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Research Paper

Siblings, You Matter: Exploring the Needs of Adolescent Siblings of Children and Youth With Cancer¹

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Purpose: The purpose of the study was to further understanding and knowledge about the psychosocial needs of non-bereaved adolescent siblings who have a brother or sister with cancer.

Design and Methods: Within a theoretical framework of phenomenology, retrospective narrative interviews were used to collect narrative interview data from 7 now-adult sisters of a sister ($n = 4$) or brother ($n = 3$) previously diagnosed with and treated for cancer. Inclusion criteria required participants to have been of adolescent-age (11–18 years) when a sibling was treated for cancer, and who had survived cancer. Data were analyzed using thematic analysis.

Results: Eight need-based themes were identified. The needs for *being a kid* and for *family humor, laughter, and light-heartedness*, appear new to the existing literature's considerations of the needs of adolescent-aged well-siblings of children and youth with cancer.

Conclusion: Findings extend the current literature by providing a different perspective of the needs of well-siblings during the cancer experience as specifically related to adolescent-aged well-siblings.

Practice implications: It is important to separately recognize, understand, and support adolescent-aged well-siblings' needs during the cancer experience. It may also be useful for professionals to encourage and support the positive role of humor within families of children and youth receiving treatment for cancer. Follow-up support even years later may be helpful for well-siblings, including non-bereaved siblings.

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I never really thought about how [cancer] impacted me. it was just your experience.—Jasmine Stonebridge, *personal communication, July 3, 2013*.

Two weeks after her 18th birthday, the primary investigator (PI) was diagnosed with Hodgkin's Lymphoma. It was a difficult time for her whole family, and life-altering for her. Ten

years after diagnosis, she began working at a recreational camp for children with cancer. While leading a sharing circle for young campers, the PI heard a well-sibling say, "They always ask me how my brother is. I just wish they would ask me how I am!" Well-siblings around the circle echoed this sentiment. Some of the sick siblings said how they too had not considered what their well-siblings' experience was, others expressed how much their siblings' support mattered to them. It was apparent that many in this large group of campers had not spoken or thought about the cancer experience from the well-sibling perspective, and the PI began to wonder about her own sister Jasmine's experience as a well-sibling. The PI's realization that well-siblings also hold a perspective of the cancer experience, was the motivation for this study.

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Well-siblings of children and youth with cancer are reported in the literature as believing their own needs and problems are insignificant in comparison to their sick-sibling's and parents' (Prchal & Landolt, 2012; Vermaes, Susante, & Bakel, 2010; Wilkins & Woodgate, 2005). At the same time, well-siblings are emotionally and psychosocially affected by the cancer experience (Alderfer & Hodges, 2010; Alderfer & Noll, 2006; Alderfer et al., 2010; Barrera, Fleming, & Khan, 2004; Malone & Price, 2012; Woodgate, 2006), and researchers (Alderfer et al., 2010; Malone & Price, 2012; O'Shea, Shea, Robert, & Cavanaugh, 2012; Patterson, Millar, & Visser, 2011; Patterson et al., 2014) have suggested that this is possibly because one or more needs of siblings go unmet when their sibling is diagnosed and receiving treatment for cancer. Needs are internal forces—biological, psychological, or both—operating within, and as a response to, the contingencies of the internal and external environments of a person. As such, needs arouse and organize human perception and behavior in the direction of need–satisfaction (McAdams, 2001, p. 458); how sufficiently and consistently needs are met, influence a person's development, adaptation, and well-being. The purpose of this study was to further understanding and knowledge about the psychosocial needs of non-bereaved adolescent well-siblings. Our research question was: What are the needs of adolescent well-siblings of children and youth with cancer from the retrospective-perspective of well-siblings themselves? Six of the eight needs we identified corroborate and extend those described in the existing literature for well-siblings generally. The needs for *being a kid* and for *family humor, laughter and lightheartedness*, are two novel findings to the literature regarding adolescent-aged well-siblings' psychosocial needs during the cancer experience.

Review of the Literature

Between 1990 and 2009, the publication of studies on the experience of well-siblings of children and youth with cancer grew exponentially (Alderfer et al., 2010). Within this body of literature, there has also been a relatively recent shift from focusing on bereaved siblings to focusing more specifically on the needs of well-siblings (possibly related to the increased survivorship among children diagnosed with cancer; O'Shea et al., 2012). However, problems within this overall body of literature have been noted. For example, Alderfer et al. (2010), and Wilkins and Woodgate (2005), discussed that, with small exception, studies were contemporaneous and mixed well-siblings across ages, making it difficult to make inferences based upon developmental level of well-siblings. In reading the literature, we realized that the well-sibling perspective was often represented through proxies (e.g., nurse-report in O'Shea et al., 2012), literature reviews or meta-analyses (e.g., Wilkins & Woodgate, 2005), or included with the perspectives of sick-siblings (e.g., Di Gallo, 2003), program staff (e.g., Patterson et al., 2011, 2014), or well-siblings of children with other chronic illnesses (e.g., Knecht, Hellmers, & Metzger, 2015; Vermaes

et al., 2010). To this point, in a very recent paper, Knecht et al. (2015), called again for the importance of data gathered directly from the well-sibling perspective. Questions have, however, been raised about the quality of contemporaneously rather than retrospectively-reported well-sibling perspectives (e.g., Lehna, 1998).

Nonetheless, a sibling's cancer diagnosis and treatment was described in the literature as having the potential to disrupt the structure and functioning of the family (O'Shea et al., 2012; Patterson et al., 2011; Wilkins & Woodgate, 2005; Woodgate, 2006) and sibling relationship—possibly because cancer heightens the intensity of feelings, tensions, and interactions between siblings (Breyer, Kunin, Kalish, & Patenaude, 1993). Well-siblings of all ages were inclined to internalize emotions and discount their own problems, likely because of a desire to not be a burden on parents (Prchal & Landolt, 2012; Vermaes et al., 2010; Wilkins & Woodgate, 2005; Woodgate, 2006), or being unable, or not wanting, to share their emotional stress (Prchal & Landolt, 2012; Vermaes et al., 2010; Wilkins & Woodgate, 2005). Overall, well-siblings were reported to feel lonely, isolated, peripheral, and like a burden, putting them at risk for psycho-social adjustment issues (e.g., Alderfer & Hodges, 2010; Alderfer & Noll, 2006; Alderfer et al., 2010; Malone & Price, 2012; Woodgate, 2006). These issues included: the development of depression, anxiety, social withdrawal (Alderfer et al., 2010; Houtzager, Grootenhuys, Caron, & Last, 2004; Patterson et al., 2011), moderate to severe posttraumatic stress symptoms (Alderfer & Hodges, 2010; Kaplan, Kaal, Bradley, & Alderfer, 2013); and increased risky behavior (Lown et al., 2013). Di Gallo (2003) and McCubbin, Balling, Possin, Friedrich, and Bryne (2002), claimed recognizing and understanding well-siblings' needs would help them better cope with the cancer experience.

Theoretical and empirical links have been reported between the impact of cancer on well-siblings and how satisfactorily psychosocial needs are met during the cancer experience (Barrera et al., 2004; Malone & Price, 2012; O'Shea et al., 2012; Patterson et al., 2011, 2014). For example, related to our age-group of interest, Patterson et al. (2011) found a positive and significant relationship between unmet needs and higher levels of difficulties in psychological functioning in well-siblings aged 12–17 years (for further review, see Alderfer et al., 2010; O'Shea et al., 2012; Patterson et al., 2014; Wilkins & Woodgate, 2005). Yet, what exactly do well-siblings need during the cancer experience?

In their meta-analysis of 27 qualitative studies on the childhood experience of having a sibling with cancer, Wilkins and Woodgate (2005) reported and discussed four unmet needs of well-siblings, as did O'Shea et al. (2012) who conducted a qualitative study assessing the needs of well-siblings from the perspectives of 13 pediatric oncology nurses. The work of Patterson et al. (2011, 2014) in developing the Sibling Cancer Needs Instrument (SCNI)—the first psychometrically validated instrument available for assessing well-siblings' psychosocial needs, and for measuring

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