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In-between stories: Negotiating liminality of life-threatening illness.

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Stories of liminality: Living with life-threatening illness

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Stories of liminality

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Stories of liminality: Living with life-threatening illness

People in economically advantaged regions such as Europe, North America and Australia are living longer with chronic health challenges (CIHI, 2009; OECD Health Data, 2009). While the outcomes of treatment are often not certain, the experience of living in-between a promise of prolonged life and the threat of disease progression is not well understood. The experience of what happens for people in this in-between or liminal place and the impact of this experience remains unexplored. In this paper, we present findings from a narrative study examining how people living with life-threatening illnesses story experiences that are uncertain, difficult to speak of, or do not easily fit into established categories. In particular, participants' narratives of liminality and the ways liminal spaces are experienced are examined. For the purposes of this study, 'life-threatening illness' refers to chronic kidney disease (CKD), human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), and cancer, where risk of death is significant. The prevalence and uncertainty of these illnesses provided the rationale for selecting participants from these populations.

Background

People are living longer with chronic and life threatening health challenges, with some reporting a good quality of life where wellness within illness exists (Lindsey, 1996; McWilliam, Steward, Brown, Desai, & Coderre, 1996). The Canadian Cancer Society (2012) estimates that in 2012 there were 97, 600 new cases of people living with cancer. At the end of 2009, 23,300 people with CKD were being treated by dialysis therapy (hemo and peritoneal) which is more than double the number of people from a decade ago (CIHI, 2011). The average age of new adult patients starting hemodialysis is 65 years in 2009 (up from 55 in 1990) with the majority of the population having either diabetes or cardiovascular disease which significantly increases mortality risk. It was estimated that at the end of 2011, Canada had 71,300 adults and children living with HIV/AIDS (PHAC, 2012); the country's adult HIV prevalence rate in 2011 was 208 per 100,000 (PHAC, 2012). These three illnesses carry risk to life, but the messages from health professionals about risk and prognosis of each are very different. The characterization of the diseases influences the narratives of people experiencing these illnesses. Frank (1997, 2004) is a strong proponent of the contribution of personal narratives in understanding experiences of illness that help to challenge the privileged status of medical narratives and illuminate the complexity with which people make sense of the uncertainty of illness events.

Liminality

Liminality is a term used to describe an experience of in-between and uncertainty and has been studied by scholars in diverse disciplines (Broom & Cavenagh, 2011; Syme, 2011). It is used to identify qualities of transitioning or a state of being in-between. The term is attributed to anthropologist van Gennep (1908, cited in Turner, 1967) who used it to identify a quality of transition in rituals ‘betwixt and between’ pre and post-ritual states. Van Gennep’s conceptual model of rites of passage included tripartite phases of separation, transition (liminality), and incorporation. Within this anthropological context, liminality refers to a space where people are “neither one thing nor another; or maybe both” (Turner, p. 96). In researching experiences of illness, liminal experiences are closely linked to uncertainties of disruption in identity or personal narrative (McAdams et al., 2006). For example, Navon and Morag (2004) describe ambiguous situations for men with advanced prostate cancer receiving hormonal treatment. Hoel Felde (2011) describes liminality as an “in-between grey area between two well defined and known everyday categories” (p. 606) where experiences or identity no longer fit easily into categories. Similarly, Forss et al. (2004) use liminality to describe women receiving abnormal Pap smear results. These uncertain, ambiguous experiences are often difficult to talk about and point to an un/sayable aspect (Rogers et al., 1999) of liminal experience. In the context of life threatening illnesses, liminality is used to describe a psychosocial space for people living with end-stage renal disease (Martin-McDonald & Biernoff, 2002), HIV/AIDS (Kelly, 2008) and cancer (Miles, Jordens, Paul, Montgomery & Philipson, 1998). Molzahn, Bruce, and Sheilds (2008) depict liminal spaces for people with chronic kidney disease that include being both independent-and-dependent, having simultaneous restrictions-and-freedoms, feeling alone-and connected and feeling normal-and-not normal. In this study, we use liminality as an analytic concept for understanding the ‘grey area’ of living with life threatening illness.

Purpose of the study

The purpose of this inquiry is to examine liminal experiences of living with the uncertainty of life-threatening illness.

Methodology

A qualitative design using narrative inquiry (Reissman, 2008) within a social constructionist perspective was used. A social constructionist perspective is founded on the premise that individuals, groups, and cultures create understandings of reality and sustain these perspectives through the stories they tell (Berger & Luckmann, 1967).

Narrative inquiry (NI) 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). Accepting that experience happens narratively (Reissman), stories can be a ‘window’ into how individuals understand (Sakalys, 2003) and make sense of what is happening to them.

Participants and Data Collection

Thirty-two people agreed to participate in the study. There was balanced representation from each of the disease population groups: (a) 10 people living with cancer including breast, ovarian, prostate, colon, and bladder cancers, (b) 14 with CKD, and (c) 8 people living with HIV, 2 of whom had AIDS at the time. Participants include 14 women and 18 men from 37 to 83 years in age and a range of 1 to 50 years post-diagnosis. Seven participants had a dual-diagnosis of cancer and either CKD or HIV/AIDS. One participant withdrew after the first interview (no reason provided) and 5 participants died during the course of the study, all with CKD. The majority of interviews were conducted by the same interviewers (KSM and RB) providing continuity and a deepening relationship over the three years.

Recruitment was accomplished using convenience sampling via newspaper advertisements and posters in community agencies and snowball sampling. Semi-structured in-depth interviews were conducted lasting one and a half to three hours. Participants were asked to take part in four interviews over three years. The first interview focused on establishing rapport, the second and third interviews explored living with illness and during the last interview closure, updates on findings and copies of the transcripts were provided to interested participants. Interviews were guided by exploratory, descriptive questions such as: please tell me about your experience of living with … (CKD, HIV/AIDS or cancer); How do you make sense of having….; has anything changed since our last interview; and how has living with this disease affected your values and priorities?

Ethical considerations

Ethics approval was granted by the university ethical review board. In addition, an Advisory Committee consisting of 5 members, who were either living with HIV/AIDS, CKD, cancer, or worked with one of these populations, met periodically. The Advisors assisted with participant recruitment and provided guidance with interview questions, procedure, analysis, and knowledge dissemination.

Data analysis

Riessman's (2008) approach to thematic analysis was used to inductively generate themes and sub-themes from peoples' narratives of liminality. Transcripts were read by all team members with one investigator (AB) taking the lead in analysis. During team analysis meetings, investigators shared initial perceptions of liminality grounded in participants' stories. After reading transcript sets from the first two interviews, the team developed a coding scheme for liminality. All four interviews were subsequently coded by two team members (KSM & RB) using N-Vivo software. A thematic analysis of coded data explored recurring, overlapping and opposing themes and patterns, and illustrative narrative quotes. Through a process of refinement, patterns and relationships were collapsed into an overarching theme and four key narratives. Steps taken to ensure trustworthiness of the findings include: extensive immersion in the data, discussion of coding and interpretations amongst team and checking for resonance by presenting key findings to the advisory council.

Findings

Participants shared stories of acute uncertainty during the early days of their medical diagnosis and treatment decisions. In addition, they narrated complex experiences where an ‘in-between’ occurs that is difficult to categorize. Four narratives of pervasive liminality are identified: 1) storying into fear (lessness); 2) being alive but not living; 3) the (in)visibility of disease; and 4) knowing and not knowing.

Pervasive liminality

The notion of pervasive liminality is intended to differentiate these experiences from a more frequently used notion of liminality as an in-between phase in a multistage process (see Blows, 2012) such as life pre-diagnosis, diagnosis, and post-diagnosis. Pervasive liminality points to stories that convey being in the midst of what may otherwise be seen as discrete experiences that overlap and fluctuate over time. As one participant describes, “*I’m living a double existence*.” In referring to her remission she states, “I do have cancer *and* I don’t”; pervasive liminality points to this ‘overlap ⁻ the in-between experience of both having *and* not having cancer. These in-between experiences pose particular challenges when trying to clearly describe experience.

English language does not easily accommodate paradoxical experiences such as these where there is an ‘in-between’ at play. We use parentheses such as fear(lessness) and (in)visibility for these experiences to convey their complexity and what Meyers

(2008) describes as going beyond polarities to create overlapping spaces of being *both* fearful and fearless or being visible and invisible at the same time.

Storying into fear(lessness)

Living with serious illness evokes fears relating to loss, suffering, and dying that are a constant presence for many participants: "*it's not in capital letters perhaps but it's there.*" Even though the acuity of fear varies depending on time since diagnosis and progression of their illness, there remains a subtext of concern, "…*the more years go by you feel more positive- definitely. But it never, ever goes completely. And you never, ever feel that you're cured*…." Stories of fear were more often implied rather than stated. However, stories of fear were frequently private stories, sometimes raw, and tinged with energy "… *the things that you want to talk to me about--- they're in a very deep place, a very deep, sometimes buried place where I don't talk about it that often.*" Paradoxically, participants' willingness to talk about such hidden experiences evokes fearlessness. Narratives of fear-and-fearlessness were frequently conveyed through long silences and in-the-moment connections between narrator and listener. Consequently, the limits of language make these narratives difficult to convey through speaking or text alone. Perhaps Tony, living with colon cancer, said it best: "*we all think that articulation is the spoken word. It's not-- because for some people it's painting; for some people it's poetry; for some people it's silence.*" What was unknown to the researchers at the time was that Tony was developing a form of dementia. His storying was becoming more urgent and poetic over the four interviews as his grasp of language and words became less reliable.

Holding onto momentary feelings of wellness intermixed with an undercurrent of fear that everything could change was a common narrative among participants. As

Teresa, diagnosed with breast cancer 9 years ago, shared, "*…right now, I have a really good, balanced life … but I'm on Lipitor and need to go for baseline blood work…Do I want to do this? Should I do this? Yes I should do this, no reason not to…but there's that voice just over my shoulder-- it's like, what if they see something*?"

Some participants responded to intense fear and uncertainty by becoming more certain and taking control within the (un)controllable. Participants described making plans and getting their affairs in order. One participant joined a Buddhist meditation group to learn more about the dying process and transformation of consciousness. Taking charge and "*getting on with my life*" was an effective way of dealing with fear for many. Meghan, diagnosed with breast cancer, expressed a liminality of frustration-and-excitement in this process: "*... you know if I get the diagnosis of hemachromatosis, I'm going to go and have a phlebotomy and I'm going to [travel] and I'm going to go with the disease, so be it.*" She continued,

> *So no matter what I have, unless I have to stay here for treatment every day, I'm going to go. I'll continue to live on the edge. And you know… that makes life frustrating, it makes it exciting, it means I'm living, not just sitting around waiting for something to happen—so I'm going to die.*

Being alive but not living

Participants shared stories of life being diminished into a much smaller world of illness. They described a time of realization that their life had been reduced to managing their illness—they were alive—but they were not really living. Evan, living with HIV/AIDS, said this directly, "*That was it—I worked, thought about HIV, and slept—that was my whole life. I didn't live.*" Kelly, diagnosed with ovarian cancer, told a story of her wedding ring requiring a costly repair and she hesitated because she was not sure if it was worth the expense. Her husband rolled his eyes and retorted, "*does all this mean that we don't buy anything new, you don't do anything – like---what does this mean*?" Kelly was five years post cancer diagnosis and she had lived beyond her expected prognosis. She said, "*I probably should not have been alive.*" She went on," *I realized that I'd prepared myself to die. I hadn't actually prepared myself to live with this, and if you really come right down to it, I was confused that I wasn't dead because it's not the norm for evading cancer*."

There was a temporal aspect to participants' stories where during early diagnosis they focused intensely on the disease, treatments, and what it meant to be living with their disease. Later, if their illness stabilized, participants shared stories of yearning for life that was larger than illness. Chris, living with CKD and cancer shared, "*I'm living again. I'm not sitting here feeling sick all the time. Since I started dialysis I was sick and fighting the doctors.*" At the same time, participants like Michael, with bone metastasis, expressed a wish for the ordinary and everyday, "*People who know they are dying still have to do things like the laundry; they still eat and drink if they can …, they still go out for walks and cut flowers and they go to art galleries.*" While this wish for the everyday is expressed, it is offset by the reality that such normalcy is not always achievable or perhaps not in the same way.

Some participants described the urge to live fully by keeping busy and doing as much as they could, yet at the same time they questioned whether life was getting lost in busyness. Meghan, who was waiting for the five year anniversary post breast cancer diagnosis, expressed this tension of doing-and-being, "*I try and cram everything in today… because I don't know what tomorrow will bring*." At the same time, she questioned, "*am I in such a hurry that I'm missing out … if I could just slow down, I could appreciate things a lot better*." She described "*a paradox between frustration and wanting to get it all done in case I don't have tomorrow… but yet knowing that I'm doing it so fast I might be missing out on some of the pleasures in life*." A sense of being changed by illness and yet carrying on with life in the same way was reflected in participants' wish to not have their illness take over completely– they were not their disease and yet it was part of them.

The (in)visibility of illness

Narratives revealed a tension in identity of being a person with a serious illness, "*you're the same, only different.*" The overlap of high and low visibility of the illness in participants' lives was often in flux. Lenora, living with HIV/AIDS described how it has been important to not always be focused on the disease and her identification with it. "*I think there are times when you need to just be normal and not totally surrounded by people who are HIV positive; it's much healthier to join the calligraphers' society and just be a calligrapher like everybody else.*" Another participant shared, "*What bothers me, about [the expression] 'your life will have changed forever', is the histrionics. Your life— does and doesn't (change forever)…..*" Like many participants, she did not want to focus solely on her illness and believed that her lifestyle overall had not changed dramatically, "*I go where I want to, I do what I want to, yeah - I haven't changed,*" and yet there was an urgency and awareness that this too might suddenly shift.

Subsequently, there was an acknowledged awareness that having a life-threatening illness included the potential that it may become more visible and threatening in the future. There was a tension about how much to share with others about their illness. For example, giving information- but not too much- and the uncertainty of what to say, and to whom, presented a quandary for many participants in the early days of diagnosis. "*You don't want to give away too much information, but enough so that if I never come back [post surgery], it's not a total surprise*." For participants living with HIV, this tension was more evident. Owen who has been living with the disease for 10 years explained, "*My sister lives in Arizona and as far as I know she has no knowledge that I'm HIV positive,… I just don't get into it….*" Similarly, Evan spoke about the shame of living with HIV-AIDS and how he hid this from everyone. "*I just didn't talk about it and I didn't tell anyone. I just kept it internalized and it almost killed me…I isolated myself and that was not a good place to be.*"

Participants' narratives were often tailored to the audience and function of the story. Allen was diagnosed with bladder cancer and explained that different kinds of stories needed to be told to either make his diagnosis visible or invisible. He had to tell his employer, co-workers, children, family, and friends. The storying for each of these groups seemed to be different and there were inherent challenges in the telling. He found it difficult because it was often an emotionally charged situation and he did not know how the listener would respond; there was trepidation. As Harold, another participant, shared, he was frequently the one comforting the person who heard that he had been diagnosed with cancer. He talked about bracing himself and preparing what he will say "*so you don't break down.*" Participants live within the liminality of their illness being (in)visible at times: it was a process in flux and depended on the context and who needed to know.

Stories of knowing and not knowing

Stories of liminality

When participants were asked about their experience of living with cancer, CKD, or HIV/AIDS, it was not surprising that for many, their medical stories of being diagnosed and treated were central and important narratives framing the first interviews. The initial phases of illness and receiving a diagnosis were seen as intrinsically liminal, marked by waiting for surgery or test results, as well as uncertainties about decisions and what the future held. There was a sense of disorientation for many, of believing-and-not believing what was happening. Participants described a process of trying not to think about the disease or its impact by "*putting it out of my mind*" and willing oneself to "*just live as normally as you can.*" Attempts to normalize the periods in-between diagnosis and treatment or waiting for blood tests reflected their opposing wishes of both 'wanting-to-know' and 'not-wanting to know.' Some participants did not want to know too much about their condition because it would induce worry. For example, "*I know just enough [about cancer]; it's just enough to keep me on edge. So if I knew nothing it would be better I think! (chuckling).*" Others wanted to know as much as possible:

> *I think that the more you know, the more you understand, and it's easier to accept the ailment you have. The more you know, the more comfortable you are in your skin kind of thing, and the terminology may take you a while to catch on in the beginning but after awhile you're not overwhelmed because it's just one more word you're learning.*

The accessibility of health information through internet sites meant that participants had more available information than ever before. Participants saw this as both a gift and burden.

The uncertainty of not knowing the disease trajectory was difficult for many: "*When you don't know, it's really hard to make plans. So you just have to say well okay, so [I'll work with] three months to six months from now.*" The complexity of this liminal space is seen in Meghan's story. She was diagnosed with breast cancer and then another lump was found after the second interview and was told by her doctor*, "'I really don't think it's anything but come back in August' and I just thought (raises her voice) Jeez! Somebody tell me something … that it either is or it isn't!"* Meghan shared the following story.

> *I didn't quite know what I wanted to do about the fact that I was going to die, I didn't know about that. I didn't know whether I had to know about it. So then I just thought, well okay, I will approach things as if I am [dying], this is it. And then I started making plans….I'm going to live from day to day, I'm going to take these trips, I'll go and see my grandchildren as much as possible—I'm just going to spend my money and have fun. And once I reached that point, then I was all right. The only thing I haven't done is arrange my funeral (laughs). And I'm not doing that because now that I've made these decisions and I've…. (taps on wood) it's really not going to happen. I'm not going to die for awhile….*

By not making funeral arrangements and hoping they would not be necessary, Meghan exemplified a liminality of knowing she will die and yet she was not ready to act as if this was so.

Discussion

These findings suggest that participants experience living with a serious illness through a variety of overlapping narratives including storying into fear(lessness), being alive but not living, the (in)visibility of illness, and knowing and not knowing. Descriptions of liminality in health literature often focus on transitions and temporary experiences which patients work to resolve and move beyond (Kelly, 2008; Sawhney & Suri, 2008). The use of stages (Miles et al. 1998), and the betwixt and between phase (van Gennep cited in Turner, 1967) have emphasized the transitioning from one stage to another. While findings from this study are not radically different, they differ in kind. The notion of pervasive liminality and experiences of 'overlap' are emphasized.

Findings suggest that many participants are living in a pervasive in-between, not seeking to resolve and move on, but are learning to live within sometimes opposing stories. For example, Meghan who is waiting to find out whether a recent lump in her breast is cancerous and is told by her health professional ‘not to worry about it’ and at the same time to ‘come and see me in six months.’ Like many participants, she is caught within a polarity, “I shouldn’t worry” (it’s not cancerous), *or* “I should worry” (it possibly could be). While she does not explicitly identify a third possibility, it is implied when she decides to travel, “*Get lots of medical insurance and enjoy! …I’ll continue, to live on the edge. And you know… that makes life frustrating, it makes it exciting, it means I’m living, not just sitting around waiting for something to happen--so I’m going to die*”. The possibility of *both* worrying and not worrying was liberating for Meghan. The in-between in participant stories as they moved in-between contrasting stories support Meyers’ (2008) view of liminality as, “resistant to representation and thus frequently elicits paradoxical description” (p. 80).

Liminality of life-threatening illness is rarely a single story, as Lather and Smithies (1997) in a study of women living with HIV/AIDS remind us, “there is never a single story and that no story stands still” (p. 220). The in-betweens of fear(lessness), (in)visibility, being alive but not living, and knowing and not knowing, highlights a fluid aspect of stories when they are ‘not standing still’ (Lather & Smithies, 1997, p. 220) and cannot easily be categorized. Meyers’ (2008) construction of liminality provides a helpful interpretive lens to further understand the storying process in these findings. Meyers describes liminality as not only living in spaces between opposites (of fear or fearlessness), but can also point to something that goes beyond the polarity in question.

The narratives of (in)visibility reveal how participants consciously make complex decisions about what to tell, to whom and when. Participants were often aware that they told different versions of the same story as a strategy to manage the responses of the people with whom they needed (or wanted) to share their story. Their need to manage people's responses was an important consideration for many participants. The need to protect themselves through the stories they told was often a useful strategy that has implications for care providers. When hearing different 'versions' of peoples' stories, health providers can engage with patients in trying to appreciate the rationale for how and why patients choose to make visible and invisible particular stories in particular ways.

Patients trying to express experiences of both 'wanting to know-*and*-not wanting to know' about their illness, or 'being afraid-*and*- not afraid' can be challenging to articulate and to understand. Wolcott (2010) queries how fully or accurately we can ever assign motives to others. To avoid simplifying and underestimating the layers of human behavior, Wolcott suggests we assume that all behavior is "overdetermined" (p. 10). That is, "there are, or could be, many other possible (or probable) related factors that have not been taken into account" (p. 10) when trying to understand people's behavior and the stories we tell. Therefore, we can use such occasions to better understand the complexities of human experience and the challenges in reducing it to this or that.

Finally, narratives of being alive but not living speak to the in-between of liminal experience when disease is present, even in its absence (i.e., a participant in cancer remission declares, "*I have cancer and I don't"*). The threat of cancer returning, complications with CKD, or progression of HIV/AIDS is a constant albeit sometimes hidden narrative. This finding supports Frank's (1997) notion of a restitution narrative that begins with the story of becoming ill, then focusing on getting better, and eventually becoming healthy again. The restitution narrative is described as the culturally preferred narrative in the West as it affords the greatest sense of independence. Re-centering life amidst the shadows of illness also reflects Frank's (1997) notion of 'deep illness' which are described as situations where illness is always present and defines one's life. Deep illness invokes suffering that medicine alone cannot address. In order to survive this kind of suffering, Frank suggests that people narrate stories that allow them to take control of their reality through narrating what is meaningful. For many participants, desire to take control of their life-story narrative included foregrounding their plans, activities, and everyday lives within the uncertainty of living with life threatening illness. The liminality of participants' experiences extends Frank's notion of restitution narrative by acknowledging that participants' narratives of getting ill, focusing on getting better, and eventually becoming healthy again are often and simultaneously accompanied by narratives of loss, not becoming healthy, and life changing forever. The possibility of such opposing stories co-existing without need for resolution offers additional and usually more difficult stories to articulate.

Conclusions and Implications for Practice

An understanding of liminality has implications for how nurses elicit and listen to patient narratives that may not readily fit into checklists found in today's fast paced health care environments and electronic information systems. Entering into a liminal space with patients living with life threatening illnesses raises opportunities for strengthening holistic nursing care and also raises challenges.

These findings contribute to a growing body of literature and provide ways of narrating overlapping, non-dual experiences. Liminality is a useful construct that can help us make sense of ambiguous experiences of wellness within illness, or living while dying (Frommer, 2005), and is consistent with a growing interest in aesthetic forms of knowledge and inquiry (e.g., Chinn, Maeve & Bostick, 1997; Gadow, 2000a, 200b). Awareness of liminal experiences supports nurses to better understand the breadth of possibilities that exist for patients and families. Liminality calls upon nurses to more consciously listen to patients' narratives in ways that hold contradiction without needing to resolve ambiguity or paradox. Nurses can be more sensitized to that which doesn't fit into categories by understanding liminality and thereby recognizing possibilities of certainty and uncertainty at the same time.

It is essential that nurses develop knowledge to support people with serious illnesses to continue to be active, non-dependent contributing members in their communities. During this difficult time of uncertainty between the promise of cure and the recurrence of disease, a better understanding of liminal experiences is important to develop meaningful supports and resources to improve quality of life.

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