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Contrasting stories of life-threatening illness: A narrative inquiry

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ABSTRACT

Background: Advances in science and technology have resulted in longer lives for people with life-threatening illnesses. However, little research compares the stories of people with different life-threatening illnesses.

Objectives: The objectives of this study were to explore and contrast how people story and re-story life-threatening illness specifically cancer, chronic kidney disease (CKD) and HIV.

Design: Narrative inquiry within a social constructionist perspective was used.

Methods: A total of 113 in-depth interviews were conducted with 32 participants over a period of three years.

Participants: Study participants included 32 people: 10 with cancer, 14 with CKD and 8 with HIV/AIDS. Participants varied in age (37–83 years old, mean = 61.2 years), gender (17 men and 14 women), location (urban and rural), time post-diagnosis (median = 8 years), intensity or invasiveness of treatment, and prognosis (continuous treatment, remission, cure, palliative).

Results: Participants described living with a life-threatening illness as a delicate balance. They focused on living their lives yet were fully and acutely aware of their own mortality. There was an undercurrent of sustained uncertainty that permeated their lives. Stories of life-threatening illness differed across the three illness groups and shifted over time as disease trajectories changed. Each disease brought specific challenges. With cancer, turning points and uncertainty were prominent. With CKD, a stealthy beginning to life-extending treatment through dialysis or transplant was evident, and with HIV, a shift from a perceived death sentence to a focus on hope and living was notable.

Conclusions: Findings revealed that trajectories of illness for participants living with cancer, CKD and HIV are complex and differ markedly across the groups. Narratives shifted across all of the illness groups as participants navigated and re-storied the terrains of their life-threatening illness. Findings illuminated the need for health care providers to focus on person specific and contextualized aspects of the illness experience.

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What is already known about the topic?

- People with life-threatening illness, including cancer, chronic kidney disease (CKD) and HIV, are living longer and healthier lives.
- The outcomes of treatment and the experience of living with a life-threatening illness are not well understood.
- The promise of treatment and prolonged life as well as the threat of recurrence or progression of the disease are liminal experiences associated with life-threatening illnesses.

What this paper adds

- Participants described living with life-threatening illness as a delicate balance of focusing on living their lives while at the same time having an acute awareness of death and their own mortality.
- Stories of life-threatening illness differ across the three illness groups and reflect illness processes that are often variable and complex.
- There was continual change, shifting cognitive and emotional responses, and fragility of narratives across all of the illness groups as participants navigated and re-storied their illness experience.

People with life-threatening illnesses including cancer, chronic kidney disease (CKD) and HIV now live longer and healthier lives because of advances in science and technology. However, there is considerable evidence that the threat to life from these diseases is real (CIHI, 2011). People living with these illnesses describe the challenges of living in-between the hope offered by life-prolonging treatments and the realities associated with disease progression and possible recurrence (Lynn, 2005; Lynn and Adamson, 2003). The experience of life-threatening illness may extend over years. Lack of understanding of these tensions by health care providers may result in misperceptions of needs, miscommunication about prognosis (positive and negative), insensitive communication and unnecessary anxiety (Frank, 1991, 2001). Further, these factors have the potential to impact decision-making as well as effective provision of care (Kings Fund, 2012). Health care professionals may not know the answers to many of the questions facing people with life-threatening illness but ignoring the questions is clearly unhelpful (Frank, 2001).

With more effective treatment, the distinction between life-threatening illness and chronic illness has been obscured (Lynn and Adamson, 2003). The literature on life-threatening illness has focused on disease-specific research while the literature on chronic disease tends to focus on similarities across illnesses (Corbin, 1998) without acknowledging the impact of perceptions concerning threat to life. Cancer, CKD and HIV are three examples of diseases where the distinction between life-threatening illness and chronicity has blurred. This means that people with life-threatening illness may live for an extended period of time resulting in an unexpected illness experience. Growth of the aging population along with greater chronic illness and multi-morbidity further accentuate the need to understand this new phase of illness (PHAC, 2012).

In this article, we report findings of a three-year narrative inquiry focused on narratives of life-threatening illness. Narrative research provides an opportunity to delve deeply into people's complex experiences of illness. We describe how people story and re-story their lives in the context of illness. The study included three illness groups (cancer, CKD and HIV) where the perceptions of threat to life vary. The term *re-storying* is used to describe a dynamic, ever-changing process whereby participants' illness stories shift and change over time (Madigan, 2011).

1. Literature review

Life-threatening illness is a term that is often undefined in the literature. For the purposes of this study, we use this term to refer to three illnesses that pose a significant threat to life, specifically cancer, CKD and HIV. In this section, we provide an overview of the experience of living with each of the three life-threatening illness. We then summarize the interrelationships between the illness experiences.

1.1. Living with cancer

Cancer is perhaps the most identifiable life-threatening illness within western society. As Frank (1991, p. 1) says, it takes one to the "threshold of life, from which you can see where your life could end". Extensive research related to the experience of people with cancer includes studies focusing on psychological adjustment (e.g., Lee et al., 2006; Schroevers et al. 2006), communication (e.g., Thorne et al., 2006), decision-making (e.g., Hack et al., 2006), coping strategies (e.g., Thune-Boyle et al., 2006), meaning making (e.g., Appleton et al., 2013; Fife, 2005) and quality of life (e.g., Sarna et al., 2002). Schroevers et al. (2006) suggest that cancer survivors are remarkably resilient in the years following recovery. In a longitudinal study, they found that survivors do not differ significantly from healthy individuals on measures of depression, anxiety, life satisfaction, self-esteem, social support and marital satisfaction. Similarly, other studies show that cancer survivors fare well on global measures (Kornblith et al., 2003). In contrast, others have found that cancer survivors experience distress and uncertainty as a result of their diagnosis (Higginson and Costantini, 2008).

1.2. Living with renal disease

CKD is less likely to be considered a life-threatening illness. Dialysis treatment offers hope for continuing longevity, but mortality rates are higher than for other life-threatening illnesses (Schell et al., 2013; Sud et al., 2014). While long-term survival rates have gradually improved, the unadjusted 5 year survival rate for all people on dialysis is 43.2% (Canadian Institute of Health Information, 2011). There have been numerous studies about the well-being of people with CKD, and a smaller number describing the qualitative experience of living and making decisions with this life-threatening illness (Morton et al., 2010; Polashek, 2003). In a systematic review, Morton et al. (2010) reported on findings of 18 studies. Four major themes were identified: confronting mortality, lack of