



'Having cancer was awful but also something good came out': Post-traumatic growth among adult survivors of pediatric and adolescent cancer



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ABSTRACT

Purpose: The cancer experience may cultivate positive psychological changes that can help reduce distress during adult survivors of childhood and adolescent cancer life course. The aim of this study is to examine the positive impact of cancer in adult survivors utilizing posttraumatic growth as a guiding framework.

Method: Participants were identified and recruited through the Utah Cancer Registry. Eligible cases were diagnosed with cancer age ≤ 20 years from 1973 to 2009, born in Utah, and were age ≥ 18 at study. Semi-structured phone interviews ($N = 53$) were analyzed using deductive analysis.

Results: The primary five themes that emerged were similar to Tedeschi and Calhoun's (1996) themes for measuring positive effects, and were used to frame our results. The primary themes along with uniquely identified sub-themes are the following: personal strength (psychological confidence, emotional maturity), improved relationship with others (family intimacy, empathy for others), new possibilities (having passion work with cancer), appreciation for life (reprioritization), and spiritual development (strengthened spiritual beliefs, participating in religious rituals and activities).

Conclusions: For survivors, cancer was life altering and for many the experience continues. Understanding survivors' complex cancer experience can help improve psychosocial oncology care.

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1. Introduction

Cancer during childhood or adolescence is a life altering event that can result in posttraumatic stress disorder symptoms later in life (Rourke et al., 2007), but at the same time, can also be interpreted as positive by some survivors. These positive effects have been associated with the cancer experience in several studies with childhood cancer survivor populations (Bellizzi et al., 2010; Garland et al., 2007; Jim and Jacobsen, 2008; Koutrouli et al., 2012; Yi et al., 2015; Zebrack et al., 2012). Findings from these studies emphasize how growth in survivors can occur in different areas such as spirituality and appreciation for life by, intentionally or unintentionally,

imparting meaning through the cancer experience (Lee, 2008). With nearly 85% of adolescent survivors of childhood cancer reporting at least one positive outcome from their cancer experience (Barakat et al., 2006), further investigations can inform interventions that promote growth and resilience.

Researchers have made efforts to understand the multiple domains of positive growth (Park et al., 1996) and have postulated that through the cancer journey, survivors can grow in the following areas: spirituality (Connerty and Knott, 2013; Denney et al., 2011; Mehrabi et al., 2015), interrelationships (Chambers et al., 2012; Connerty and Knott, 2013; Sabiston et al., 2007; Tomich and Helgeson, 2002), resilience (Chambers et al., 2012; Mehrabi et al., 2015; Rinaldis et al., 2010), personal cognition and mentality (e.g., priorities and worldview) (Connerty and Knott, 2013; Helgeson, 2011; Mehrabi et al., 2015; Rinaldis et al., 2010; Sabiston et al., 2007) and social activity (e.g. paying back society) (Duran, 2013).

In this study we use the term posttraumatic growth (PTG)

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(Tedeschi et al., 1998) as it best expresses the meaning of our study phenomena. PTG describes a cognitive process for how, from a traumatic event, an individual can experience a feeling of emotional and mental growth that is beyond their previous level of adaptation, psychological functioning, and awareness. Positive growth has also been referred to as ‘adversarial growth’ (Linley and Joseph, 2004), ‘perceived benefits’ (Calhoun and Tedeschi, 1991), ‘positive psychological changes’ (Yalom and Lieberman, 1991), ‘stress-related growth’ (Park et al., 1996), or ‘thriving’ (O’Leary et al., 1998). However, terms like “stress-related growth” or “thriving” do not articulate psychological distress and may inadequately acknowledge the severity of disruption that occurs from the cancer experience (Ben-Zur et al., 2015; Tedeschi and Calhoun, 2004).

Multiple instruments have been developed to identify the domains of PTG, (Frazier et al., 2001; Joseph et al., 1993; McMillen and Fisher, 1998; Park et al., 1996; Phipps et al., 2007). The most well-known instrument for measuring positive effects is the Post-traumatic Growth Inventory (PTGI). PTGI is a 21-item questionnaire originally developed by Tedeschi and Calhoun (1996) that includes five domains: personal strength, new possibilities, relating to others, appreciation for life, and spiritual change (Calhoun and Tedeschi, 2006; Tedeschi and Calhoun, 2004). The constructs in this instrument have been confirmed as relatively robust, with good construct validity (Yi et al., 2015).

The PTG construct has been sufficiently examined in quantitative studies with the development of related instruments (Zoellner and Maercker, 2006); the five domains are well known and supported by existing literature. Due to the nature of quantitative methodology, however, there have been limits to developing a deeper understanding of each domain, including how cancer survivors express their experience related to each of the five PTG domains and how the process of growth and factors mediate the positive changes of childhood and adolescent cancer survivor populations. A qualitative approach may help to enrich the comprehension of the PTG concept by filling the unmet part of the existing quantitative research. Therefore, this study sought to qualitatively examine the positive impacts of cancer in this population, using posttraumatic growth as a theoretical framework, in order to better understand how they derive meaning-making from their cancer experience.

2. Methods

This study was conducted as part of a larger study at the Huntsman Cancer Institute (HCI) examining health care, health insurance, employment, educational, and life course experiences of adult survivors of childhood and adolescent cancer. This study was approved by the Institutional Review Board at the University of Utah.

2.1. Participants and recruitment

Potential participants were identified by the statewide Utah Cancer Registry (UCR), part of the National Cancer Institute’s Surveillance, Epidemiology and End Results Program. Eligible cases were diagnosed with cancer age ≤ 20 years from January 1, 1973 to December 31, 2009. We limited participants to those born in Utah, currently age ≥ 18 and alive at the time of study contact, due to the eligibility criteria of the overall study. We included all diagnoses meeting International Childhood Cancer Classification criteria. Non-melanoma skin and cancers in-situ were excluded due to concerns in completeness of registry and the perception of these cancers by participants as rarely life threatening.

To recruit a diverse sample, residence location (rural versus urban community at diagnosis), gender, and age were considered in

recruitment; accordingly, the UCR sent letters to a random sample of 150 of 2686 eligible participants on their registry. Of these, 70 could not be reached due to outdated contact information, and 3 were out of the country or deemed ineligible because they pilot tested the interview script. Of the remaining 77 eligible participants, 63 agreed to participate, yielding a response rate of 82%. In this study, 53 participants actually participated because our research team halted interviews under the judgement that data were theoretically saturated.

2.2. Data collection

Phone interviews (N = 53) were conducted between April 2012 to July 2012. Each interview lasted between 30 and 45 min. Informed consent was obtained prior to each interview. Study participants were asked sociodemographic questions regarding sex, age, race, educational attainment, and work status. Zip code was obtained from the cancer registry and was used to determine current residency location (rural vs. urban community) using Rural Urban Commuting Area Codes from the University of Washington Rural Health Research Center (n.d.). Religious affiliation was not explicitly asked and was determined by self-report.

We started the interview with a guiding question: What positive effects have cancer had on your life? Following this, probing questions were asked to elicit participants’ growth experiences from having cancer. Before implementation to study participants, pilot interviews were conducted with 5 childhood cancer survivors receiving care at the HCI’s Late Effects Clinic. Under the participants’ agreement, interviews were recorded and later transcribed. Participants received a \$20 gift card for their participation.

2.3. Data analysis

We analyzed the qualitative data to achieve the study aim: To examine the positive impact of cancer in adult survivors utilizing posttraumatic growth as a guiding framework. The research team was intimately aware of Tedeschi & Calhoun’s research and analyzed the data within this framework. Two leading researchers independently coded the transcripts word by word, line by line, and segment by segment, and kept comparing the coded data through email until reaching consensus. The initial coding was continuously revised based on online discussions with all six members of the research team. The two leading researchers again independently categorized the codes into themes and then the larger research team met in-person until all agreed on these categorized themes.

We then purposefully compared the themes to Tedeschi & Calhoun’s PTG domains. We examined if the themes that we came up with could expand more on this PTG concept. After discussions amongst the research members, we found that our themes were in line with the five PTG domains identified by Tedeschi and Calhoun. Furthermore, we expanded these themes through the development of sub-themes. Throughout the analysis process, we were aware of the fact that “the researcher is the instrument” (Patton, 2002). We recognized the inherent potential for researcher bias in the analysis given our prior knowledge with PTG and the positive growth literature. To address this issue, the researchers discussed the coding and analysis process frequently. The sub-themes identified were unique and not explicitly used by Tedeschi and Calhoun.

3. Results

3.1. Characteristics of the sample

Ages ranged from 18 to 56 years (M = 40, SD = 11) at the time of the interview. On average survivors were 13 years old at diagnosis

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