Learning from Stories of People with Chronic Kidney Disease

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As a result of advances in science and technology, many people with chronic kidney disease (CKD) live longer and healthier lives. Nevertheless, the outcomes of treatment are not certain and the experience of living in-between a promise of treatment and prolonged life and the threat of death is not well understood. The experience of what happens for people in this in-between or liminal space and the impact of this experience remains unexplored.

At the end of 2004, 18,827 people in Canada were being treated by dialysis therapy for end stage renal disease (Canadian Institute for Health Information [CIHI], 2007). The 5-year survival rate of this population is 40%. In this population, 34.6% have diabetes and 34.9% have heart disease, both of which significantly increase mortality risk (CIHI, 2007). CKD carries risk to life, but the messages from health professionals about risk and prognosis are very different. The characterization of the disease influences the narratives of people experiencing the illness and inscribes their experience (Frank, 1995, 2004). The unraveling of personal narratives and the quest to re-story one’s life has been eloquently addressed by Frank (1995, 2002, 2004). However, little is understood about how people talk about these liminal experiences that are at times beyond words, uncertain, and difficult to speak of.

It is critically important that health care professionals develop a better understanding of peoples’ narratives. Misperceptions about the needs of people during this time can result in miscommunication about prognosis (both positive and negative), insensitive communication, and unnecessary or unrealistic expectations, anxiety, and trauma. These misperceptions may also be related to poor decision-making and ultimately impact the access to and effectiveness of the provision of care. Health professionals may not know the answers to many of the questions facing people with CKD yet may benefit from an awareness of the uncertainties of living within such “un-knowables” [referring to things that are both knowable and unknowable at the same time]. Ignoring the questions is clearly unhelpful (Frank, 2001). During this difficult time of uncertainty between the success of treatment and the risk of death, a better understanding of the liminal experience is important so that people with CKD can continue to be active, contributing members of society. Narrative studies are necessary to understand how people traverse experiences of liminality and in

The purpose of this study was to explore how people with chronic kidney disease (CKD) describe/story experiences of liminality associated with CKD and its treatment. This narrative inquiry was undertaken using secondary data. The people relating the stories described a number of liminal spaces, including living/not living, independence/dependence, restrictions/freedom, normal/not normal, worse off/better off, and alone/connected. Awareness of the liminal spaces can help nurses provide care that addresses the complexity of CKD.

Goal
To increase awareness in nurses caring for patients with CKD about the experiences of patients with CKD who experience life in liminal spaces.

Objectives
1. Define liminal spaces.
2. Relate the need for awareness of liminal spaces to nursing care.
3. Summarize the research findings regarding the stories of patients with CKD about their experiences with living in and managing liminal spaces.

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particular how they re-stor(y) (i.e., story, restory, and restore) their lives. Hence, the purpose of this study was to explore how liminal experiences affect understandings of health and living with CKD.

Research Question

How do people describe/story experiences of liminality associated with CKD and its treatment?

Literature Review

Many people with serious illnesses are confronted with fundamental questions about the meaning of life. Fife (2005) developed and tested a model in which constructed meaning was a key variable in individuals’ responses to traumatic events, specifically cancer and HIV/AIDS. Mellors, Erlen, Coontz, and Lucke (2001) described how people with AIDS transcend suffering. In a qualitative study of five people, they found three themes: creating a meaningful life pattern, connectedness, and self-care. Albaugh (2003) in a phenomenologic study of people with a variety of life-threatening diseases has described how spirituality provided comfort, strength, many blessings, and trust in a higher power. All participants described a sense of meaning in their lives despite the illness. Thomas-MacLean (2004) explored narrative structures in women with breast cancer and found evidence of Frank's narrative types including restitution, chaos, and quest narrative structures. McGrath (2004), in a study of survivors of hematological malignancies, found that the language of a secular spiritual journal was used rather than a conventional religious or theological approach for making meaning. These works support the theoretical works of Frankl (1959), who described existential and developmental components to self-transcendence in people confronted with their own mortality.

Living with Renal Disease

There have been numerous studies about the physical and psychological well-being of people with end stage renal disease (ESRD) (i.e., stage 5 CKD), and a smaller number describing the qualitative experience of living with this illness (Polashek, 2003). In the qualitative research relating to patient experiences with ESRD, the concerns regarding threat to life are not raised. For example, Rittman, Northsea, Hausauer, Green and Swanson (1993), in a phenomenological study, identified three themes: “taking on a new understanding of being,” “maintaining hope,” and “dwelling in dialysis.” The constitutive pattern, “control: the meaning of technology,” referred to the control of the renal replacement therapy on the person’s body. Similarly, Nagle (1998) used hermeneutics to understand the meaning and experience of technology for 11 people on hemodialysis. The constitutive pattern in this study was “struggling to remain embodied while being transformed by reluctant partnering with technology.” Nagle (1998) presented the paradox of experiencing dialysis as a “lifeline” but also as a source of suffering. Three themes, “coming to terms with loss and limitations,” “abiding with technology,” and “enduring the treatment environment” were expressed. Hagren, Pettersen, Severinson, Lutzen, and Clyne (2001), in a qualitative interpretive study, found two main themes associated with suffering: “hemodialysis machine as a lifeline,” with the sub-themes of loss of freedom, dependence on the caregiver, and disrupted marital, family, and social life; and “alleviation of suffering” which consisted of two subthemes “gaining a sense of existential optimism” and “achieving a sense of personal autonomy.” These themes point to transitions and the re-evaluation of identity (Hutchinson, 2005).

Liminal Experience: Living With Un/certainty

“Liminality” as a concept describing the experience of in-between and uncertainty has been used in various disciplines, including sociology (Walker, 2005), post-colonial studies (Ashcroft, Griffiths, & Tiffin, 1998), literary arts (Herman, 2005), and nursing (Menkesa, Davison, Costello, & Jaye, 2005). The term is attributed to anthropologist von Gennep (1908, cited in Turner, 1967) who used it to identify a quality of transition in rituals “betwixt and between” the pre and post-ritual states. Within this context, liminality infers a space where people are “neither one thing nor another; or maybe both” (Turner, p. 96).

Although no consensus exists in the literature regarding the conceptualization of the term liminality, it is used to identify in-between, or ambiguous spaces. Liminality describes complex changes in personal narratives when people such as children of immigrants live in bi-cultural spaces and develop what has been called liminal identity (Fanetti, 2005; Xie, 1996). Similarly, McGuire and Georges (2003) studying the effects of global migration on health, identify liminality as a health variable in their work on undocumented migrants from Mexico into the United States. Undocumented migrants spurred by economic hardship are described as living in multiple liminal spaces. In the discipline of sociology, Walker (2005) uses liminality to depict physical spaces such as porches that are private while simultaneously also public. In nursing, Forss, Tishelman, Widmark, and Sachs (2004) use liminality to describe women receiving abnormal Pap smear results that “can be seen as an unintentional transition from routine confirmation of health to ambivalence, or a liminal state, as the women expected to have health confirmed but instead neither health nor disease was confirmed or excluded” (p. 307). These uncertain, ambiguous experiences are often difficult to talk about and point to “un/sayable” (i.e., both sayable and unsayable) aspects (Rogers et al., 1999) of human experience.

Liminal experiences are closely linked to uncertainties of disruption in self-identity or personal narrative. For example, Navon and Morag (2004) describe ambiguous situations
for men with advanced prostate cancer receiving hormonal treatment. Some experience bodily feminization, loss of libido, and impotence that provokes an inability to classify themselves into available cultural categories of gender and identity. Similarly, in an ethnographic study of patients with kidney disease, Crowley-Matoka (2005) reports protracted situations where people grapple with their identities of having ongoing illness as well as possible health through organ transplantation. In this study, liminality refers to the ambiguous experience of one’s life story being disrupted through illness and the re-Story(y)ing process of living with on-going uncertainties of life within life-threatening illness.

In summary, the realities of ESRD as a life threatening illness may engender anxiety, stress, uncertainty, and fear of death in people living with ESRD. There is little research that addresses the liminal experiences of people with ESRD or other life-threatening illnesses. Narrative inquiry using an existing group of narratives could be useful to health care practitioners who often feel unable to deal with the existential questions raised by threat to life.

**Methods**

**Study Design and Theoretical/Philosophical Approach**

A qualitative design was used to study the liminal experiences of people with CKD. A constructivist perspective frames the study (Gergen, 2004) and is founded on a premise that individuals, groups, and cultures create understandings of realities and sustain these perspectives through the stories they tell (Gergen). Accepting that experience happens narratively (Clandinin & Connelly, 2000), stories are individuals’ constructions and perceptions of events, and, as such, can be a window into how individuals understand and make sense of what is happening to them (Salkalys, 2003). From a constructivist perspective, individual stories about life and illness flow from cultural narratives and back into them (Plummer, 1995), and, in this way, stories are inscribed and constituted through discursive processes (Lather, 1991). Connelly and Clandinin (2006) identify the three essential components of narrative inquiry, namely temporality, sociality, and place. In their view, understanding people as being in transition, constructed through personal and social conditions, and living within the context of specific places is integral to the design and analysis of rigorous narrative inquiry (Clandinin, Pushor & Orr, 2007). Therefore, narrative inquiry provides a window into the multiple narratives and discourses (cultural narratives) that shape how individuals story and re-Story(y) human experience.

Narrative inquiry is particularly well suited to studying illness experiences where receiving a diagnosis is often experienced as a disruption of one’s life/story (Gaydos, 2005; Salkalys, 2003). Frank (2001, 2002) is a strong proponent of the contribution of narratives in understanding illness experience, suggesting that illness stories challenge listeners to question the privileged status of medical narratives of disease and treatment and, in particular, illuminates the “erasure of suffering from illness” (Frank, 2001, p. 358). Receiving a life threatening diagnosis can be seen as a ‘narrative wreckage’ (Dworkin, cited in Frank, 1995) resulting in a significant disruption of perceptions of self and life story (Fife, 2005; Gaydos, 2005; Salkalys, 2003). Intensive treatment within technologically complex settings further exacerbates this disruption. These changes provide an opening for the storytelling and re-storying process and are integral to how people make sense of illness events (Frank, 2005). In fact, it is this “perpetual generation” of re-storying that offers those with life-threatening illness a means of living with uncertainty (Frank, 2005) and therefore narrative inquiry is congruent with the aim of this study.

**Data**

This narrative inquiry was undertaken using secondary data. The book *Heroes: 100 Stories of Living with Kidney Failure* (Dialysis and Transplant Units of the Royal Victoria Hospital, McGill University Health Centre [DTU], 2000) was used to provide the narratives. The stories were collected in approximately 1997 for the purposes of educating people about living with kidney failure. Approximately 19,000 copies of the publication were distributed free of charge to people with CKD as well as to nephrologists, renal nutritionists, pre-dialysis clinics, dialysis and transplant nurses, and medical students in Canada. The narratives range in length from less than a page to seven pages. A variety of formats were used including interviews, poems, letter to a media personality, and cartoons, as well as traditional written narratives. A few of the stories were told by partners or adult children for their family member.

**Participants**

The participants of this study were those people who provided a story for the book *Heroes: 100 Stories of Living with Kidney Failure* (DTU, 2000). They were all people receiving treatment at the Dialysis and Transplant Units of the Royal Victoria Hospital, McGill University Health Center in Montreal. The book includes 100 narratives, 62 from men and 38 from women. They ranged in age from 21 to 88 years, and span a range of treatment modalities (as well as changes in modalities as is common in ESRD) and a wide range in the length of experience with the treatments. Eleven of the narratives were originally written in French and were then translated into English.

**Data Analysis**

Data analysis was situated in a constructivist approach and in keeping with narrative inquiry, we attended to temporality, sociality, and place (Clandinin, 2006). We examined narratives to identify how liminal experiences affected peoples’ understandings of health and living. All three investigators reviewed all of the narratives and identified themes relating
to liminality. We then met to discuss the emerging themes, agreed on the categories and shared the writing/description of the themes.

**Rigor of the Study/Reflexivity**

Because this was a secondary analysis, we were unable to conduct member checks or go back to the original participants. However, we worked on the analysis as a team, discussed differences, and reviewed the analysis of other investigators.

**Ethical Considerations**

Approval by an institutional review board was not required because this was a secondary analysis of a published work. Although names and some photographs were provided in the original book, no names or identifying information are used in this paper.

**Findings**

It was evident from the analysis of the narratives that the experience of receiving treatment for CKD is a liminal experience. Living with dialysis therapy or transplantation becomes a ‘new and uncertain normal’ for many. Narrators illustrate this through descriptions of dialysis as “my second life” and “like going to work.” However, for a few, dialysis is an in-between phase that persists until a transplant is received. The goal is transplantation and dialysis is a necessary encumbrance; “it’s just a waiting room until you get another kidney.” Viewing dialysis in this way was considered potentially problematic; as one man warned, “you can’t put your life on hold until a kidney comes in…which I did during my second stint on dialysis.” One 62-year-old individual exemplifies this ability of “still waiting for a transplant” after four years. For him, the possibilities of a transplant or perpetual dialysis seem to co-exist without difficulty. People’s attitudes and relationships with dialysis were both straightforward and complicated and as one person says, “it’s like a hate and love relationship. You have to rush here and you hate that but then realize that if you didn’t have it you wouldn’t be here.” The people relating the stories described a number of liminal spaces including living/not living, independence/dependence, restrictions/freedom, normal/not normal, worse off/better off, and alone/connected.

**Living/Not Living**

“You just do what you have to do to stay alive.” People with ESRD undergo renal disease and treatment within the context of their own mortality. They described a quintessential awareness of being brought to the brink of living/not living: “It was a short distance between life and death.” Within individuals’ stories, there is a rawness - an everyday consciousness that treatment and, in particular, hemodialysis and peritoneal dialysis are the fine line between living and not living. “I just come and have this done because I know that this is what my life depends on.” As another person states, “I don’t think I’m very brave, but rather I think that dialysis is a necessity for my health and for my life.” This reality of living with treatment is described with resignation: “all this is part of surviving. We have no other choice and neglecting treatments is self-defeating,” with hope: “...so I was put on hemodialysis treatments three times a week. I take life as it comes for as long as I live,” with acceptance: “I saw dialysis as a sign of failure and as an extension of my agony, but later on I realized that it was my second chance to live,” and with gratitude: “Dialysis helped me considerably and more important, it saved my life.” With treatments readily available, people’s stories describe the tension of living or not living, rather than being focused on the process of dying. While awareness of mortality is a pervasive theme, it is frequently coupled with an uneasy alliance with treatment and a determined recognition that “dialysis helped me considerably and, more important, it saved my life.” For some, this reality appears to be associated with a present day perspective, “I learned to take life one day at a time,” for others, dialysis simply becomes a “part of my life, it doesn’t run me.” How people created meaning from their illness experience also varied widely with some being matter-of-fact, such as, “I just accepted dialysis, I didn’t worry about it” to others who gain perspective by comparing their experiences with those of others. For example, one person noted “different things happen to everybody and sometimes it is not a sickness but it is something else that is worse.” Renal transplant occasionally intensified the questions regarding dying, living, and not living. For those for whom transplantation went smoothly, the questions regarding living or not living seemed to become invisible within the text of the stories.

**In)Dependence**

The experience of feeling both dependent while at the same time independent was a theme within the narratives. This liminal experience is represented by the paradoxical term (in)dependence. Although people on dialysis acknowledged their reliance on treatments and machines, they varied about whether this reliance curtailed their freedom or not. For some, dependence meant they could not venture far from their dialysis unit. One person on dialysis for eight months stated “there is no such thing as saying I’ll go somewhere for a couple of weeks...It has never even entered my mind to go anywhere.” Another person was able to do all the things that he wanted to do, “I could travel, we went to Europe many times while I was on dialysis, I could work full time, and adapt my schedule...it was doable.” Similarly, a young woman who chose peritoneal dialysis so she would be less dependent on other people and schedules stated, “I’m always on the go. I would take my bags with me to my friend’s house and do a dialysis there; during trips I would do it in the car.” Even with a transplant, some people described the freedom offered through transplantation while still being dependent on immunosuppressive medication for the rest of their lives.

People also spoke of emotional (in)dependencies they faced. One young man reflected on the emotional debt he would incur if he received a live donor transplant: “it’s a huge
responsibility and emotional debt that could never be paid back.” His sense of anticipated indebtedness felt so burdensome that he decided to only accept a cadaver kidney. He later shared how his relationship with his partner who cared for him during his transplant ended because he “owed her so much and would never have been able to pay her back in my lifetime.” For this person, independence alongside his inevitable dependence was a source of struggle.

A desire for self-reliance and psychological independence was evident among young narrators. One 24-year-old woman said:

“...there are times when everybody needs to lean on people, but when you look at the past and you see that you have battled big obstacles in your health history, sometimes you feel that you can go to yourself instead of going to somebody else, and that's really powerful.”

Narrators valued being in control of their lives yet, when faced with situations beyond their control, they took solace in being able to choose their attitude. In the subtext of the stories was recognition that the choice to accept dialysis was really not a choice and this reflected the liminal experience between dependence and independence.

Restrictions/Freedom

Hemodialysis and peritoneal dialysis require substantial commitments of time and limitations in diet and activities. The necessary changes to daily living were often experienced as restrictive in the stories. As one person says, “I don't feel I am my own boss anymore.” Another suggests that the experience is like being restrained, in that “nobody likes it at first, it ties you down and you can't do what you want to do.” The depth of this perception of restraint varied among the story tellers and was described in pragmatic terms, such as, “dialysis ties you down a little bit, but thanks to it you can live.” The most frequently mentioned restrictions were related to travel and daily life, including work. For a few, the restrictive quality of treatment was experienced as invasive and an affront to the integrity of their lives. “Morally I feel that I have lost my freedom. I am tied to dialysis machines.” People who were working full-time when diagnosed with CKD faced the difficult choice of no longer working or attempting to balance their commitment to work with the time commitments of dialysis and, in the situation of hemodialysis, the accompanying fatigue. Over time, people described coming to terms with the commitments required in treatment to stay alive. As one person said:

“Everything has a cost in life, even more so when you are sick but you continue, you go on and that’s the way it is. In life, your imagination is your limit, for everyone out there, even people who don’t have disease.”

These perceptions and responses to illness and treatment varied extensively, showing the impact of the broader life stories within which people live as well as the unique experience of living with CKD. For example, some people viewed the travel restriction as meaning they were unable to visit family living within their region whereas others perceived travel as possible with some planning and, in fact, traveled often, including to overseas destinations. Some of these differences were closely associated with people’s perceptions of the meaning of disease and their ability to move beyond their illness. For instance, one person noted, “I would like to advise new patients to be active. Don’t think about the disease. Make plans, have a hobby, have dreams to keep you going.”

If hemodialysis and peritoneal dialysis (to a lesser degree) were seen as restrictive, transplantation was viewed as a ticket to freedom. As one man said, “I was ecstatic when I learned I was going to have the kidney transplant. It was my ticket out of dialysis.” This experience of freedom was exalted: “Let me out, I’ve got a life to live!” even in situations where the realities of failed transplantation became obvious. Transplantation was viewed as the “opportunity to lead a normal life, free of the mechanical beast, which was my kidney” and it was this freedom that many people covet in travel, in work and in the ability to flexibly engage in their daily lives.

Not Normal/Normal

People talked about trying to maintain a normal life, while struggling with changes that were not “normal.” For some people, the goal of “being normal” was more important than for others. One 24-year-old woman said:

“I really tried not to let it hold me back...I lived in Atlanta for a summer, and at that point I felt like I could do anything on dialysis. It’s kind of ironic, because it seemed as soon as I got to that stage, I had my transplant. I think it was a lesson for me that I needed to learn in life.”

For some people, ‘normal’ referred to activities of daily living. A 42-year-old woman discussed the problems that she experienced before dialysis and went on to say:

“Now I think I have a normal life…I can eat normally but they said not to eat chocolate but the secret is out and I do eat chocolate once in a while without any problem. I like to go shopping, cook and clean, read, and do crochet. I also like to go up to the country in the Laurentians.”

A 75-year-old woman said, “I try to live a life as normal as I can.” However, she acknowledged:

“There are some things I can’t do, hard work like painting the house, I can’t do. I still go out a lot, I do all my housework and shopping...Don’t get me wrong, it is still pretty bad, not everything is good.”

One professional woman went to great lengths to maintain a normal professional life; she talked about a “double life...a professional and a medical one.”

Many people viewed the opportunity for transplantation as offering the chance to become “normal”. A 66-year-old man who said “I try to run my life as normally as possible,” also noted that:

“All I can say is to cope with the situation and put your name on the waiting list and sooner or later a kidney will become available and then you can get back to a more or less normal life. It can’t be completely normal because you still have
to come in occasionally..."

The physical well being after transplantation felt “normal;” “What was normal ... was how good I felt.”

There were some people who very clearly expressed their perceptions that they were not normal. “When you are a sick person, it can never be normal....” A very articulate 30-year-old woman described how she was forced to accept the identity of “the girl with kidney problems” she talked about her “identity by virtue of her disobedient body which had come to rule her existence.”

Worse Off/Better Off

Many of the stories illustrated how life had changed as a result of kidney disease and its treatment, for the worse, for the better and sometimes both. In some of the stories, people talked predominantly about the ways that the disease and the treatment left them worse off. They talked about their inability to travel, difficulty working, dietary restrictions, fatigue, and financial concerns:

“So if you say that I was better off for having had this illness and this setback, the reality is that I would be far better off not having had it. I could have been with my wife and children more, I could have been more productive, done more for society and for my family, had I not had this setback.”

Another 47-year-old man noted, “But it is the truth, when you get sick it is bad.”

A few people talked about how they were better off. Some people developed closer relationships with family members and spouses; others learned new skills and developed the ability to adapt. A woman who lost her kidney transplant talked about the meaning of that loss to both her and her husband. “I felt in one moment the loss of everything I held dear. And yet, we both had never felt closer to each other than in this moment of pain.” A woman talked about how dialysis had helped her become more patient because she had to sit for three to four hours without moving. It seemed that this experience built fortitude and character.

A number of participants insightfully noted being both being better off and worse off in the same story. For instance, one 39-year-old man said, “If I had to go through the whole procedure again [referring to transplantation], I would. I learned to take life one day at a time, to enjoy nature, the sun and the birds.” However, he also noted that “It has made me more nervous and stressful [sic].” A 21-year-old man talked about his frustration with dietary restrictions but also noted:

“There have been some very positive things in my life since I started dialysis. One thing that’s been good is that I always have fun when I come to the hospital for dialysis. The nurses are very nice … the atmosphere is really good, it’s almost like a big family.”

He went on to describe a new significant friendship that he made with another dialysis patient.

Alone/Connected

A strong theme of support from family members and health professionals was found throughout stories. At the same time, people also expressed feeling alone within their circle of support. As one person states, “I tried to put on a brave face for everyone, but my spirit was sinking. I felt very alone even though I was surrounded by family and friends.” Sometimes fear and not wanting people to feel sorry for them evoked the move to maintain a “front” of bravery. One narrator tells of her experience as a child feeling that her sickness was a punishment from God. She knew this was difficult for her parents however, “the need to ‘cover up for each other’ seemed equally important at the time.”

Some people expressed philosophical perspectives about the complexities of feeling connected yet alone. For example, one senior attributed his survival after diagnosis to the support and presence of his wife. At the same time, he shared that “Ultimately, this was something that nobody else could help me with” and “… I felt that my horizon shifted. I now had to lead a different type of life, and dealing with that was up to me.”

This liminality of aloneness within connection was also shared by younger contributors. One woman wrote that as a child with a chronic illness, her support system was in-built. As an independent young adult, things were different because friends had their own busy lives; “many times when I need an intimate level of support, I feel quite alone. Even boyfriends and best friends can’t always be there for you.”

Discussion

It is clear from the 100 narratives, that the experience of treatment for ESRD is filled with diverse liminal spaces. Liminality is linked with notions of “threshold” or betwixt and between where opposites intersect (Turner, 1990). In liminal spaces of in-betweeness, there is room for that which does not fit easily into one category or another, for that which is neither and both. In this study, examples of intersecting opposites include spaces of independence within dependence on dialysis or perceiving a normal life while living with a serious disease. Liminal spaces invite complexity that goes beyond opposites of independent-dependent or normal-abnormal to experience that is simultaneously (ab)normal and (in)dependent.

Why is this important for nurses and nursing care? Acknowledging liminal spaces opens nurses to the complexities of living with ESRD and may help them support patients who dwell in such in-between spaces. As nurses become aware of liminal spaces, they may be better able to communicate with patients whose experience does not easily fit into categories. Support can be in the form of accepting in-betweeness as a “new normal” or refraining from too quickly imposing a nursing narrative onto patients’ stories. For example, one narrator explains how she does not want friends and colleagues to know she is receiving hemodialysis and finds ways to hide her treatments from them. Her story of living with kidney disease is complex and no doubt multifaceted. Nursing care can include openness and interest in how this patient is negotiating her story and identity and what is most impor-
tant to her. Remaining aware of liminality here means listening carefully to the patient’s narratives at each dialysis session, and not assuming that professional narratives (such as theories of denial or pathology) are more legitimate than the patient’s narrative of hiding her illness. Acknowledging liminal spaces would encourage exploration of the patient’s stories and acceptance that multiple, perhaps contradictory narratives can co-exist without difficulty.

The stories also provided rich insights into the diversity of experiences of people living with ESRD. Examination of the liminal experiences in the stories suggests that people with CKD have vastly different experiences. This makes it difficult to characterize the experience of all people or groups of people living with CKD. Each person’s experience is unique and the experiences are filled with contradictions and challenges, so people with CKD can feel both dependent and independent, restricted or not, normal and not normal, alone and connected—all at the same time. It is important that nurses recognize the uniqueness of each person and the possible range of experiences with CKD, rather than assuming that everyone follows a specific pattern or trajectory. Further, listening to the individual’s story and providing time to hear about the “in between places” that relate to the experience are key nursing implications emerging from the study findings. While previous research has clearly documented experiences of people with CKD and themes related to dependence, restrictions, normality, and isolation emerge from data, we also need to listen carefully for things that are unsaid and difficult to articulate.

The findings of this study also demonstrate how stories or narratives are both individually and socially constructed. Many participants spoke of the social aspects of the renal unit. Through the culture created within the renal unit, nurses are involved in creating and contributing to people’s stories. It is important for nurses to engage in this process mindfully, respecting the diversity of people’s stories while at the same time recognizing the tremendous impact the renal unit may have as a place of sociality. By listening to patients and hearing many diverse stories, nurses become aware of the possibilities and the liminal nature of kidney disease—the realities of living and dying. This quintessential awareness can allow nurses to engage in dialogue with patients with hope and a commitment to living as well as possible within serious illness.

Limitations
As with all qualitative research, we are unable to generalize findings from the research to other populations, since the sampling strategy was purposive rather than random. However, the findings will likely have theoretical generalizability and could be used by practitioners who see that the paradigm cases represent situations that they recognize. Because we used existing narratives that were published, we were unable to explore some areas as fully as others. Further, we were unable to examine changes in the narratives over time, because the stories were static and data were not collected longitudinally.

Suggestions for Future Research
Since there has been little research exploring liminality in experiences of people with CKD, there are many questions that require further research. For instance, it would be interesting to explore whether the experiences of liminality differ with various treatment modalities. It would be useful to examine how transplantation is storied, and what the experience of ‘the in between space’ is for recipients. It would be interesting to explore whether comfort in a liminal space is affected by how one deals with uncertainty, or whether other factors influence the experience of liminality. While we examined stories that people provided, we wondered about stories that people might not have talked about. For instance, it may be that concerns regarding mortality were not fully acknowledged. We would also suggest examining nurses’ experiences of working with people in the ‘in between’ places in order to better understand how to provide care to people in liminal spaces.

Summary and Conclusion
In summary, there has been little previous research that addresses the narratives of people with CKD. In this study, using secondary data, we noted the presence of liminality, specifically in relation to living/not living, dependence/independence, restrictions/freedom, normal/not normal, worse off/better off and alone/connected. Awareness of the experience of CKD particularly in the liminal spaces can help nurses provide care that addresses the complexity of CKD.

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ANSWER/EVALUATION FORM
Learning from Stories of People with Chronic Kidney Disease
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Complete the Following:
Name: ____________________________________________________________
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Payment:
ANNA Member: ____ Yes   ____ No    Member #___________________________
Check Enclosed □   American Express □   Visa □   MasterCard
Total Amount Submitted: _________________
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Special Note
Your posttest can be processed in 1 week for an additional rush charge of $5.00.
□ Yes, I would like this posttest rush processed. I have included an additional fee of
$5.00 for rush processing.

1.3 Contact Hours
Expires: February 20, 2010
ANNA Member: $15
Non-Member: $25

Submit Online!
Online submissions through a partnership with HDCN.com are accepted on this posttest at
$20 for ANNA members and $30 for nonmembers. CNE certificates will be available immediately
upon successful completion of the posttest.

Note: If you wish to keep the journal intact, you may photocopy the answer sheet or access this posttest at
www.annanurse.org/journal

1. What would be different in your practice if you applied what you have learned
from this activity?
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________
____________________________________________________________

Evaluation
2. By completing this offering, I was able to meet the stated objectives
a. Define liminal spaces.
1 2 3 4 5
b. Relate the need for awareness of liminal spaces to nursing care.
1 2 3 4 5
c. Summarize the research findings regarding the stories of patients with CKD about
their experiences with living in and managing liminal spaces.
1 2 3 4 5
3. The content was current and relevant.
1 2 3 4 5
4. This was an effective method to learn this content.
1 2 3 4 5
5. Time required to complete reading assignment: _________ minutes.
I verify that I have completed this activity ________________________________________________________________________________
(Signature)