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The meaningfulness of time; Narratives of cancer among chronically ill older adults

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ABSTRACT

This study, using ethnographically-based interviews, sought to describe how chronically ill older adults experience a new cancer diagnosis and the effects of this on their interpretations of personal health, aging, and the future. Three semi-structured interviews were conducted with each of the fifteen informants. We asked questions that explored each individual's life history, chronic illness occurrence, and direct experiences with cancer. Interviews were structured to provide social and historical contexts to enhance our understanding of the informants' illness narratives. Interview transcripts were analyzed thematically to describe how individuals described the cancer experience, its meaning, and its consequences. One of the major findings of our study was the role of cancer in disrupting individual biography, an interruption that fragmented time into three distinct segments: the Recalled Past, the Existent Present, and the Imagined Future. We highlight three main themes around the experience of illness-related time: (1) disruption found in individual biographical accounts as a result of fragmented time dimensions; (2) altered projections of a continuous sense of self into the future; and (3) modified treatment decisions resulting from a perceived altered life course and the finitude of advancing age. We further introduce the concept of Anomalous Time as a permutation of time central to individual experiences of cancer. Implications for how older adults understood their cancer and individual reactions relevant to seeking care are discussed.

Introduction

Research on the separate domains of meaning in the cancer experience and on chronic illness in later life is not well established. What is specifically lacking is how co-occurring experiences of cancer and chronic illness interact with one another in later life. The current article looks at the effects of time, age, and meaning on reactions to a new cancer diagnosis that co-occurs with pre-existing chronic illness, an event that is common among older adults. The theoretical perspective adopted here is found in both symbolic interactionism (Berger & Luckmann, 1966; Blumer, 1969) and phenomenology (Gubrium & Holstein, 1999), particularly in how these approaches illuminate ideas about time, an element that has been found to be a critical aspect of meaning-making in illness. This article sheds light on notions of time through analysis of ethnographically-based interviews with fifteen older cancer patients. The theme of time, in relation to meaning and the larger illness experience, was closely examined to describe how time was implicit in meaning making and affected treatment-related decisions. A central question this article thus discusses is: *What is the effect of a new cancer diagnosis in later life notions of the future*? This research seeks to better inform health care practitioners about how time becomes a meaningful component of the cancer experience in the diagnosis and treatment of cancer throughout later life. That is, how projections of and decisions for the future may be significantly influenced by one's current health conclusions.

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Background

As of January 2014, there were approximately 14.5 million people living in the United States with a history of cancer, with an expected 1,658,370 new cancer cases in 2015 (American Cancer Society, 2015). Older adults represent a disproportionate number of these cases; 77% of all cancers are diagnosed in those aged 55 years or older (ACS, 2015). In addition, the number of new cases diagnosed in those 65 + is expected to increase by more than 40% over the next ten years (ACS, 2015).

Disease impact and the illness experience

Limitations from cancer can occur variously; risks of limitations and disabilities are associated with primary cancer site, stage of cancer at diagnosis, and the type and extent of treatment (Koroukian et al., 2007; Reeve et al., 2009; Satariano, 2006). Pertinent to older cancer patients, Lawton (1991) described perceived quality of life as defined through a metric — one derived from individual health status, functional capacity, and social behaviors (Given & Given, 2008; Patrick, Kinne, Engelberg, & Pearlman, 2000; Reeve et al., 2009; Stineman, Wechsler, Ross, & Maislin, 2003; Thomé, Dykes, Gunnars, & Hallberg, 2003; Wedding, Röhrig, Klippstein, Pientka, & Höffken, 2007). Aside from Lawton's paradigm, quality of life can also be negatively affected by social stigmatization felt by the chronically ill, who might isolate themselves or experience diminished social contact as a result of their illness (Choi & McDougall, 2007; Engberg et al., 2001; Holley, 2007). Older cancer patients might additionally experience profound suffering specifically related to the treatment, progression, and potential recurrence of their cancer, as well as generalized anxiety and uncertainty about the future (Conrad, Garrett, Cooksley, Dunne, & MacDonald, 2006; Morse & Johnson, 1991). The root of this suffering is often in personal beliefs that one's future is highly uncertain or that illness itself represents a future of pain and physical deterioration. In this regard, older cancer patients might revise their senses of both personal identity (who they are in the world) and agency (how they act in the world), mediating negative psychosocial effects of a cancer diagnosis and resulting in a renewed sense of self and personal identity (Kaufman, 1988; Zebrack, 2000).

The illness experience

Lee (2008), following many others, described a general sense of “global meaning” in lived experience, noting that “global meaning” refers to a personalized life schema that provides order and purpose to one's life and which results from a set of personal beliefs and assumptions about the self and the self in the world. She found that an orientation to “global meaning” is generally what enables each person to function in their normally occurring world, with its known contexts and rewards. This system remains intact and unquestioned until moments of radical change, such as the diagnosis of a serious illness like cancer. This break marks the beginning of new meaning-making associated with the cancer experience and ends only when the person is able to incorporate the changes, limitations, and identities created by serious illness into a new life schema, thus establishing and sustaining a new system of time, order, and purpose (Lee, 2008). The structure of time as well as temporal bracketing, in the relationship of human experience and time can be very complex and often cloudy (Brockmeier, 2000; Crossley, 2000).

Illness itself appears to bear great impact on individual conceptualizations of and responses to the experiences of symptoms, treatment, and debility (Morse & Johnson, 1991). Research from an experiential perspective presents chronic illness as a threat not only to the body but also to an individual's sense of personhood (Lawton, 2003; Lutpon, 2012; Morse & Johnson, 1991; Pierret, 2003). A review of research in this area throughout the previous 25 years (Lawton, 2003) identified three key findings, each implicated by time:

1- ‘Loss of self’ associated with chronic illness and as an element of the life course (Charmaz, 1983),
2- ‘Biographical disruption’ through temporal dislocation caused by chronic illness (Becker, 1997; Bury, 1982), and
3- Narrative reconstruction as a process over time to account for and mitigate biographical disruption and leading to a sense of recovery or renewed identity (Williams, 1984).

The theoretical framework for the current study thus involved two levels: one that was socially oriented and one that was personally oriented. Symbolic interactionism, as a socially oriented concept, enables an understanding of how people see themselves, the world around them, and the two in relationship (Berger & Luckmann, 1966; Blumer, 1969). It further accounts for the experience of social roles and identities, which the individual embodies. The second level involved both constructivism and phenomenology, which framed our understanding of the personal interpretations of and meanings attributed to a cancer diagnosis (Gubrium & Holstein, 1999). These critical perspectives guided analyses relevant to the subjective experience of time, in the contexts of cancer, comorbidities, and aging, for this analysis.

Materials and methods

In this research, we utilized in-depth ethnographically-based interviews to identify and describe (1) patterns of meaning throughout the life course and (2) how new meaning was attached to illness experiences among older, chronically ill cancer patients (Black & Rubinstein, 2004; Rubinstein, 1995; Rubinstein, 2002; Maly, 2000; Spradley, 1979). On receiving approval from the Institutional Review Board of all sites, a total of fifteen men ($n = 2$) and women ($n = 13$), aged 65 years and older, were recruited to and enrolled in the study. The sample size of fifteen people is appropriate for a qualitative research project through which a major goal is to establish information specific to a particular phenomenon (Eisenhandler, 2008; Kvåle, 2007). Our sampling was based on a specific set of inclusion criteria: adults aged 65 or older; at least one pre-existing chronic condition self-reported as having a negative impact on a participant's daily life; Stage I–III solid tumor cancer diagnosis; and cancer diagnosis within the past year (excluding those with a previous cancer diagnosis within the past five years). We also assessed individuals for a willingness to participate, English speaking ability, local residence, and the ability to consent (as measured via the Mini-Mental State Exam or Verbal Fluency cognitive test). We did not further restrict the sample, to allow for maximum variation.