and participants' stories of these symbols. Descriptive themes of the symbols include hopes and inspirations, reflections on "who I am," and confrontations of illness. Participants' expressions through symbols are further described through the use of memories, emotions, and poetic devices. We contend that symbols convey aspects of experience that cannot be translated into oral expression.

By analyzing representational symbols, we provide another avenue to examine that which can be challenging to directly discuss. It is somewhat ironic to propose that one can research the concept of the unsayable by only focusing on what is said. Incorporation of representational symbols provides us with alternative, aesthetic means to examine experiences of living with CKD.

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[61] This manuscript was co-authored with Drs. Laurene Sheilds and Anita Molzahn. Dr. Sheilds was the principal investigator on the *Re-stor(y)ing* research project and Dr. Molzahn was a co-investigator. Both contributed substantively to the intellectual development of this paper. My role was to review all supporting literature for the manuscript, code all the data in NVIVO, analyze the symbols and narratives according to Riessman's (2008) three sites of narrative visual analysis, create themes across all narratives and symbols, draft the manuscript, and revise the paper and themes according to the co-authors' feedback.

Manuscript Four

Communication and dissemination of qualitative research often relies primarily upon the spoken and written word. Incorporation of visual data may contribute understanding of experience other than what may be fully expressed through traditional means. In this study, we incorporated symbols to be photographed because, as Riessman (2008) explained, "visual representations of experience – in photographs, performance art, and other media – can enable others to see as a participant sees, and to feel" (p. 142). Symbols were not limited to tangible materials[62] and they were identified by participants to represent their experiences of living with chronic kidney disease (CKD), a chronic and life-threatening illness. Our purpose was to explore how experiences of CKD were portrayed through symbolic representation and narratives. Two research questions guided our inquiry: "What are the symbols that people identified to represent their experiences of living with CKD?" and "How are experiences of living with CKD expressed through symbols?"[63] In this paper, we share some of our expectations and learning about narrative visual analysis of participants' symbols and their stories related to these symbols. Working with symbolic representations and participants' narratives challenged our familiar reliance upon spoken discourse in qualitative inquiry, and we contend that symbolic representations convey aspects of experience that cannot be translated into words.

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[62] Although we initially set out to examine objects chosen by participants to represent living with CKD, we soon realized that focusing on objects themselves may be restrictive. For example, what if someone thought the color green best represented their experiences? Remen (2011) has also suggested that objects become symbols when they are imbued with meaning. Thus, we made a strategic shift to use the word symbol instead of object.

[63] We also tried to answer the research question, "What are the unsayable aspects of experience in CKD that are expressed through symbols?" However, when we reviewed the transcripts we found that participants often offered little description to articulate their reasons for choosing a particular symbol.

Photographs of Representational Symbols

The use of images in research is anything but new. There is a long history of incorporating images with research in disciplines such as anthropology and sociology. In 1936, Bateson (1958), a pioneer in this area, visually documented how knowledge was generated relationally in the Iatmul people from New Guinea. Over the past two decades, visual imagery through photography has gained momentum within qualitative research, particularly in methods such as photonovella (Chircop & Sheppard-LeMoine, 2004; Close, 2007), photovoice (Wang & Burris, 1997), and photo elicitation (Harper, 2000). These approaches involve use of photos to draw out and evoke responses (Riley & Manias, 2004). Within nursing, which is our disciplinary vantage point, the majority of the research incorporating photography focuses on understanding human experiences of health and illness (Riley & Manias, 2004). Through photography we may understand a little more of our own and others' experiences (Bach, 1998). Further, photographs may open the door for individuals to share their experiences (Close, 2007; Riley & Manias, 2004). Photographs may be a helpful medium because they can evoke emotions, thoughts, and imagination prior to being expressed through spoken or written language.

Harper (2000) has suggested that photographs are interpretive and socially constructed because the social locations of both the researcher and the participants are at work when a photo is taken. Social aspects may include histories, institutions, and identities. Kruse (1999) also proposed that photographs are extensions of "self-portraits, a reflection of the self" (p. 144-145). Photographs that represent personal events may offer alternative expressions of experience. Photography is not only a research method but

also a form of visual language (Close, 2007; Fyfe & Law, 1988). In this study, we examined how the experiences of living with CKD were expressed through symbols.

Chronic Kidney Disease

CKD refers to a decrease in kidney function or damage to the kidneys for a minimum of 3 months (Kidney Foundation of Canada, 2011). CKD characteristically begins slowly, devoid of apparent symptoms, and develops over years. End stage renal disease is the final stage of CKD when the organs have less than 15% of normal function (Kidney Foundation of Canada, 2011). People who are at this stage require dialysis and they may be considered for kidney transplants. Treatment is multifaceted and involves dietary and fluid constraints, medications, and dialysis. Dialysis may be delivered through hemodialysis (where blood is cleaned through an artificial kidney) or peritoneal dialysis (where the inside of a person's abdomen is filled with a special dialysis fluid and drained periodically to remove water and toxins). Those who are not candidates for renal transplants have a significantly shortened life expectancy (Moss, 2002; Robert Wood Johnson Foundation, 2003). Consequently, CKD is both a chronic and life-threatening illness, and when diagnosed, individuals face a transformed quality of life (Finkelstein, Wuerth & Finkelstein, 2009; Fukuhara, Yamazaki, Hayashino & Green, 2007; Mapes et al., 2003; Molzahn, 2006).

Methods

Narrative Inquiry

We undertook a secondary analysis of data from the project entitled *Re-stor(y)ing Life Within Life-threatening Illness* (Sheilds et al., 2011) that explored people's stories of facing life-threatening illnesses within the context of cancer, CKD, and HIV/AIDS. In

this study, we analyzed the symbols identified by people living with CKD and the interviews about their symbols. Narrative inquiry, located in a social constructionist perspective, guided our study. Through the lens of social constructionism, stories can be seen to be created by people who are influenced by society as they generate their accounts and interpretations. Telling stories has been one of the predominant ways we have filled our lives and communities with meaning. It is through our stories that we compose meaning from the world. Yet such construction does not happen in isolation. We are further constructed or inscribed by our world (Crotty, 1998; Lather, 1991). Our narratives are consequentially co-authored in relationship with others and the world. Expression of our experiences can be expressed in language that is not limited to oral or written forms, but encompasses the visual (Riessman, 2008).

Participants

Participants were recruited through purposeful and snowball sampling via advertisements in strategic locations. Thirteen people with CKD volunteered.[64] We asked them to identify symbols that represented their experiences of their illness and, if possible, we would photograph their symbols. They were interviewed on two separate occasions approximately 10 months apart. Interviews were audio-recorded and transcribed. Twenty-two interviews were included in this study. Three participants died before the second interview and one individual was too ill to complete it. The participants were diverse in age (43-83 years; mean=65), gender (9 male, 4 female), time from diagnosis (1-50 yrs), and treatment modality (conservative management, dialysis, and 3 kidney transplants). Several had more than one illness (five had cancer and one had

[64] Thirteen people were included in this study. One additional participant was included in manuscript three because after the first interview, he withdrew from the study. Thus, he did not go on to identify a representational symbol.

HIV). All participants resided in a midsized urban area in Canada. Inclusion criteria were ability to speak English, at least 12 months experience with CKD, and willingness to share experiences of their illness and its impact on their lives.

Ethical Considerations

We received ethical approval by a University Human Research and Ethics Board (HREB) for this secondary analysis. The original project also had HREB approval. Confidentiality of all participants was protected. In this paper, pseudonyms are used[65] and quotes are verbatim.

Photography of Symbols

In this study, we have used the word "symbol" with intention. As Remen (2011) has suggested, objects become symbols when they are imbued with meaning. According to Emmison and Smith (2000), visual research incorporates, but is not limited to, images and photography. Symbols that represented participants' experiences of living with CKD offered a means of expression that both augmented and transcended oral description.

All participants identified symbols that represented their experiences. However, two participants described symbols that we could not photograph because of their abstract nature. When possible, we asked participants if we could photograph their symbols. Participants were also given the option to take their own photographs so that images could be constructed by participants; however, all declined. We offered this option because the participant acting as photographer retains control in aiming the camera and

[65] Different pseudonyms are used in manuscript three. The reason for this is that many publications will come out of the *Re-stor(y)ing* project. All participants will be sent copies of publications. We did not want participants to be able to compile stories related to certain participants that might breach confidentiality and reveal identities.

choosing what and how to frame an image (Emmison & Smith, 2000). Generating an image itself may be considered a construction of reality.

In this study, symbols incorporated the use of photography but were not limited to it if the symbol was abstract. Symbols were photographed in context, usually in the person's home. We placed the symbol on a grey backdrop for consistency and for close-up photographs. All photographs were taken with a digital camera. Either electronic or paper copies of all images were given to participants on completion of the study.

Visual Narrative Analysis

Our analysis was guided by Riessman's (2008) approach using three sites of narrative visual analysis. Riessman drew on Rose (2001) to develop these methods. The first site is to look at the story of the production of an image including the image-making process and the social identities of the image-maker and recipient. The second method is to focus on the image itself, what it includes, how components are arranged, and what story it may suggest. The last site of inquiry is to look at how the image is read by different audiences and what stories viewers may bring to an image.[66] We went through each site of analysis for all images and integrated close readings of the transcripts to analyze the stories that participants brought to their own symbols. In this manner, participants were able "to story their meanings collaboratively with investigators" (Riessman, 2008, p. 143). We chose to focus on visual narrative analysis that pivoted upon participants' narratives and not purely analysis of symbols and the meanings that they conveyed to us as researchers. NVIVO was used to assist in coding the transcripts.

[66] We created a photo album that included all the photographs of all symbols. We continually looked at this album as we worked through the three sites of visual narrative analysis.

As we engaged in narrative visual analysis, we acknowledged that we were not just listeners but also narrators. Attention to rigour and truth claims was pivotal during analysis. Given that we engaged in secondary analysis, we could not return to participants. Instead, we kept audit trails of coding, sub-coding, and analytic decisions so that another researcher could examine and verify our decision-making and interpretation of findings. Conversation among researchers throughout the analysis was beneficial in evaluation of results. Reflexivity was a key component of our analysis, particularly when we were faced with surprises in the data. Reflexivity in narrative inquiry offered us methodological awareness of the assumptions we brought into our inquiry and how we engaged in our research (Oberg, 2004; Riessman, 2008). We engaged reflexively in our analysis through creating memos in NVIVO, journaling during analysis, and discussing analytic decisions and questions with each other.

Findings

A Snapshot of Their Lives

Each participant chose his/her own symbols. When we looked across participants, the symbols and the stories of the symbols were diverse. Our expectations were that qualitative interviews would provide thick, rich descriptions of the meanings participants brought to their symbolic representations of living with CKD from which we could create themes. Despite our anticipation of cogent explanations, these were rarely expressed.[67] Rather, the language that people used was minimal, vague, and stilted as they struggled to articulate why they chose their symbols. However, we did see three descriptive themes: hopes and inspirations, reflections on "who I am," and confrontations

[67] With unmet expectations about participants' descriptions of the symbols, I encountered many questions about how symbols and narrative could best be analyzed.

of illness. Not all participants are represented in each theme; however, all participants are represented across the three themes. The thematic analysis is descriptive in nature meaning that findings are presented descriptively so that we convey the range of responses.[68]

Hopes and inspirations.

The symbols that participants chose often represented characteristics of hope and inspiration while living with CKD. For example, Erica showed a photograph of her two children hugging on the beach because they were her reason to keep living. As she said, "they've just kept me going." She said,

> So I've sort of stopped planning long term – I mean I plan to be here for my daughter's grad – she's in grade 11 so that's not too far down the road and I plan to be here for all of that – their grads and weddings and - but nobody knows, right? So that's really where I'm at. Right now I'm just taking one day at a time.

Erica alluded to the possibility of dying and missing momentous occasions. While she hoped to live, she paradoxically acknowledged she may not and repeatedly stated that "nobody knows."

Griffin displayed a picture of a musician because the artist was his inspiration and he said, "I get lost in [the music] you know…it's a sound painting." He told stories of attending concerts, collecting memorabilia, writing about this music, and listening to his favourite songs. Griffin explained,

> So that's um that's my inspiration there...and his music have always been able – I listen to it all the time but I haven't listened to it for a year. I've shut it off. I've

[68] I struggled with creating themes that would not be presented as generalizations within the group of participants. My struggle was to not use themes as if they were creating order out of disorder and inadvertently imposing tidiness out of people's messy experiences.

> shut myself off from everything because of this, I have to concentrate on getting healthy and become more zen-like maybe, I don't know.

Griffin had not been out of bed for over a year due to illness. When the interviewer asked Griffin why he hadn't been listening to this artist's music, he explained that it was because he had "been in bed. Got to call people up all the time you know." In other words, he needed assistance to listen to his music. Although Griffin had been "shut off" for a year, the artist inspired him and memories of this music still represented his experiences of living with CKD. Griffin died before the follow-up interview.

Hopes to stay alive were represented in Contessa's photograph of her eight grandchildren about whom she said, "they mean more to me than anything else right now." Her hope was to see her grandchildren grow up. Yet at the same time, she thought of wanting to die.

> Interviewer: How often would you say that you think about wanting to die? Often?
>
> Contessa: No. Not very often at all. Maybe once a month – I don't think it's that often because most of my push is towards, I don't want to die. I want to stay with them [grandchildren] at least for five more years. And I'd prefer 10 or 20. I think 20 might be a bit optimistic.

Hope in light of death provided Contessa with reasons to persist through illness, surgeries, and dialysis.

John chose two framed photographs of people he had met on his diving trips prior to living with CKD. These photographs reminded him that he "had a good life" and these memories provided both strength and inspiration. He explained, "I think one of the reasons why we have such in our lives, such a good outlook to doing this [dialysis] was

no trouble is that I have no regrets what I've done. I don't feel cut off." While many individuals living with CKD, such as John, could not travel due to the dialysis, John had previously travelled and dived extensively prior to his illness and these memories sustained him during illness.

Another participant, Douglas, did not have a symbol to show but he told of his hopes to buy a Jeep Grand Cherokee to pull a trailer so that he and his partner could go camping like they used to before he got sick. He hoped that future days would be like days of the past. He said, "Actually, [my partner] and I used to go camping every day off. Every day off without fail." These plans became "something to work at." Douglas had a long history of camping. As a child he was a part of a camping club that taught survival training. Douglas died before the next interview and although we do not know if he got to go camping one more time, we know that his love of the outdoors remained.

Reflections on "who I am."

Many symbols were chosen because they reflected a person and the things that were important in that person's life which included, but were not limited to, CKD. For example, Bryce said that food brought him joy in life. He said, "that's all I really care about is food." Food was the most important thing in his life. His career had also been in food services until he needed to retire early due to his ill health. His symbol was a cluster of apples (see Figure 2). When the interviewer asked him how it was important to him, he replied, "Um, yes, this is food and if you take some away then I'm totally lost…with this group of apples I feel whole and when you take a few apples away then I'm losing something." Bryce's reflections on identity were expressed through feelings of wholeness and loss.

Figure 2. "With this group of apples I feel whole."

While Bryce chose food as a reflection of himself, Elsie described her piano as her symbol because, as she said, "it was a part of me" and "part of my life." She further explained, "My piano was something important to me…because I started playing the piano when I was six." Just before the first interview, Elsie had given her piano to her grandchildren. She said, "when the grandchildren came the first thing they did was rush to the piano and start tinkling on it and so we gave that to them ah a few months ago." Elsie gave away her piano, one of her most treasured possessions, only months before she died after illness compounded with CKD.

CKD was the "first major setback" of Jake's life. His life had been good and he had found "honour" in his career as a flight engineer with the Air Force. His symbols were a copy of his flight engineer wings and a picture of a plane. Jake referred to his work on this plane as "my biggest and most important job" and "my favourite time of

life." He said "I never had a bad time" until diagnosed with CKD and then "it of course changed my whole life." Jake described life in two stages: before and after CKD. Yet he chose the symbol of the airplane, associated with life before CKD, to represent his experiences of life after CKD. His symbols reflected who he was as a person and were not limited to his illness.

Roger said, "I'm a very emotional person but I never cried over [CKD]." One exception was offered through the symbols that he chose: memories of Filipino woman on a cruise line and a painting hook. He took a painting hook, stamped with the corporate name "Sears," on his first cruise after starting peritoneal dialysis so that he could hang up his bag of dialysis solution (see Figure 3).

Figure 3. "It was just a practical solution."

But when he first boarded the ship, they could not locate his 28 boxes of dialysate solution which were essential for him to travel (and live). A woman employed by the

cruise line facilitated a search of the ship and his supplies were located only 25 minutes before the ship set sail. He said,

> And when she hugged me to say we found it, you know, she was uh she didn't want to let go kinda thing. **Nobody knows how long a hug is supposed to be.** It's just lasts how long it's supposed to last. And hers seemed to last longer. And then when we separated she was crying and I was crying. And she said I apologize for holding you for so long but **you're the first man of your age that I've hugged since my father died.** So that was emotional.

The bolded sections were repeated verbatim in two interviews, seven months apart. It was as if these expressions were ones that Roger found best expressed his experience. The intensity of the shared vulnerability between Roger and this woman seemed to influence the magnitude of this event. In contrast, the painting hook was pragmatic. He said, "It was just a practical solution" and said very little else of this second symbol. These symbols represented who he was as a person, in his own word, "very emotional" and yet also pragmatic.

Confrontations of illness.

As participants faced the threat of life in CKD, they confronted their illness in numerous ways. Dennis made sense of his illness by seeing himself as lucky. As a symbol, he selected a photo of himself with his four siblings and spoke about his youngest brother. While he considered himself "really lucky" and supported, his brother did not have support and "had a lot of rough luck." Although Dennis shared five illnesses, in addition to CKD, with his brother, it was luck that had helped him confront CKD and remain alive. His brother had died 6 years earlier.

Katelyn chose Tchaikovsky's first violin concerto because she fell asleep many nights listening to this music which her husband played as he cleaned out her home dialysis machine after her dialysis. She said that this piece of music had "been with me in my journey" and she "loved it." Her daily confrontation of her illness was symbolized melodically.

Trevor was also regularly reminded of his illness and his need for technology to extend his life. He selected a coffee filter as his symbol because "dialysis filters things" and he referred to this as a "positive" symbol. He also identified a "negative" symbol, a chain "because you're chained to a [dialysis] machine." The tensions inherent in the interplay of positives and negatives coexisted and created complexity in facing a chronic and life-threatening illness.

One participant, Carlton, selected a photo of himself at 18 years of age with his parents. The photo was taken in Europe in 1944 during WWII. He and his family were Jews who successfully hid from the Nazis. For Carlton, his father was his inspiration. He said,

> I think dad knew he had a bad kidney and he must have been fighting it but medical knowledge was not as good as today….Well the only thing I would recommend is that to live with a chronic sickness, you better get used to it, in a way, and fight it all the way. Cause you, sooner or later you're going to die anyways so (laughs) you might as well did something useful even if it's the end.

His stories about this photograph focused on surviving the war. His father made illegal papers for Carlton indicating that he was 16 years of age when he was in fact 18, so that he would not be conscripted. His father also made illegal papers for others. As his father

fought underground against the Nazis, Carlton applied the same principles to confronting illness as a "daily fight" to prevent advancement of CKD. He explained that in light of surviving the war, CKD is "just one thing of your life."

The symbols that the participants chose were snapshots of their lives. Characteristically they drew attention to the hopes and inspirations in their lives as they lived daily with CKD. The symbols highlighted who they were as individuals while they also characterized the ways that participants grappled with CKD as they confronted living with a chronic and life-threatening illness. Most participants did not find it easy to discuss their symbols, and they used innovative forms of language when they could express the symbolism.

Challenges in Describing Symbols

In relation to our second research question of how experiences of living with CKD were expressed through symbols, we were intrigued by the ways in which participants worked to translate symbols into verbal language. Expression through symbols was augmented through categories of stories of memories, emotions, and poetic devices.

Stories of memories.

All participants chose symbols that represented profound memories from the past as told in stories. For some participants, such memories evoked visceral, embodied responses. By embodied, we mean more than bodily senses (Gadow, 2000a, 2000b), but also bodily "knowledge and information about ourselves, others, and the sociopolitical context that we may not yet be capable of languaging" (Doane & Varcoe, 2005, p. 160). For example, when Carlton told long stories from WWII he paused and explained, "oh

there is so many things coming up in my mind." The memories came quickly, one after the other. Carlton literally shook, saying "I'm sort of shaking by the memory." When the interviewer asked him if there were some things related to his symbol that were challenging to put into words, he said,

> Well, it's constant fear. Uh, there was a constant fear. Well I had a Jewish grandmother so I was supposed to wear, after so many weeks of the Germans got worse, yellow star. But dad said, hide it, don't do it. So he and me, I remember that we only did that for about two or three months. We wore the thing but hid it. And of course that was illegal. And that was scary.…I knew Jewish people or Jewish-origin people who were tortured in our building.

Carlton expressed visceral, embodied memories of this significant event from 67 years ago. Yet he also told of these memories to symbolize his current experiences of CKD.

Katelyn's symbol was chosen due to the memories associated with music. She said,

> I cannot hear that violin concerto to this day without being taken back, sitting on the chair being hooked up with needles with dialysis. So I wouldn't say it's something that's been with me in my journey. It's something that is really up here, is so in my brain that when I hear that piece of music I think: dialysis. Fascinating isn't it because – The connection is very, very strong, even after all these years…. Um so yeah I would say that's the one thing that, that I viscerally associate with dialysis.

While it did not encompass the totality of her metaphoric "journey" with CKD, she described the embodied memories associated with visceral and cognitive ("in my brain")

responses. Similarly, for Douglas, hopes of a jeep were spurred on by memories of camping. When Douglas was asked about what camping meant to him, he identified a visceral response. He said, "Relaxation. Go out, sit by the fire – Well you're away from home. You've got your little home away from home you know."

Other people did not have visceral responses but still described their remarkable memories as reasons for choosing their symbols. In reference to his time with the Air Force, Jake said "I think about those days all the time." In his work, he travelled all over the world and he told detailed stories of these travels. Similarly, John had done extensive travel on diving trips before being diagnosed with CKD. He said,

> That's sort of it – just see, keep us going because I don't need keeping going, I'm not depressed, I haven't been, but it's nice to have the memories – we can look back upon you know. A lot of people don't have that. So on a gloomy day or a day or just drag out a photo album and all the memories come rushing back.…It triggers things. When you sit down with someone and start talking like we do. Here one thing tricks to another, you know, the old memories come flooding back.

John poignantly depicted the interconnection between symbols and memories. His photographs served as inspiration, to "keep on going" even though he paradoxically negated needing this inspiration, linking such need with depression. For John, memories were embodied experiences that cyclically triggered stories and more memories.

Emotions.

All participants described symbols with the aid of emotions. A number of participants also had symbols that represented intense emotional experiences. As previously noted, John said that his photographs made him "feel good" and reminded him

to live with "no regrets." Roger referred to himself as "emotional" and he shared of both his pragmatic choice of the hook and of his shared vulnerability with the woman on the cruise. Dennis meaningfully connected with his symbol, which was his youngest brother who reminded him that he was lucky. His perception of his own luck was juxtaposed with his brother's "rough luck." Even as Dennis spoke of his brother, his eyes welled with tears as he recounted stories of his brother's suffering and his death. Participants laughed, cried, used humour, shook, or expressed fears when they told stories of their symbols. While some of these emotions were present at other times during their interviews, what was notable to us was that emotions were more frequent and a vehicle of expression when participants endeavoured to find the words to narrate about their symbols. For some participants, they only displayed certain emotions, such as crying or shaking, when they were attempting to discuss their symbols.

Poetic devices.

Discussions of symbols were frequently framed through the use of poetic devices or figures of speech as participants transformed abstract symbols into oral language. Poetic devices are also referred to as figures of speech in literary terms and examples include, but are not limited to, metaphor, paradox, and allusion.[69] The following quotation by Trevor shows how he described symbols through poetic devices. Trevor saw a coffee filter as a metaphor to positively represent dialysis filtering the blood. The negative metaphor was being chained down in dialysis, which he described this way,

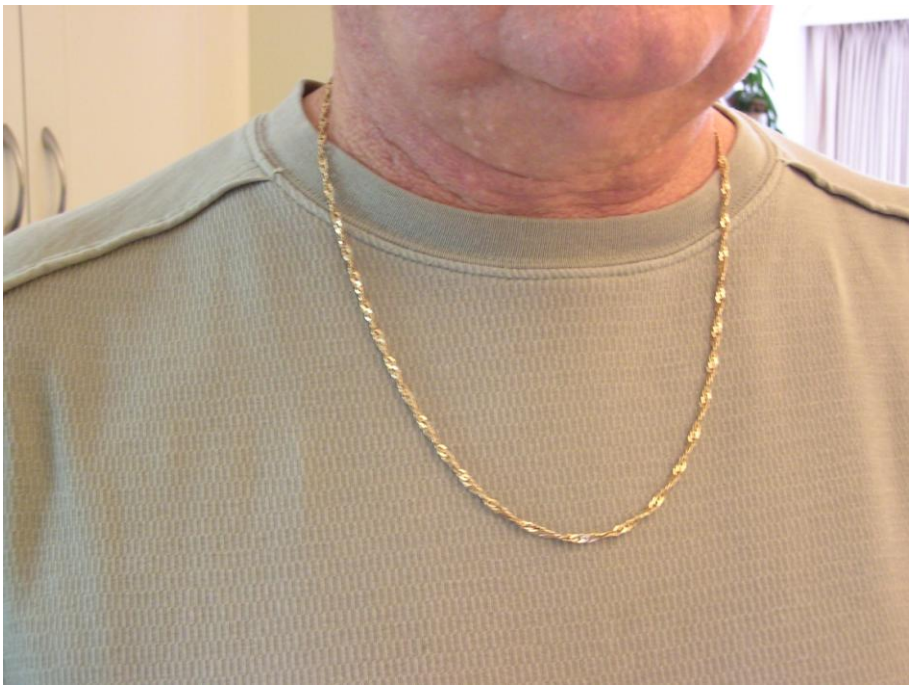
> It just slows you down. It's like a weight. So yeah it's - yeah it can be just being the chain around your neck.…It's not very heavy. It's just there. Actually I picture a,

[69] Other poetic devices used by participants included irony, oxymoron, and simile. However, they were not used often and we did not have space to provide more examples.

> yeah, actually when I picture a chain I don't mean a real heavy thing you pull a car around with. Actually it's for some reason it's just a chain around your neck that you might see a cross on. And I'm not religious.

As Trevor described the chain, his explanation shifted as he tried to express the symbol he had in his mind. He showed a fine gold chain (see Figure 4) but initially his description was that of a heavy weight. He described it as both a "weight" and "not heavy." Trevor held these paradoxical explanations simultaneously, perhaps because some days the "weight" of dialysis was heavy and other days it was light. While struggling to describe his symbols, his words were not only metaphorical but also paradoxical.

Figure 4. "A chain around your neck."



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Poetic devices also included allusion to unsayable characteristics. By unsayable, we mean that which is not expressed yet alluded to through language, and may be

conscious or unconscious (Schick Makaroff, 2011a). The presence of unsayable aspects of experience was evident in allusions through language when participants sought to discuss their symbols. For instance, when John spoke of his photographs as inspiration to "keep on going," the interviewer asked,

> What does it mean to you to kind of keep on going?
>
> John: Well I didn't – I don't really think of it on-going or coming to an end or whatever since it's been such an easy thing to do. Mind you a little drawback – that's nothing here nor there. It's a daily routine.

For John, thoughts of death ("coming to an end") resulting from CKD were unsayable. In addition, "on-going" future treatments were also unthinkable. Photographs of good memories served to keep him going in the "daily routine" without thinking too far into the future.

Overall, oral language seemed to fail participants from fully translating symbols of living with CKD into verbal expression. This was evident in the participants' challenges in discussing why they chose their symbols to represent living with CKD. As Roger said, "there's not too much I can say about a little hook, is there?" Aspects of experience which were displayed through symbols made comprehensive telling impossible, yet poetic devices provide an alternative conduit for expression.

Discussion: Is a Symbol Worth A Thousand Words?

As the cliché goes, "A picture is worth a thousand words."[70] We found that a picture can indeed replace a thousand words. Even though most participants provided

[70] One of my expectations was that people would be able to express their reasons for choosing their symbols to represent CKD. I originally assumed that at least a thousand words would be expressed about the symbols. However, this was not the case. In retrospect, given my interest in the unsayable, it is surprising to me that I thought participants would be able to express their choices with greater verbal acumen. While I

explanations, they were frequently incomplete, as though the symbols represented inexplicable aspects of experiences of living with an illness that threatened life. Although we expected participants to story their meanings (Riessman, 2008), we learned in our study that spoken language does not fully bridge expression from symbolic representation to verbal articulation. While the ineffable nature of living with a life-threatening illness, and the unsayable aspects inherent in symbols were not unanticipated, the degree to which we found this in the data was nonetheless surprising. Scholars have found that while we struggle to express the unsayable in speech (Rogers, 2007a; Mitchell, 2009; Rominger, 2010), alternative expression has been found through metaphor (Harrell, 2005; Mitchell, 2009; Rogers et al., 1999), poetry/creative writing (Harrell, 2005), music (Rogers, 2007a), and art (Rominger, 2010; Rogers, 2007a). As we studied the interface between narratives and symbols, as in the research of the previously mentioned authors, we too found alternative expression through aesthetics. Incorporation of symbols into qualitative research illuminated for us the poly-vocality (Bakhtin, 1981) or multiple expressions of experiences that accompany responses to a life-altering event such as a serious illness. Our findings confirm Bakhtin's (1981) notion that speech may be inadequate to express the multiplicity of meanings that we seek to convey. Our unmet expectations made us wonder if other qualitative inquiries have perhaps inappropriately expected more of oral language in its representation of experience than is possible.

E. Bruner states that "irony arises in the open space between what is said and what is experienced" (1984, p. 14). Irony means, as a noun, "the expression of one's meaning by using language that normally signifies the opposite, typically for humorous

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encourage qualitative researchers not to over-rely on spoken discourse, it is easy to forget this message given our Western Euro-centric learned social reliance on speech as a rational expression (Reiss, 1982).

or emphatic effect" ("Irony", 2011). In a literal sense, we saw participants use irony and other poetic or literary devices to bridge the translation of expression from symbols. In a figurative sense, it is ironic to expect spoken and written language to encompass all that is experienced, as E. Bruner has aptly pointed out.[71] While we do not contend that images or symbols speak for themselves in qualitative research, we question whether discourse can fill this void or is always necessary. Certainly we interpret and contextualize symbols with participants' explanations along with the theories and concepts that we bring to the conversation. We also make claims in writing about images that we use in our inquiry. We recommend, however, that we do so with a reserve that acknowledges that all cannot be encompassed either verbally or cursively. An unsayable aspect of symbols may reside innately in their aesthetic nature.

Throughout the long history of nursing, scholars have discussed the aesthetic nature of knowledge. Carper (1978) proposed aesthetic knowing as one of four patterns of knowing. Other nurse scholars have gone on to develop aesthetics as a form or inquiry and knowledge (Chinn, Maeve & Bostick, 1997; Gadow, 2000a, 2000b). Alternative approaches to knowledge in practice such as strength-based knowing (that builds on capacity) or person / family centered care (Doane & Varcoe, 2005) are in stark contrast to approaches that stem from a focus on deficits (Orem, 1991). While medical conditions seen as deficits can be easy points of access for practitioners, the findings from this study remind us that even when we asked people to represent their diagnosed illness, they identified symbols that represented themselves as whole people, full of hopes and

[71] All that we experience cannot be said. Parts of our experiences are inherently unsayable because we are bound by language. Language cannot express the totality of experience or life. And yet we hold tightly to language as if it is the "be all and end all," but this is a myth. Experience is more than language. Language is simply one representation, a good one, yet an incomplete representation of life as it is lived and experienced.

inspirations as they confronted their illness. What is significant for healthcare practitioners is that knowing people as people, not as patients with deficits, can offer a profound shift in an approach to practice.

Symbols provided a medium to express noteworthy characteristics that participants attached to living with CKD. We were surprised that none of the symbols were inherently medical despite the highly technical nature of treatment for CKD and the fact that we asked them to represent their experiences with medical illness. For example, symbols did not include dialysis access sites (fistulas in arms for hemodialysis or catheters in abdomens for peritoneal dialysis), bags of dialysis fluid, or dialysis machines. Rather, symbols were pictures of participants' lives as a whole, of which CKD was one aspect. Symbols with the closest linkages to the medical lifeworld included a painting hook, memories of an employee on a cruise ship, Tchaikovsky's first violin concerto, a coffee filter, and a chain – none of which are immediately obvious until we look at the stories participants told about these symbols. While symbols did not reference medical intervention, neither did they refer to the participants' own bodies. Why? Perhaps, as others have suggested (Bell, 2002; Frank, 2002; Riessman, 2008), one may experience convoluted feelings of control over one's own body once it is constructed as the body of a patient. In the qualitative nursing research on lived experiences of CKD, authors have also found that people living with CKD struggled to remain embodied while having a reluctant partnership with dialysis technology (Moran, Scott, & Darbyshire, 2009; Nagle, 1998; Rittman, Northsea, Hausauer, Green, & Swanson, 1993). Further, these authors have suggested that participants actively sought to sustain wholeness. These findings are supported in our study as expressed through both verbal and visual languages.

Symbols constantly surround us. We construct and give meaning to them consistently. Emmison and Smith (2000) have asserted that visual data are all around us in our lives and in our research. However, much of this data is often overlooked. Visual inquiry may transcend the study of images towards investigation of the meaning of what can be seen in patient's everyday surroundings. In this study, the symbols that participants chose were readily available to us as researchers. They were photographs that were on their wall, stories they had told repeatedly of food or important people in their lives, and objects that were in the very room where the interviews were conducted. These findings remind us that when we engage with people in healthcare practice and research, we can be aware of visual images and recognize them as potential openings into people's worlds and the meanings of their illnesses and their lives.

Within healthcare, our points of contact with people living with CKD typically revolve around their medical and physical issues. However, in this study we see that the medical world may be just one aspect of the whole experience of living with illness. Although we asked people to identify symbols that represented living with CKD, they displayed symbols that were snapshots of their lives. These symbols illustrated that participants interpreted their illness within the tapestry of their lives as a whole, not as a separate entity, and the medical lifeworld was not at the fore but rather in the background. Representations of illness were integrated in symbols of all of life. Healthcare practitioners may wish to consider engaging with people living with CKD about what matters to them most in their lives as a whole rather than focusing primarily on the medical or physical aspects of their illness.

Participants' stories offered us critical insights into the meanings that symbols had for them as they lived with CKD. In retrospect, we placed undue expectations on participants' ability to convey through words the meaning of the symbolic representations. Qualitative researchers, including narrative inquirers, have relied heavily on spoken and written texts. Symbols and visual images offer an alternative form of communication but we found that they cannot be fully expressed in words due to the aesthetic nature of the medium. How narratives are expressed, in addition to the content of the stories, may offer researchers multiple layers of interpretation. While we recognize that we need to continue to explore how experiences of illness are expressed through the stories that we tell and the images that we portray, we would be remiss to overlook either the relationship between oral and visual language or our cultural expectations of an ability to elucidate symbols.

Chapter 6: Discussion

The goal of this qualitative study has been to examine the concept of the unsayable and to illuminate how this concept may be helpful in exploring individuals' stories and symbols of living with CKD. The overarching research question has been, "What are the unsayable aspects of experience for people living with CKD as portrayed through their stories and symbols?" Returning to this question and examining the papers from this dissertation, I now synthesize the findings and discuss the significance of the study. Further, I consider not only the issues and questions I encountered in this research, but also the limitations of this study and recommendations for future research.

Synthesis of Findings

Three main themes thread through these four manuscripts. The themes relate to 1) that which is not expressed yet alluded to; 2) suffering; and 3) communication.

The first theme that is echoed in each paper reflects two attributes of the unsayable from my concept analysis: "not expressed through language," and "alluded to through language." In the first attribute, I expand Rogers' (2006, 2007b) conceptualization of the unsayable. While she primarily focuses on language, I suggest the unsayable encompasses that which is not expressed because it is beyond articulation. The second attribute of the unsayable is echoed in my qualitative meta-synthesis (QMS) finding that experiences of living with kidney failure are not directly expressed, yet are alluded to through paradox. Although allusion and paradox are fixed in language, I suggest that they are also figures of speech we use to gesture towards that which transcends language. Nurse researchers (Curtin et al., 2002; Hagren, Pettersen, Severinsson, Lützén, & Clyne, 2001, 2005; Maxwell, 1990; Molzahn et al., 2008; Nagle,

1998) suggest that people living with kidney failure have experiences of a paradoxical nature where they hold seemingly contradictory experiences at the same time.[72] Likewise, my QMS findings are expressed paradoxically as "restricted freedom" which brings "distant connection," "dependent autonomy," "abnormal normalcy," and "uncertain hope." For example, people living with kidney failure may have experiences of *both* restriction *and* freedom, as well as experiences that extend beyond these ostensible inconsistencies. In our exploration of what 14 people living with CKD narrated as their unsayable aspects of experience, we[73] suggest five themes of that which they alluded to yet did not express. These themes are "living with death," "embodied experiences that were difficult to language," "that which was unthinkable," "unknowable mystery," and that which was "untold/unheard." Their experiences were in some ways both sayable and unsayable. We heard participants allude to experiences that are beyond language and include embodied experiences, unthinkable aspects of living with CKD, and unknowable mystery. And lastly, experiences of living with CKD are conveyed through aesthetic symbols. Symbols provide a conduit for expressing unsayable aspects of experience which transcended language. Participants' articulations of unsayable aspects were facilitated with the aid of poetic devices. Paradox was one figure of speech used by participants, but other examples included metaphor and allusion. Through allusion, participants referenced unsayable characteristics where language failed to express experiences of living with a life-threatening illness.

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[72] It is worth noting that paradoxical experiences are not limited to those who are ill. Parse (1999) contends that paradox is inherent in being human.

[73] I use "we" here to refer to myself, Dr. Laurene Sheilds, and Dr. Anita Molzahn who were co-authors on both the third and fourth manuscripts in chapters 4 and 5.

The second theme that threads through the papers pertains to the storyline of suffering as an unsayable aspect of experience for people living with CKD. Etymologically, suffering comes from "suffer" and the Latin root *sufferre*: "suf" meaning sub or under, and "ferre" meaning to bear. Suffering in this sense does not just pertain to enduring something that is painful, but also relates to passing through, undergoing, or experiencing ("Suffer", 2011). Similarly, suffering as both enduring and undergoing an experience is a theme woven through this dissertation. Scholars also link suffering with the unsayable (Cunningham, 2008; Ehrensaft, 2008; Frankl, 1959/1984; Gentile, 2006; Kruger, 2005; Lieberman & Van Horn, 2009; Mitchell, 2009; Nye, 2008; Ready, 2010; Rogers, 2007a; Rogers et al., 1999; Rominger, 2010; Rykov, 2008; Schwappach, 2008). I identify suffering as an antecedent to the concept of the unsayable. Nurse researchers also find that people living with kidney failure experience suffering (Clarkson & Robinson, 2010; Curtin et al., 2002; Hagren et al., 2001, 2005; Leung & Shiu, 2007; Maxwell, 1990; Molzahn et al., 2008; Nagle, 1998; Namiki et al., 2010; O'Brien, 1983, Rittman et al., 1993; Walton, 2002). In my QMS, I suggest that suffering is attended to in experiences of living with the restrictions and freedoms that accompany kidney failure. The subtheme of "abnormal normalcy" represents searching for "normal life" while confronting changes, suffering, and restrictions that are not "normal." Experiences of kidney failure also revolve around enduring the uncertainty and hope that accompany this chronic and life-threatening illness. Suffering for these people conjoins restriction, abnormalcy, and uncertainty with freedom, normalcy, and hope. When we examine what participants storied as unsayable aspects of experience, we observe suffering in their narratives of both "living with death," as well as embodied experiences that are difficult

to language. Suffering is evident in participants' descriptions about the symbols they chose. Specifically, in the theme "confrontation of illness," individuals' symbols reflect the intensiveness required to face living with CKD. Suffering can be identified in "stories of memories" and "emotions" that participants used as vehicles to express their experiences through language and symbols. In light of this theme that threads through the papers, I suggest that unsayable aspects of suffering may not always be resolved through speech and that they may transcend articulation. If we take this suggestion into nursing practice or research, we may enter into relationships without the expectation that aspects of suffering can or must be portrayed in language.

Unsayable aspects of suffering and illness may not be within the societal discourses of what is acceptable to discuss; thus, they may be overlooked and outside the societal privileging of language and speech. If we can acknowledge that aspects of illness and suffering are beyond articulation, then the concept of the unsayable is relevant and within the purview of nursing. Given that nursing's metaparadigm is focused on the interconnections between human beings, environment, health, and nursing (Fawcett, 2005), then understanding of illness experiences and suffering are foundational to the discipline. In this dissertation, I contribute to the development of nursing knowledge through the recognition that promotion of health and healing may or may not include expressions of all aspects of illness and suffering. Understanding sayable and unsayable aspects of experience related to suffering will augment nursing's disciplinary knowledge.

The third theme that runs through the four papers pertains to communication. In chapter 2, I propose that two antecedents of unsayable aspects of experience are "challenges in communication" and communication as it arises in relationships. Scholars

who study the experiences of living with kidney failure also identify communication as an integral element. For example, in the theme "distant connection," I draw attention to both the isolation and the closeness that unfolded in relationships. In the theme "dependent autonomy," I explain that people with kidney failure depend on communication with healthcare professionals, yet also assert their autonomy as they interact with the healthcare system. In chapter 4, we recognize communication in the last theme regarding that which participants believed was unsayable for others to say to them, a theme entitled "untold/unheard: 'they never told you.'" Participants shared stories of times that healthcare professionals either did not talk to them, did not listen to them, or did not tell them about aspects of the their care. Although participants perceived they were not told, I wonder if practitioners had made statements that had been unheard. In the final paper, we acknowledge that, regarding their chosen symbols, participants used both "stories of memories" and "emotions" to communicate experiences of living with CKD. The "stories of memories" and "emotions" were vehicles for expression pertaining to that which was otherwise hard to put into language and perhaps beyond language. Furthermore, incorporation of the representational symbols themselves offers an alternative form of communicating or conveying that which surpasses language.

Significance of the Study

Looking back retrospectively, I can now see a number of ideas that I did not understand when I initiated this dissertation, but learned along the way. Many of these emergent ideas are what make this dissertation significant. I now address these ideas in relation to gaps in the literature and implications for nursing.

Addressing Gaps in the Literature

When I conducted this study, I found a number of gaps in the literature that I had not anticipated. For example, when I studied the most commonly used definitions of the unsayable, I realized that they were not necessarily appropriate for nursing because a predominant, underlying assumption was that the unsayable can be − perhaps *needs to be* − resolved through bringing thought to spoken words. Further, the unsayable is assumed to exist solely within language. In response, I define the unsayable as that which is not expressed yet alluded to through language and may be conscious or unconscious. This new definition provided me with a clear position from which I could examine what people portrayed through stories and symbols as unsayable aspects of their experience with CKD as well as elements that transcend language. Further, I could challenge the assumption that the unsayable should be resolved through speech by a transformation of unconsciousness to consciousness. These assumptions are perhaps underpinned by modern Western expectations of a rational culture (Reiss, 1982). We can trace such rationalist assumptions back to Plato who valued reason above all else. Plato outlined in the *Republic* (1956) a hierarchy of the faculties:

> And now, corresponding to these four divisions [knowledge, being, arts, and geometry/cognate sciences], let there be four faculties in the soul – reason answering to the highest, understanding to the second, faith (or conviction) to the third, and perception of shadows to the last – and let there be a scale of them, and let us suppose that the several faculties have clearness in the same degree that their objects have truth. (p. 478)

It is clear that Plato revered intellect over the senses and he believed the two were clearly separate.[74] Plato's connection between the truth of objects and the ranking of faculties implied that truth also encompasses the faculties with reason at the pinnacle. In contrast to this rationalism, I challenge these assumptions through my conceptualization of the unsayable, and I call for inquiry into aspects of experiences that may not be known, languaged, or named. Such inquiry does not abandon the need for reason but acknowledges that it is but one of many pursuits of knowledge.

In this dissertation, I offer the first QMS on the experiences of people living with CKD. When I looked at all the nursing research literature in this area, I was surprised to find only 13 studies (Clarkson & Robinson, 2010; Curtin & Mapes, 2001; Curtin et al., 2002; Hagren et al., 2001, 2005; Leung & Shiu, 2007; Maxwell, 1990; Molzahn et al., 2008; Moran et al., 2009; Nagle, 1998; Namiki et al., 2010; Rittman et al., 1993; Walton, 2002). While I am grateful to the scholars who have pioneered this topic and added to the literature, more qualitative and interpretive inquiry related to the complex experiences of people living with kidney failure is warranted. In this inquiry, I add to this body of qualitative research on the experiences of people living with CKD.

This study is the only one of its kind, and through it I study the unsayable as it has been portrayed in the stories and symbols of people living with CKD. Through examining 46 interviews that were gathered over 3 years, we received rich, longitudinal data for secondary analysis. No other authors have either studied the unsayable aspects of experience for people living with CKD or incorporated aesthetic expressions in such a pursuit.

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[74] Although Plato did not dichotomize between language and thought, this distinction was established in the seventeenth century by what Reiss (1982) calls "analytico-referential" or the modern form of discourse.

Although a few authors address the experiences of people living with CKD who have considered death (Kataoka-Yahiro, Conde, Wong, Page & Peller, 2010; Tanyi & Werner, 2008), I recognize a gap in the nephrology literature that needs exploration. In my QMS, I identify an absence of recognition regarding the life-threatening nature of kidney failure. Only three researchers had themes which reflected people confronting death (Curtin et al., 2002; Molzahn et al., 2008; Walton, 2002). The unsayable aspects of facing a life-threatening illness are a significant element of this dissertation. One of the most predominant themes from chapter 4 focuses on participants' unsayable aspects of of living with death. This theme is echoed in chapter 5; participants acknowledged that in living with CKD, they encountered their own mortality, but they also retained a focus on life. In these 46 interviews, people wanted to talk about death. I would suggest that nephrology nurses not only acknowledge patients' desires to extend life, but also create openings for people to express their concerns, which may include discussion of death.

Another area with a shortage of literature is research that considers how narrative inquiry may contribute to nursing's body of knowledge. Development of narrative research in nursing may offer resources to future students and scholars. Specifically in the chapters 4 and 5, we add to this needed body of literature. Narrative inquiry is useful to nursing because stories offer patients and nurses a way to share individual and collective or common narratives. Narrative inquiry does not guide nurses to empirically verify truthfulness of stories, but rather it provides an opening through which stories may be (re)interpreted from one telling to the next by patients/participants and nurses. One of the powerful benefits of incorporating storytelling in practice and research is that it offers people the potential to shape not only their identities, but also their own understanding of

their experiences and their world (Holloway & Freshwater, 2007; Mehl-Madrona, 2007; Riessman, 2008). Narratives, when viewed through a social constructionist lens, offer a view of individuals' realities that are constructed or inscribed by our world (Lather, 1991) and in turn, reinforced by cultural narratives. Significantly, narrative inquiry offered me a way to explore the unsayable aspects of experience because when participants were invited to tell their stories, they were presented with an opportunity to express in other ways that which might have been otherwise difficult or perhaps impossible to put into language. This, in turn, has implications for narrative inquiry. The ways in which researchers conduct narrative inquiry may develop when they study experiences through alternative expressions such as through the arts, embodied experiences, or silence. Stories do not arise solely from language in a definitional sense of the term (Reiss, 1982), but they encompass aesthetics, emotions, or figures of speech (such as metaphor, irony, allusion). Narrative inquiry will develop when expressions of reality are not limited to language but might encompass unsayable aspects of experience.

Implications for Nursing

My thesis in this study is that unsayable aspects of experience related to CKD should not and cannot always be brought to speech because they rest both within and beyond language. It is for this reason that this dissertation is entitled *Listening for the Unsayable* rather than *Saying the Unsayable*. How nurses listen for unsayable aspects of living with CKD will likely be highly subjective, interpreted from language (such as stories and figures of speech) and that which is beyond language (such as symbols or embodied responses). There is no scale or test to alert us to "evidence" of the unsayable, nor do I suggest that such a test be developed. As a starting point to becoming aware of

the unsayable, in my definition I do not suggest that the unsayable refers simply to that which is missing from language. The unsayable includes that which is not named or missing (Allphin, 2007; Frankl, 1959/1985; Kruger, 2005; Livingston, 2006; Rogers et al., 1999; Rominger, 2010; Rubin & Winrob, 2010; Rykov, 2008; Schwappach, 2008), but is not limited to this notion. The reason I believe this is important is because nurses cannot assume that individuals living with CKD can always say all they experience (E. Bruner, 1986; Riessman, 1993). Further, listening for what is not named or missing from language still constrains unsayable aspects of experience solely to language. When we recognize that in listening for the unsayable we attend to what is beyond articulation, we may listen differently; for example, we may listen in a manner that is neither an action nor an end or goal, but rather listen as those fully attuned to the other, finding a way of being in relation with the other.

Listening for unsayable aspects of experience has implications for nursing practice. I believe that listening can be directed either by the nurse as a mechanistic task to receive required information, or by the patient when the nurse facilitates an opening to allow another to lead the process. The former view of listening allows nurses to prioritize their agenda and direct communication according to their purposes; the latter view prioritizes patients, empowering them to direct communication (through language and non-language). Allowing patients to direct care based on their needs not only honours people as "existential selves"[75] (Gadow, 2009) but empowers them to express what they choose to say or not to say. Listening in this manner promotes a sense of agency,

[75] Gadow (1999) explains that "respect for persons as existential selves involves more than detached regard for abstract autonomy; it entails attentive discernment and valuing of an individual as unique" (p. 575).

narrated from embodied experiences which are significant in the development of nursing knowledge (Gadow, 2000b).

In this dissertation, I focus on listening for unsayable aspects of experience and, in turn, I contribute to the nursing knowledge in a number of ways. From a paradigmatic perspective, this study is positioned in the social constructionist paradigm which presents a unique avenue to engage in theory development and critical thinking within the discipline (Cody, 2002). Through this lens, I highlight elements of experience related to CKD that are beyond words, only "alluded to", due to the recursive interplay between the individual and society which shapes thought and language. According to Carper's (1978) four patterns of knowing in nursing, this study is broadly situated in two of these patterns: aesthetics and personal knowledge in nursing.[76] Chinn (1994) states that "personal knowledge and aesthetics can only be represented in symbolic forms such as actions, sounds, or pictures, or in metaphoric language such as poetry or story" (p. 24). My methodology (narrative inquiry of personal narratives and symbols) and my findings from this study resonate with Chinn's statement pertaining to these two forms of knowing in nursing. First, aesthetics include knowing that is intersubjective. It is a pivotal aspect to nursing as a discipline because of nursing's relationship with profound life experiences (i.e. birth, death, and suffering) that may be expressed within or beyond language (Chinn et al., 1997). Aesthetic knowing requires modes of inquiry (such as narrative inquiry) that are unique from and complementary to modes used in empirics (Carper, 1978; Chinn, 1994; Chinn et al., 1997). Second, personal knowledge centers on interpersonal relationships and interactions between the nurse and the patient (Carper, 1978). Communication is a key element in such personal knowing and it is attended to in

[76] The other two fundamental patterns of knowing for Carper (1978) are empirics and ethics.

practice, nurse-patient relationships, and nursing theories (McGeehin Heilferty, 2009; McGilton et al., 2009).

I believe communication that offers generous listening (Remen, 2011) honours individuals as existential selves (Gadow, 2009) and adjusts the emphasis from what nurses want patients to say, to what the person chooses to narrate. The nurses' role then shifts from "intervening" to listening. In this manner, a relational narrative can be composed between the nurse and patient as a critical element in the provision of care (Gadow, 2009). When nurses enter this relationship, perhaps through being present or bearing witness, and are open to listening for the unsayable, they enact respect for people. This gives rise to valuing and attentive discernment of the uniqueness in each person.

In this study, I raise what I believe are legitimate questions about communication in nursing. Once we accept that unsayable aspects of experience are both within and beyond language, then we free our thinking and ourselves from the dominance of the discourse of modernism (Reiss, 1982). Communication now focuses less on message giving/receiving and more on human, personal expression. Rogers' (2006, 2007b) view of communicating about the unsayable is consistent with a mechanistic trajectory as psychotherapeutic endeavours transfer the unsayable from unconsciousness to consciousness. By focusing solely on resolution through language, Rogers appears to overlook her own statement that the unsayable lies beyond speech. I purport that when we start with a view of communication that assumes unsayable aspects of experience transcend language, we may shift from a mechanistic view, which focuses on "transferring" information based on people's needs or deficits (Orem, 1991), towards an aesthetic view of communication (Chinn et al., 1997; Gadow, 2000a, 2000b). By an

aesthetic view of communication I mean a perspective that encompasses inquiry that is intentionally intersubjective and includes deeply felt life experiences that may be expressed through language, silence, or art forms (Carper, 1978; Chinn et al., 1997; Gadow, 2000a, 2000b, 2009). From a social constructionist perspective, I acknowledge that cultural inscriptions of communication pertaining to profound life experiences are iteratively constructed between individuals and their societies. An aesthetic approach to communication recognizes that something may be knowable (i.e. at a visceral level) but not necessarily expressible. Future research on aesthetic views of communication is certainly warranted and would augment research on unsayable aspects of experience.

Undoubtedly there will be times when nurses will communicate with individuals and listen to their stories about aspects of experience that are unsayable, but these circumstances will always be contextual and dependent upon timing, opportunity, or individuals' willingness to talk. Nurses frequently find themselves in situations that include profoundly unsayable aspects of experience such as confronting mortality or large life questions for people with CKD as well as people in other areas of nursing practice. Such times are a part of life that does not necessarily require resolution through speech. Ultimately, when nurses are aware of the possibility of the unsayable, they may purposefully consider how they may communicate and respond.

When nurses are aware of the unsayable, they may respond in numerous ways. One response is to be present with patients (Finfgeld-Connett, 2006; Mitchell, 2009; Newman, 2008; Parse, 1992; Patterson & Zderad, 1988) to witness their experiences (Charon, 2006a, 2006b; Cody, 2007; Drought, 2001; Eifried, 2003; Tschanz, 2006), whether they are expressed or not. Another response may be to listen generously

(Remen, 2011) to the stories that people tell about CKD or other illnesses, even when it does not seem relevant to the situation at hand, because through stories patients may navigate the terrains of their illnesses (Frank, 2002, 2009; Kleinman, 1998; Mattingly, 2007). Welcoming people to tell their stories may create a conduit of expression for experiences that are otherwise hard to language.

Being present, bearing witness, and listening generously to stories may be critiqued as unrealistic in today's fast-paced practice settings that value efficiency. The shift from "doing" to "being" is anything but easy, especially given our long history with the nursing process where nurses have learned to assess, diagnose, plan, implement, and evaluate (Doenges et al., 1995; Schmiedling, 2002). I am not suggesting that we stop "doing" or providing technical care for people with CKD. Rather, it is to *how* we give this care that I am calling attention. Being present with another to listen or bear witness to experiences that transcend language is a skill that requires education and practice (Charon, 2006; Mehl-Madrona, 2007; Mitchell, 2009) that benefits not only the person with CKD, but perhaps benefits the nurse as well.

Another response to unsayable aspects of living with CKD or other illness might be to incorporate symbols that are in people's lives that have meaning to them. A simple question a nurse could ask might be, "Could you tell me about a symbol in your life that is meaningful to you?" As we show in chapter 5, such a question may provide potential openings into people's lives and exploration of meaning within illness. In this study, the symbols identified by participants reflected their interpretations of their illness within the whole of their lives, not as a distinct entity. In spite of the fact that we asked participants to represent their medical illness, they did not show symbols that were inherently medical

despite the highly technical nature of treating CKD. The significance of this finding is a reminder that although as healthcare practitioners we can become centered upon medical aspects and technical care, this may not be what matters most to people in their lives.

When nurses are aware of unsayable aspects of experience, they may not only see the complexities inherent in the lives of people living with illness or suffering, but may also seek to support them during these times of uncertainty. For example, in chapter 4 we identify that unsayable aspects of experience surface in stories or are alluded to through paradoxes, seeming contradictions, tensions, incomplete sentences, counter points, double meanings, and poetic devices where language falls short (Charon, 2006b) of encompassing experience. I would suggest that when nurses encounter these figures of speech by people with CKD, they may acknowledge that the unsayable is, at times, irresolvable because language fails to fully encompass experience. I also recommend that nurses should not necessarily press for resolution (speaking the unsayable), but rather respond to cues from the individual.

When I have spoken with nurses, other healthcare professionals, and people living with CKD about the findings from this dissertation, the most predominant "knee-jerk" response is an expectation that the unsayable should be expressed in language. The unsayable is perceived as a problem that needs to be fixed. This perception may stem from a problem-based perspective used in nursing and healthcare in which practitioners are meant to intervene (Doenges et al., 1995). Or perhaps this response stems from influence by societal understandings of communication and the therapeutic goals of many psychologists to bring the unconscious into consciousness. Scholars also identify a societal privileging of language (Adams, 2010; Gentile, 2006; Horner, 2006; Kruger,

2005; Rogers et al., 1999; Rykov, 2008; Vivona, 2006) and this plays a role in our expectation that the unsayable be resolved through speech. I suggest, however, listening for the unsayable may be easier if we can remain open to the possibility that not all things are entirely sayable and that the unsayable is only partially represented in language.

Issues I Encountered

There were a number of issues and unanswered questions that I encountered while engaging in this research. Four of these challenges pertained to maintaining confidentiality, analysing symbols, understanding concepts as evolutionary, and examining conscious and unconscious aspects of the unsayable.

First, I encountered ethical questions about confidentiality because the renal community is small and many patients know each other through treatment and patient resource groups. Some participants had also been visible in the media so their stories were easily identifiable on the internet. We chose not to provide quotations from some stories, although they were incredibly poignant, in the interests of ensuring confidentiality. Further, a number of identifying features had to be changed so that people would not be recognizable to healthcare professionals, patients, and *Re-stor(y)ing* participants who will read these manuscripts. Although I did not have problems changing these details, other researchers might have disagreed (Close, 2007). What became more uncomfortable to me was the issue of confidentiality surrounding the use of symbols.

Many participants identified symbols that showed people or images that would make them (and others) easily identifiable. Although the original *Re-stor(y)ing* consent clearly stated that these images could be shown in publications and presentations, I questioned if participants fully understood the implications of their consent. Further, the

Re-stor(y)ing team did not pursue consent from other people who were shown in photographs and therefore would not publish these photos. In some instances, participants died during the study so it was not possible to discuss the issue. I chose to err on the side of caution and did not show a number of symbols in this dissertation.

A few identifying features in the quotations about symbols were also altered to maintain confidentiality. While I did not have qualms changing features in narratives, it is difficult to determine an "ethical line" in this practice. For example, could I have altered or shown other images similar to the ones chosen by participants? Researchers are charged to protect participants' identities and attend to confidentiality when considering what images may be shown to the public (Chircop & Sheppard-LeMoine, 2004). Yet I am left with questions about whether confidentiality can be assured when symbols are included in studies. How such issues are discussed with participants needs to be clearly negotiated, often on numerous occasions. Ethical concerns are rarely discussed in the use of photography as a method, and this must be addressed in the literature.

Second, although we conduct a narrative visual analysis of symbols, I am aware that analysis of symbols is a vast area of inquiry that is not fully represented in this dissertation. Broadly, this study is related to larger bodies of literature that attend to theories of representation or the relationship between thoughts, words, symbols, meanings, and understandings. When attending to the unsayable in stories and symbols, I contest assumptions of language that are often taken for granted. Through symbols I challenge the rationalist assumption that that there is a word for every experience.

Charles Sanders Peirce (1839-1914), often recognized as the founder of pragmatism, wrote a theory of signs. Peirce (Hartshore et al., 1994) proposed that all

modes of thinking depend on the use of signs. From a philosophical perspective in structuralism, Peirce acknowledged that all experience is associated with signs (such as thought or consciousness), but not necessarily words. Signs function as mediators between external objects and our interpretive processes. In symbols, Peirce recognized one type of sign which is interpreted in reference to a "dynamical object."[77] Although Peirce's assertions that symbols cannot necessarily be translated into words are similar to our findings, his semiotic use of symbols provides an alternative approach to the analysis of participants' representational symbols. Symbols provide one of many alternative approaches to studying the unsayable in a manner that does not limit it to language.

Third, I appreciate some of the challenges surrounding the perspective of concepts as evolutionary and not static. I raise this topic here but acknowledge that I do not fully address it in my dissertation. I use Rodgers' (2000) evolutionary concept analysis method because she recognizes that concepts shift over time. However, once we define a concept, it is easy to forget that this definition is not static. When I refer to the phenomenon of concern in this dissertation as "*the* unsayable," I wondered if I am solidifying the idea. How can we discuss and research concepts in a manner that recognizes that they are not static? In reflecting on concepts and ideas, Reiss (1982) suggests that in the turn to modernism we learned to name things, define them, and place parameters around what is and is not included. In this manner, a set of discursive practices have formed our ways of thinking, being, and acting. In our postmodern era, such discursive practices, which include analyses of concepts, need to be reviewed.

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[77] Examples of symbols in Peirce's theory could include a trophy, word, phrase, or sentence.

I agree with the need for a renewal of our discursive practices, and welcome consideration of concepts within context (Duncan, Duff Cloutier & Bailey, 2007; Hupcey & Penrod, 2005; Paley, 1996; Risjord, 2009). Consideration of a concept outside of context seems to present it as if it is a single, unified idea. How do we get around these limitations in our research? Although it is next to impossible to engage in research without using concepts, I would suggest that our use of language surrounding the contexts of these concepts may move us outside of the discourse of modernism. Rodgers' evolutionary concept analysis presents one way to try and attend to concepts as dynamic, context-dependent, and open to change. Other conceptualizations of concepts in context, such as those suggested by Bateson (1979)[78], may guide researchers towards inquiry that is both philosophical and methodological.

Fourth, there were two attributes in my definition of the unsayable pertaining to that which may be conscious or unconscious, yet they remained in the background of our findings in chapters 4 and 5. The other attributes of the unsayable, that which was not expressed yet alluded to through language, seemed to come to the fore. I am left wondering how consciousness and unconsciousness may be related to unsayable aspects of experience. Given that the majority of literature I reviewed in my concept analysis was from psychology, clearly drawing upon this discipline influenced incorporation of these attributes in the definition. I believe that these attributes of the unsayable may be attended to in nursing, particularly when informed by theories that incorporate consciousness and unconsciousness.[79] For example, could it be that one of the reasons that participants provided little description when they explained their reasons for

[78] Bateson links context to meaning, stating that "without context, words and actions have no meaning at all" (p. 15).
[79] For example, see Newman's theory *Health as Expanding Consciousness* (1986, 1994, 1997, 2008).

choosing their representational symbols was that such articulation required them to translate from unconsciousness to consciousness? Although I do not have answers to this question, it would be an interesting area for further research.

Limitations

All research has limitations and this dissertation is no different. As previously identified, in creating my definition of the unsayable I reviewed literature only from psychology, nursing, and medicine from 2005 to 2010. Reviewing literature prior to 2005 from these three disciplines, along with additional disciplines such as philosophy, theology, or English, may expand conceptualization of the definition. In chapter 3, I synthesize the findings from the nursing literature on the experiences of people living with kidney failure. It is important to acknowledge that my findings are based on other investigators' findings from research with their study participants. In QMS, it is significant to recognize that there are multiple degrees to which a synthesis is removed from the level of the original participants (Sandelowski & Barroso, 2003c). Although I did not have access to original data, this does not nullify the credibility of the findings.

In chapter 4, my colleagues and I examine unsayable aspects of experience in living with CKD. Participants included those at various stages of CKD including pre-dialysis, dialysis (hemodialysis and peritoneal dialysis), and transplantation, and there were not enough data from various sub-groups to determine whether certain unsayable elements were related to their stage of CKD or their treatment modality. Given that this is a narrative inquiry, narrative knowledge is not assumed to be generalizable. All 14 participants spent the majority of their lives in developed nations including Canada and Europe, although one participant spent his childhood in Southeast Asia. Cultural

influences certainly may have influenced what participants either consciously or unconsciously thought was appropriate to say about diverse topics ranging from interactions with healthcare professionals to conversations about death. As previously identified, not all images could be shown and not all stories could be described due to issues of confidentiality.

The social constructionist approach also presents limitations. Emphasis in social constructionism is on meanings generated by people in collective constructions through explanations and descriptions in language (Gergen & Gergen, 1991, 2004). This approach limits perspective to language, yet I claim that unsayable aspects of experience transcend language. In general, social constructionism does not examine experience outside articulation, and yet this area is replete with possibility for research. Alternative lenses may facilitate inquiry of experiences that rest outside of articulation.

I offer the findings from this dissertation as representations of experience but they are inherently limited. Riessman (1993) explains that "we are interpreting and creating texts at every juncture, letting symbols stand for or take the place of the primary experience, to which we have no direct access" (p. 15). While we strive to portray narrative truth, it is important to acknowledge that the findings from this study are constructions, narratives about others' narratives. Knowledge created from this study is contextual, constructed through multiple voices, and it represents a partial reality that is both imperfect and selective (Riessman, 1993).

Recommendations for Future Research

As I have undertaken this study, I have become aware of a number of areas that may benefit from future research. For example, I recommend additional qualitative

research related to specific phenomena of concern for people living with kidney failure. There is also a need for research syntheses on the literature pertaining not only to lay caregivers' and children's experiences of living with kidney failure, but also to patients' experiences of kidney failure as published by researchers who are not nurses. Another area for future research would be a QMS on nurses' experiences of caring for people with kidney failure through which we may learn how to provide optimal care for persons living with the "restricted freedoms" of kidney failure. Research is also warranted pertaining to people's experiences of death when they are not considered palliative.

In consideration of nephrology practice, it would be interesting to examine how nurses enact the art of listening, and how patients respond when they feel that they are heard. On a more general level, there is always a listener in storytelling. When storytelling is used in nursing practice, nurses will take on the role of the listener. Inquiry into how nurses may learn to listen would be a significant addition to the discipline's body of literature. Charon (2006a) and Frank (1997) agree that listening is a fundamental and moral imperative. Future research may also examine the moral implications of such listening in nursing practice.

In this dissertation, study of participants' unsayable aspects of experience was undertaken through secondary analysis. I would suggest that future research be conducted on this topic as original research. Expression of the unsayable could be examined through the use of both narratives (interviews) and aesthetics (music, art, or movement). Such research could be with people living with CKD or with other chronic and life-threatening illnesses. Analysis of such inquiry could focus on the content of expression, what is said (Riessman, 2008), or focus could be directed by a linguistic

perspective that studies how content is narrated. Another area of research that has not been previously undertaken is nurses' experiences of unsayable situations in practice.

Lastly, in this dissertation, I limited research on unsayable aspects of experiences to those primarily expressed through stories; analysis of symbols was also interconnected with participants' narratives surrounding the meanings of their symbols. The unsayable is a concept that would benefit from future philosophical and literary inquiry. Although I propose an alternative definition of the unsayable, I recognize that it may continue to evolve, particularly along the lines of the idea that aspects of experience rest outside of articulation. In the 17th century, the French coined the term "je ne sais quoi" to express the "inexpressible as an objective, describable *something"* (Reiss, 1982, p. 39). Reiss explains that this French phrase was used to discuss the sublime, then to study taste, and eventually to examine the science of aesthetics in the 18th century. Alternative methodological approaches to research unsayable aspects of experiences that transcend language, that reference the *je ne sais quoi* that resides beyond articulation, may develop our understandings of this concept.

Conclusion

CKD is not only a progressive illness, but also a life-threatening one. The experiences of living with this illness may be difficult or impossible to language. In this study, I attended to the expressions of living with CKD which are often challenging to discuss, ineffable, or beyond words. The purpose was to explore the concept of the unsayable and to illuminate how this concept may be helpful in exploring individuals' narratives and symbols of living with CKD. I have defined the unsayable as that which is not expressed yet alluded to through language, and may be conscious or unconscious. In

light of the findings of this study, I suggest that because the unsayable is within and beyond language, not everything experienced in living with CKD can always be said nor may it always be resolved through speech. Further, symbols convey aspects of experience that cannot be translated into oral expression. Nurses are frequently involved in care with people living with CKD, listening and responding to unsayable aspects of experiences that may never be completely resolved. Acknowledging the unsayable allows nurses not only to understand the complexities inherent in the lives of people living with CKD, but also to seek to support them and to promote quality of life for those living amid this chronic and life-threatening illness.

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