



Health related quality of life during cancer treatment: Perspectives of young adult (23–39 years) cancer survivors and primary informal caregivers

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ARTICLE INFO

Keywords:

Young adults
Caregivers
Neoplasms
Therapy
Quality of life
Minority health

ABSTRACT

Purpose: There is a paucity of information regarding health related quality of life (HRQoL) of young adults (YAs) with cancer and caregivers. Therefore, we characterize YA and caregiver perspectives on the impact of cancer and its treatment on HRQoL.

Methods: We conducted descriptive qualitative in-depth, semi-structured interviews with YAs receiving cancer care at an academic health center in Albuquerque, New Mexico (USA) and primary informal caregivers. The interviews, conducted from September through December 2015, focused on perspectives on the impact of the disease and its treatment in terms of physical and emotional effects, coping, and strategies to enhance HRQoL. We used an iterative thematic analysis approach to identify emergent themes and create a coding structure.

Results: We reached thematic saturation after interviewing 8 YAs and 8 caregivers. YAs and caregivers discussed cancer triggered challenges such as anxiety, depression, isolation, fear, and financial hardships. YAs and caregivers coped by maintaining positive perspectives, relying on friends and family, and prayer. Caregivers discussed how expectations for and experiences of a “good day” changed depending on their loved ones’ stage of cancer treatment. YAs navigated challenges by focusing on activities and thoughts that provided meaning to their lives. YAs and caregivers suggested strategies to enhance HRQoL through patient/provider communication, support services, and decision making tools as potential mechanisms for grounding patient-centered interventions to improve cancer care.

Conclusions: Implications include the development and evaluation of informational and behavioral interventions tailored and targeted to address the pragmatic needs of YAs undergoing cancer treatment and informal caregivers.

1. Introduction

A cancer diagnosis can have a profound negative impact on health-related quality of life (HRQoL) of cancer patients. A number of studies have focused on the physical and mental health of adult cancer survivors (Aziz, 2007; McCabe et al., 2013; Naughton and Weaver, 2014), as well as self-esteem, academic (Tremolada et al., 2017) and long term challenges (Mittal and Kent, 2017) described by pediatric cancer survivors. However, the impact on young adults (YAs) aged 20–39 remains understudied (Smith et al., 2016), particularly among racial and ethnic

minority survivors (Munoz et al., 2016). HRQoL for this vulnerable population is an important public health concern since more than 60,000 YAs are diagnosed annually with cancer in the United States and it is the leading cause of disease-specific mortality among YA females (American Cancer Society, 2017a). Moreover, the five-year relative survival for frequently occurring cancers has improved in children and older adults, yet survivorship rates for YAs have not kept pace with these improvements (American Cancer Society, 2017b).

HRQoL is indicative of a person's experience of cancer treatment and survivorship care as it refers to a person's overall functioning and

This work was previously presented in part at the Western Regional Meeting of the Society for Pediatric Research, Carmel, CA, January 29, 2016.

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<https://doi.org/10.1016/j.ejon.2017.11.007>

Received 30 June 2017; Received in revised form 20 November 2017; Accepted 26 November 2017
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well-being, specific to medical conditions. HRQoL is subjective and multidimensional and includes psychological, social, physical, spiritual, and occupational functioning, and somatic experiences (International Society for Quality of Life Research [ISOQOL], 2017). Assessing HRQoL during treatment is an important prognostic factor of patient-reported outcomes (Hinds, 2010; Hinds et al., 2006). However, few studies have examined HRQoL for YAs with cancer who report poorer overall and domain-specific HRQoL (e.g., physical, social, emotional, cognitive), compared with older cancer survivors (Dyson et al., 2012; Geue et al., 2014; Hall et al., 2012; Macartney et al., 2014a; Smith et al., 2013a; Smith et al., 2016; van Riel et al., 2014).

Concerns about the disease and treatment can have psychological effects that may impact YAs' HRQoL, physical health, and mortality. YAs in their early 20s are focused on developmental issues, identity formation, relationship building, and maturing cognitive functioning, all of which are disrupted by a cancer diagnosis (Docherty et al., 2015). Cancer creates existential challenges for YAs and gives rise to uncertainty about the disease and treatment effects, lingering post-treatment health issues, and recurrence of cancer (Corbeil et al., 2009; Odh et al., 2016). YAs also express concerns about insurance, financial barriers, dating and fertility (Bleyer, 2007; Keim-Malpass et al., 2013; Lee et al., 2011). Coping with the disease, its treatment, and changing social environment can bring significant emotional and psychosocial distress and evoke depression and anxiety (Bleyer, 2007; Docherty et al., 2015; Keim-Malpass et al., 2013).

The progressive transitioning of clinical cancer care from inpatient to outpatient settings (Kent et al., 2016) places undue burdens on informal cancer caregivers and caregiving (Ferrell et al., 2013; Kent et al., 2016). Informal caregivers of persons with cancer (i.e., family members, significant others, and friends who typically provide uncompensated care at home) face numerous HRQoL-related issues including financial costs, stress, anxiety, depression, and adverse health effects (Biegel et al., 1991; Hendriksen et al., 2015; Juth et al., 2015; Li et al., 2013; Romito et al., 2013; Stenberg et al., 2010). Coping with a cancer diagnosis also results in substantial changes in family dynamics and social functioning, which may also negatively influence HRQoL of YAs and the informal caregivers (Barakat et al., 2015; Grinyer, 2002; Kelly, 2008). YAs with cancer and caregivers share anxiety due to changing roles, potential loss of a loved one, financial concerns, loss of control, and physical symptoms (Hendriksen et al., 2015). YAs with cancer and caregivers may also have contrasting perceptions regarding the disease and its management, with subjective perceptions and differing coping strategies having detrimental effects on mental well-being (Juth et al., 2015).

Enhancing HRQoL of cancer survivors undergoing treatment and informal cancer caregivers is a national priority (National Cancer Institute and Division of Cancer Control and Population Science, 2017). Although there is a need to promote HRQoL for YAs and caregivers (Quinn et al., 2015; Traa et al., 2015), gaps exist in our understanding about focus and content of interventions. To lay the foundation for developing acceptable, practical, and effective interventions, we elicited the lived experiences of YAs and caregivers and incorporated perspectives of people from diverse socio-demographic and racial/ethnic backgrounds. New Mexico, as one of the four “minority-majority” states (U.S. Census Bureau, 2017) features unique multiethnic and multicultural diversity with striking socioeconomic and cancer health disparities. We interviewed YAs undergoing cancer treatment and informal caregivers to characterize their perspectives on the impact of the disease in terms of physical and emotional effects, social support needs and availability, school and home environment, coping strategies, and strategies to enhance HRQoL.

2. Methods

2.1. Study setting and sample

As part of a larger study, we conducted descriptive qualitative, in-depth, semi-structured interviews with adolescents and YAs receiving cancer care at the University of New Mexico's (UNM's) NCI-designated Comprehensive Cancer Center and informal caregivers. In this article, we report findings only for the YAs and caregivers interviewed for the study. By using a purposeful sampling approach, we identified participants from diverse racial/ethnic and socio-economic backgrounds. Eligible YAs were aged 20–39 undergoing active treatment for cancer. Eligible caregivers were aged 20 or older and self-identified as a primary informal caregiver for a person with cancer. To be eligible for the study, the YAs and caregivers were not necessarily dyads. The UNM Health Sciences Center's Human Research Review Committee/Institutional Review Board approved all aspects of the research protocol. We obtained informed consent with each participant prior to the interview.

2.2. Data collection

We developed interview guides for YAs and caregivers focusing on various facets of cancer and caregiving experiences. These included effects of cancer and its treatment, support (social, financial, emotional), coping, school/work environments, relationships, definitions of a “meaningful life”, and potential strategies to enhance HRQoL. We also collected socio-demographic information on both participants. We interviewed YAs and caregivers separately. The interviews occurred between September and December 2015 at a location convenient for participants. The digitally-recorded interviews lasted 45–60 min and were transcribed for analytic review. Each participant received a \$50 merchandise card.

2.3. Data analysis

We used a systematic iterative process to identify preliminary and emergent themes, using thematic analysis (Borkan, 1999; Rabiee, 2004) to describe the meaning participants gave to dealing with cancer and its treatment. Two research team members (SIM, HRB) independently reviewed transcripts and identified emergent themes. One team member (HRB) created an initial coding structure, based on topics of interview questions, that was revised as additional themes emerged from transcripts, until we reached consensus (Morse et al., 2002). We imported transcripts into NVivo 10 (QSR International), a qualitative data analysis software program, for coding. After coding, we examined each theme and code for a refined level of interpretive analysis. We analyzed survey data to provide a descriptive assessment of the participants. We reached thematic saturation after interviewing 8 YAs and 8 caregivers.

3. Results

3.1. Participant characteristics

The 8 YAs were mostly female ($n = 7$), Hispanic ($n = 6$), and receiving chemotherapy ($n = 6$) (Table 1). The most commonly diagnosed cancer was that of the breast ($n = 3$). The caregivers were equally divided between male and female and Hispanic and non-Hispanic White. Most caregivers had some college education or bachelor's degree ($n = 6$), were married or living with a partner ($n = 6$), and worked full-time ($n = 7$). There were 6 patient-caregiver dyads among those interviewed.

3.2. Interview context

Participants responded to questions designed to help us better

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