

5-2012

Interrelated Processes toward Quality of Life in Survivors of Childhood Cancer: A Grounded Theory

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Citation of this paper:

Tsonis, Miranda; McDougall, Janette; Mandich, Angela; and Irwin, Jennifer, "Interrelated Processes toward Quality of Life in Survivors of Childhood Cancer: A Grounded Theory" (2012). *Occupational Therapy Publications*. 14.

<https://ir.lib.uwo.ca/otpub/14>

11-5-2012

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Recommended APA Citation

Tsonis, M., McDougall, J., Mandich, A., & Irwin, J. (2012). Interrelated Processes toward Quality of Life in Survivors of Childhood Cancer: A Grounded Theory. *The Qualitative Report*, 17(45), 1-18. Retrieved from <http://nsuworks.nova.edu/tqr/vol17/iss45/1>

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Abstract

Past research has not adequately addressed the quality of life (QOL) of survivors of childhood cancer. The purpose of this study was to understand how QOL is experienced for individuals who have survived childhood cancer. Specific research questions included: (a) How do childhood cancer survivors define the concept of QOL and (b) What processes do childhood cancer survivors go through regarding their QOL? Researchers used grounded theory to analyze in-depth interviews conducted with eight survivors. Survivors use a process of specific action strategies and intervening conditions to manage impacts and effects, resulting in life enjoyment, or good QOL. The identification of this process has led to an emergent theory titled Interrelated Processes toward Quality of Life Theory.

Keywords

Childhood Cancer Survivors, Quality of Life, Grounded Theory

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Acknowledgements

The authors would like to thank the individuals who participated in this study and so thoughtfully shared their experiences.



Interrelated Processes toward Quality of Life in Survivors of Childhood Cancer: A Grounded Theory

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*Past research has not adequately addressed the quality of life (QOL) of survivors of childhood cancer. The purpose of this study was to understand how QOL is experienced for individuals who have survived childhood cancer. Specific research questions included: (a) How do childhood cancer survivors define the concept of QOL and (b) What processes do childhood cancer survivors go through regarding their QOL? Researchers used grounded theory to analyze in-depth interviews conducted with eight survivors. Survivors use a process of specific action strategies and intervening conditions to manage impacts and effects, resulting in life enjoyment, or good QOL. The identification of this process has led to an emergent theory titled *Interrelated Processes toward Quality of Life Theory*. Keywords: Childhood Cancer Survivors, Quality of Life, Grounded Theory*

Childhood cancer continues to be met with increasingly successful treatment outcomes and improved rates of survival, making survivors an important population to study (Pogany et al., 2006). With the growing number of childhood cancer survivors, it is important to assess and understand their post cancer quality of life (QOL), particularly because the extant literature in this area appears inconsistent and contradictory. Authors of past reviews of quantitative studies in this area (Calaminus & Kiebert, 1999; Eiser, Hill, & Vance, 2000; Langeveld, Stam, Grootenhuis, & Last, 2002; McDougall & Tsonis, 2009; Stam, Grootenhuis, & Last, 2001) have reported lower, higher, or similar QOL ratings for survivors when compared with population norms and matched comparison groups. Despite these inconsistencies, researchers from previous studies have indicated that most survivors were doing well overall. When looking at specific aspects of QOL, findings from previous research indicate that, in general, survivors fair significantly poorer than comparison groups with respect to physical well-being (Maunsell, Pogany, Barrera, Shaw, & Speechley, 2008; Speechley, Barrera, Shaw, Morrison, & Maunsell, 2006; Stam, Grootenhuis, Caron, & Last, 2006; Zeltzer et al., 2008). Surprisingly, a number of studies report that survivors have significantly better emotional well-being than comparison groups (De Clercq, De Fruyt, Koot, & Benoit, 2004; Pemberger et al., 2005; Van Dijk, Imhof, et al., 2007; Zebrack, Yi, Peterson, & Ganz, 2008; Zeltzer et al.,

2008). It is apparent that past research has not adequately addressed the QOL of survivors of childhood cancer.

The concept of QOL has been increasingly used in biomedical, rehabilitation, and nursing research during the past three decades (Moons, Budts, & De Geest, 2006). However, there is no consensus regarding the definition and measurement of QOL. The World Health Organization (WHO) (World Health Organization Quality of Life Group, 1998) defines QOL as “individuals’ perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns” (p. 1570). Similarly, Oleson (2002) defines QOL as “the subjective perception of happiness or satisfaction with life in domains of importance to the individual” (p. 439). In this respect, QOL refers to a broad personal valuation of the nature of one’s life (Rosenbaum et al., 2005). The WHO suggests that QOL can be categorized into four primary domains: physical, psychological, social functioning/well-being, and environmental conditions (WHO, 1996). Spiritual well-being is often captured as an aspect of psychological functioning/well-being. However, researchers have argued that spirituality is a separate and distinct core domain of QOL (Peterson & Webb, 2006).

Quantitative work in the area of childhood cancer survivorship has most often used instruments that measure QOL in terms of physical, psychological, and social functioning/well-being (McDougall & Tsonis, 2009). Well-being in these areas of life is considered to be indicative of successful survivorship (Shepherd & Woodgate, 2010). However, rarely have individuals been asked to further elucidate about these areas or about their satisfaction with life overall (Seitz et al., 2011). Indeed, few qualitative studies that invoke the stories of cancer as told by young people can be found among the extant literature in this area (Woodgate, 2006). Moreover, no qualitative study has been found that inquires specifically into how older adolescent and young adult long-term survivors of childhood cancer themselves define QOL, or what processes survivors go through regarding their QOL (Hinds, 2010).

Study Purpose

The purpose of this grounded theory study was to understand how individuals who have survived childhood cancer experience QOL using qualitative methods. Specific research questions included: (a) How do childhood cancer survivors define the concept of QOL and (b) What processes do childhood cancer survivors go through regarding their QOL?

Role of the Researcher

Four researchers were involved in this study. The research group consisted of myself, a Master’s student (M. Tsonis), two committee members who helped guide the progress of my Master’s thesis (J. McDougall and J. Irwin), and one thesis advisor (A. Mandich), who oversaw the entire process. I have since graduated with a Master’s degree in Child and Youth Health following the completion and acceptance of my thesis. During my undergraduate studies, I volunteered at a hospital where I was responsible for helping children and families cope with illness. This led me to wonder about what QOL meant to individuals in different situations, what factors facilitate and hinder their QOL, and how

children who experience cancer are affected later in life. My intention in conducting my research was to uncover the experiences of childhood cancer survivors, and giving voice to their perspectives on QOL. I am currently a Research Scientist at the British Columbia Cancer Agency. J. McDougall is employed as a Researcher at a children's rehabilitation centre in London, Ontario. Her primary research interest is examining changes in QOL for children and youth with chronic conditions and disabilities, and the factors that are related to it. She is currently conducting a study in this area that includes both a longitudinal quantitative and qualitative component. A. Mandich is an Associate Professor in the School of Occupational Therapy in the Faculty of Health Sciences and Associate Vice-Provost (Academic Programs and Students) at Western University in London, Ontario. Her areas of research include exploring meaning in occupation and activity, client-centered care, spirituality, and understanding occupational engagement and participation in children. J. Irwin is an Associate Professor in the Faculty of Health Sciences at Western University in London, Ontario. Her area of research falls under the umbrella of health-related behavior change. She is also a cancer survivor interested in the experience of others. She believes QOL from the perspective of the cancer survivor is essential to more fully understand the impact of having survived cancer. Her intention is to help share the voice of cancer survivors who might not otherwise have a suitable outlet.

Method

In this study, we used grounded theory methodology as outlined by Strauss and Corbin (1990). The goal of this methodology is to develop a substantive theory from well-integrated concepts that will provide an explanation about a **main concern for a population** and **how that concern is resolved or processed** (Strauss & Corbin, 1990). The theory should be grounded in the data, or in other words, emerge from the results. This is achieved by using the constant comparative method that allows the theory to evolve during the research process and by making comparisons of data, concepts, and categories at each stage of the analysis (Charmaz, 2006). This methodology fits well with this study, as there is a lack of a testable hypothesis, as well as a goal to uncover aspects and issues that emerge from the data, rather than to prove or disprove pre-existing ideas of QOL. The result of this type of research should be the development of a theory that emerges from the data collected, which will in turn explain processes and experiences as articulated by the participants.

Ethical Considerations

The Health Sciences Research Ethics Board at Western University, in Ontario Canada approved the study. Each individual read a Letter of Information and signed a consent form prior to his or her participation in the study. A confidential ID number for further identification was assigned to each participant and corresponding data.

Recruitment and Data Collection

We recruited individuals through advertisement postings on bulletin boards in large cities, university campuses, within cancer organizations, and throughout Internet classifieds. In addition, we sent requests to cancer and survivor organizations to help distribute the advertisements. Those organizations that agreed to help posted advertisements at their events and on their websites. Potential participants used the contact information included in the advertisements to contact the first author if they were interested in taking part in the study. We used a semi-structured interview format in the current study. As primary researcher, I conducted all interviews either in person or over the phone, depending on the preference and location of the participant. The interviews were on average one hour in length, with the longest 75 minutes and the shortest 45 minutes. I transcribed each audiotaped interview verbatim, with all identifying information removed and replaced by ID numbers. Theoretical sampling was used to ensure rigor throughout the process of data collection. Theoretical sampling refers to “sampling on the basis of concepts that have proven theoretical relevance to the evolving theory” (Strauss & Corbin, 1990, p. 176).

We used the WHO’s conception of QOL to broadly guide the interview questions, but did not present any specific definition to study participants so that their own ideas and thoughts about this concept would emerge. The interview began with questions to obtain background information, and then moved onto five broad, open-ended questions about QOL and well being with each linked to several prompts that were asked if needed. The interview questions were open-ended to allow the participants to explain their experiences in their own words. The five broad questions/requests included (a) Please define the term quality of life; (b) Please tell me about the impact your experience with cancer has had on your physical well-being; (c) Please tell me about the impact your experience with cancer has had on your psychological well-being; (d) Please tell me about the impact your experience with cancer has had on your relationships, such as friends, family, peers, significant others, and children; and (e) Please tell me about the impact your experience with cancer has had on your quality of life.

Participants

Five men and three women who were childhood cancer survivors were included in the study. Their ages ranged from 19 to 31 years, with a mean age of 26. Their age at diagnosis ranged from 3-12 years, with a mean age at diagnosis of 7. Two of the participants had survived lymphoma, three had survived leukemia, two had survived a central nervous system tumour, and one had survived Ewing's sarcoma. Six of the eight participants had gone through chemotherapy treatment, which was the only treatment received for three of these individuals. Two others received chemotherapy along with surgery, and one received chemotherapy and radiation. One participant only received radiation, and another only received surgery.

Data Analysis

It is crucial in grounded theory that data collection and analysis are interrelated, and in response the constant comparative method was used (Corbin & Strauss, 1990). In this approach, the research process directs the researcher to examine multiple ways of understanding, who seeks to analyze all relevant data as soon as they are recognized (Corbin & Strauss, 1990). As the primary researcher, I conducted the analyses. To apply this method, I made comparisons throughout the analysis to “establish analytic distinctions” (Charmaz, 2006, p. 54), and began analyzing data after the first participant interview and continued after each subsequent interview with the other participants.

To conduct data analyses, I followed the procedures of Strauss and Corbin (1990). To aid in the data analysis, I used data processing software QSR Nvivo 7 to record participant information, code the transcripts, and organize the emerging concepts and categories. I analyzed the transcripts using open, axial, and selective coding (Strauss & Corbin, 1990). Open coding was applied using line-by-line coding, which helped me avoid applying pre-existing assumptions to the data and allowed the analysis to fit closely with the data. Open coding is the part of the analysis where phenomena are identified, named, and categorized. For example, one participant stated, “The treatment was physically, emotionally, psychologically draining.” This was labeled as *undergoing treatment*. Once concepts were labeled, they were grouped to form categories (Strauss & Corbin, 1990). For instance, concepts such as *undergoing treatment* and *cancer diagnosis* were grouped to create the larger category *past illness experience*.

Axial coding was then used to relate and integrate categories together by applying the *paradigm model* (Strauss & Corbin 1990, p. 99). The paradigm model involves fitting sub-categories into a basic frame of relationships for a category such as *past illness experience* (Strauss & Corbin 1990, p. 99).

The paradigm model develops each category by examining its causal conditions, context, intervening conditions, action/interaction strategies, and consequences (Strauss & Corbin, 1990). Strauss and Corbin view causal conditions as those events that seem to lead to the phenomenon. The context refers to the properties of the phenomenon, as well as the conditions within which the strategies to manage or carry out the phenomenon exist. The intervening conditions are what facilitate or constrain these strategies, and the consequences are the outcome of carrying out the strategies.

For example, the causal condition for the category *past illness experience* was identified as *having a cancer diagnosis*. Once the illness was identified, the individual experience for each participant began. This experience was found to take place in the *context of childhood*, and at the time of the interview was a retrospective look at past events. *Undergoing treatments* was the main action strategy identified for living through the illness experience, and this was found to be influenced by the *treatments required* which, in turn, was identified as the intervening condition. The severity of the treatment, side effects, and type of treatment all impacted the course of the illness experience. Many consequences were identified as arising from the illness experience, such as *experiencing a changed developmental course* and *direct effects from treatment*.

After using axial coding and the paradigm model to fit categories, selective coding was then applied. Selective coding is the process of choosing one category to be the core category, and relating all other categories to that category (Strauss & Corbin,

1990). In grounded theory, the core category stands as the central phenomenon around which all other categories are integrated (i.e., it explains how the main concern is resolved or processed) (Strauss & Corbin, 1990). The core category emerged while considering the questions “What does all the action/interaction seem to be about?” and “What is the analytic main idea presented in this research?” (Corbin & Strauss, 1990, p. 14). This was identified as the process of *managing impacts and effects*. Following the identification of the core category, the paradigm model was applied to develop this category. The *past illness experience* was identified as the causal condition for the core category. The process of managing impacts and effects were found to take place in the *context of experiencing last impacts and an affected life*. The actions/interactions that the survivors had reported undertaking emerged as the action strategies for this category: *adopting a positive outlook, living a healthy lifestyle, and seeking others. Personal and environmental resources* emerged as the intervening conditions, as these were the barriers and facilitators to managing impacts and effects. The consequence of this process emerged as *experiencing good QOL and enjoyment*. The development of the core category led to a substantive theory of what process survivors go through with regard to their QOL: a complex interrelated process of managing impacts and effects that results in good QOL.

The quality criteria used in this study were guided by Lincoln and Guba's (1985) criteria for trustworthiness in qualitative research. These include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Credibility refers to ensuring rigor throughout the research process (Morrow, 2005). This was achieved by theoretical sampling, conducting detailed interviews, saturation, and member checking in this study. Observations were used to watch for signs of important concepts, both from prior analysis and novel emerging ones. This interrelated process worked toward ensuring a fit between the data and the emerging analysis. Detailed interviews were obtained by asking the participants to elaborate on their experiences and the contexts in which they occur. To maintain separation of researcher bias from the research process, we used coding and memoing as well as providing an audit trail. Sample size considered to be sufficient when new data no longer appreciably changed the emerging theory, and the categories and relationships between categories were well developed (Strauss & Corbin, 1990). Lastly, we used member checking throughout the interviews to ensure the data collected fit with the participant's lived experience. Member checking refers to asking participants to confirm ideas by bringing these ideas back to them (Charmaz, 2006). In this study, we incorporated this concept into the interviews by re-stating the participant's explanations, and asking for clarification and confirmation. By checking with the participants to ensure their explanations were understood, member checking helped to ensure the data fit with their lived experience.

Transferability is provided when the researcher provides sufficient information about “the self and the research context, processes, participants, and researcher participant relationships” (Morrow, 2005, p. 252), such that the reader is able to decide if and how he/she may transfer the findings. In this study, researcher biases and influences were kept to a minimum by the use of open coding. In addition, a declaration of self was presented. By providing a clear audit trail, sufficient for readers to judge applicability in their own contexts, the findings are transferable. Dependability refers to the idea that the

research process should be repeatable as far as possible by providing information of how a study is conducted. In this study, we kept a research journal and used memoing, which detailed the research process, in order to provide a clear audit trail sufficient for another researcher to follow.

Confirmability refers to the idea that the data should represent an emic view of the findings and not the biases of the researcher (Morrow, 2005). Constant comparative analysis and coding helped maintain objectivity by tying the research process closely to the data. Memoing and the audit trail were also useful in achieving confirmability, as they helped keep track of researcher ideas, thoughts, and subjectivities.

Triangulation helped to ensure confirmability in this study. Patton (2002) explains that triangulation involves the use of several evaluators to interpret themes from the data. In this study, a researcher who was not directly associated with the study was used in triangulation of the analysis. This researcher examined the participant data and the analysis to ensure that researcher biases were not included in the findings. This confirmed that the analytic interpretations resulted from the participant data (Lincoln & Guba, 1985).

Results

QOL Definitions

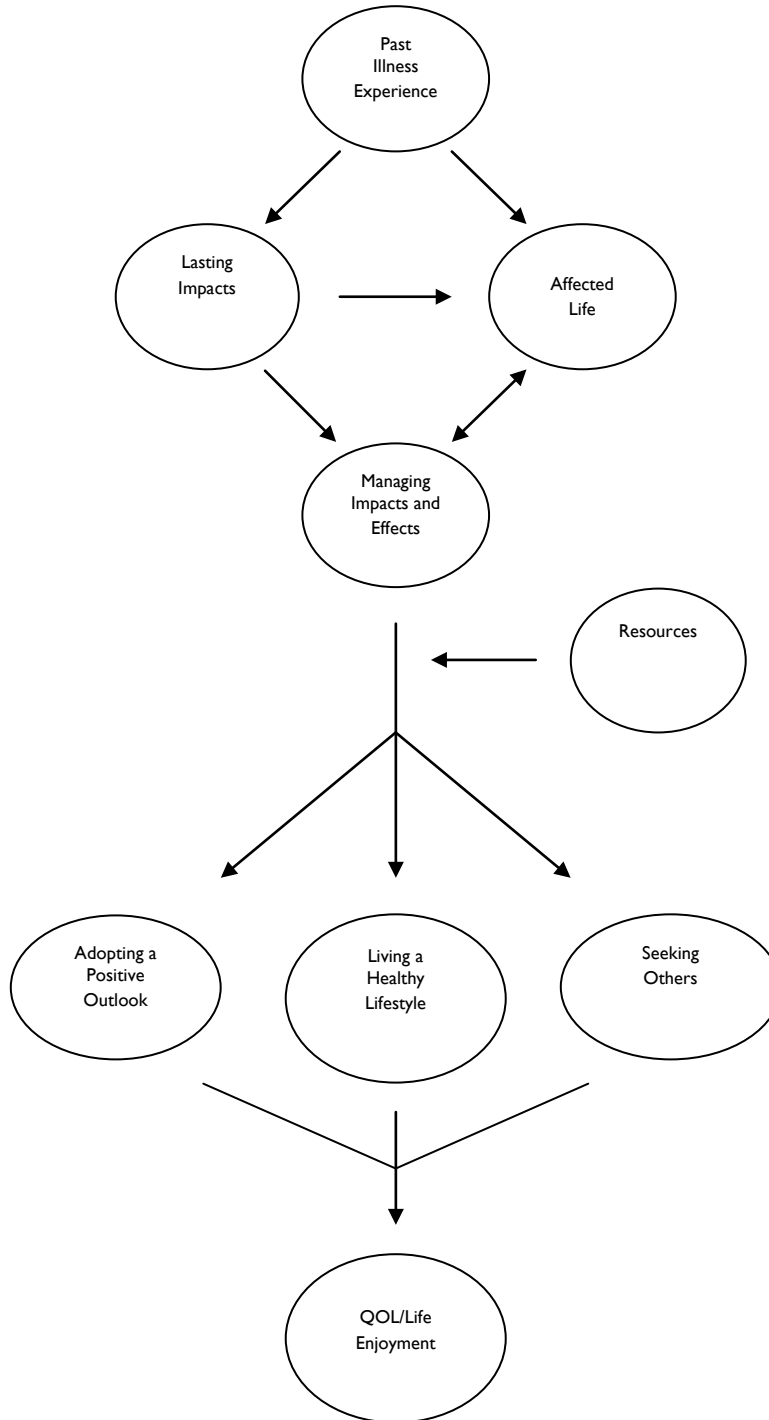
Different participants proposed varying definitions of QOL. Half of the individuals described QOL as personal enjoyment of, or satisfaction with, one's life. For example, one participant defined QOL as "enjoyment of what you're doing in everyday life." Another explained that QOL involves "enjoying your life" and that it is "what you want it to be," and later stated that, "it's hard to judge somebody else's QOL based on your standards." A third thought QOL meant "being able to enjoy your every day existence" and further explained that "it doesn't have to be anything spectacular, but just that I enjoy how I feel at any time." Two participants defined QOL in relation to others, specifically in comparison to the well-being of the average person of the same age. For instance, one stated, "I think it's a relative thing...relative to the people around me that are approximately my age." Two participants defined QOL in terms of day-to-day functioning/coping. One participant proposed that having good QOL is the ability to perform tasks without experiencing health related barriers. The other participant described being able to "get through problems, and manage them," as the deciding factor for good QOL.

Categories Related to QOL for Childhood Cancer Survivors

Eight primary interconnected categories emerged as significant to the QOL of survivors of childhood cancer. These were: (a) past illness experience (i.e., causal conditions); (b) lasting impacts and (c) affected life (i.e., context); (d) the core category: managing lasting impacts and affected life (i.e., phenomenon); the personal coping strategies of (e) adopting a positive attitude, (f) living a healthy lifestyle, and (g) seeking others (i.e., action/interaction strategies); and (h) personal/environmental resources (i.e., intervening conditions). The process of managing impacts and effects to achieve and

maintain a good QOL is visually represented in Figure 1. The process is also described below.

Figure 1. Conceptual Model of Interrelated Processes of Managing Impacts and Effects to Achieve/Maintain Quality of Life for Childhood Cancer Survivors



Past illness experience. Every participant discussed his/her past illness experiences during the interview. For many, undergoing treatment at the time of illness was the most difficult part of the cancer experience. As one participant explained, “The treatment was physically, emotionally, psychologically draining...people say if the cancer doesn’t kill you the chemo will.” Participants discussed having to miss school, worrying, feeling different than peers, and experiencing relationship difficulties throughout the illness experience.

Lasting impacts. The illness experience led to lasting physical and psychological impacts for survivors. Almost all participants felt they were tired more frequently than those who had not experienced cancer. One participant had a full leg amputation. Three participants noted the development of learning disabilities as a further result of the illness experience. Yearly follow-up medical appointments were a requirement for most survivors. Many found these follow-ups intense and stressful, usually because of concern over waiting for the test results. One participant said, “I get nervous, because I don’t know how it’s going to turn out.” Ongoing worry also had a lasting impact on survivors’ lives and arose from the fear of others becoming ill or being impacted by participants’ potential illnesses. One participant worried about relapse and how it would affect relationships.

Affected life. Participants discussed the effects of their past illness on their relationships and community life. For some, witnessing the effect of their illness experience on their families was difficult. One person explained, “My mom and I have a good relationship, but my siblings and my dad; they don’t like to talk about it.”

In addition to family relationships, some participants revealed that relationships with friends and peers were affected by their cancer. Feeling different from others was often noted. One individual, who had mobility issues, explained that currently “I don’t feel the same as [others my own age], because I was never able to participate in sports or anything like that.” Most participants were faced with school reintegration at the end of their treatment course. For some, the development of learning disabilities made reintegration all the more complicated.

Core category: managing lasting impacts and affected life. In this study, the core category was identified as managing lasting impacts and effects. This phenomenon describes how survivors attempted to enhance their QOL through efforts to resolve the lasting impacts and life effects that resulted from the experience of having had cancer by using personal coping strategies and personal and environmental resources.

Personal coping strategies. Participants identified personal coping strategies that helped them prevail over the lasting impacts and effects of their past illness on their lives. The personal coping strategies that emerged as most important to survivors included adopting a positive outlook, living a healthy lifestyle, and seeking out others. Adopting a positive outlook, for these survivors, is to experience a greater appreciation of life and a sense of acceptance, as well as a feeling of being “lucky.” Participants talked of not taking life for granted and enjoying the little things. One individual explained that, “everyday things seem like more of a gift to someone who’s been sick.”

All participants expressed feeling lucky in different ways. Three survivors stated they were grateful for the cancer itself. For instance, one stated that “having had cancer has done nothing for me but make me appreciate what I’ve got and the life that I have no matter what...It truly has blessed my life.” Others felt grateful for being better off than some who had cancer.

Adoption of a positive outlook also helped survivors accept their past illness experience. Participants used specific strategies such as “self-talk” and distraction methods to help themselves. The participant who had a leg amputated had chosen to have the amputation and as a result felt a sense of control and acceptance in the illness experience. As this participant explained, “it was my choice to be amputated, my doctors and parents were amazing and they let me make that choice, it wasn’t made for me. And so, I think that helped a lot, from an emotional standpoint.”

The strategy, living a healthy lifestyle, for these survivors, is to eat well, exercise, rest, limit alcohol, and not smoke. In response to their lasting impacts, participants reported listening to their bodies more due to their cancer experiences. They were mindful to monitor their energy levels, limit activities when necessary, and rest frequently. One individual made a decision to refrain from drinking alcohol, because it was thought to be impacting the frequency of seizures. Another participant said he watched his diet quite strictly and made all his own food. One participant also explained a similar lifestyle: “I try to do a lot of exercise, I have a low sodium diet...I take care of myself, I don’t drink too much, I don’t smoke, [I have] never participated in drugs.”

Survivors actively sought out others for support as another strategy to help them prevail over the lasting impacts and effects of their past illness on their lives. Seeking others, for survivors, is to look to other people for support, companionship, and empathy. Survivors sought support in the context of their close relationships, as well as from other cancer survivors and from others in the larger community. One participant accessed a cancer organization and stated, “Through a cancer group I talk to this woman...who has gone through similar experiences. It feels like there’s other people who have gone through the same thing and sometimes it’s good to have someone listen to you.”

Personal/environmental resources. Throughout the overall process of managing impacts and effects, the ability to use personal coping strategies was mediated by the existence of personal and environmental resources, such as knowledge, relationships, community, and technology/medications. These factors acted as the facilitators or barriers to achieving and maintaining life enjoyment.

Personal knowledge emerged as an intervening condition toward taking actions to carry out a healthy lifestyle. Once this knowledge was in place survivors chose to eat well, exercise, rest, limit alcohol, and not smoke. In this study, personal knowledge also acted as both a facilitator and/or barrier to adopting a positive outlook. Knowledge acted as a barrier to a positive outlook when survivors were aware of others who experienced less complications, lasting effects, and affected lives from their illnesses. For example, one participant stated, “I get irritated that other kids are survivors that don’t have the [longer-term] problems that I have.” However, those with knowledge about their past illness were able to view current challenges as manageable when compared with beating cancer, and were also able to feel grateful when comparing themselves with others whose illnesses had more severe consequences.

Existing relationships with family, friends, significant others, or children acted as both facilitators and/or barriers in the participants' lives. Affected relationships, feeling different socially, and worrying about others all had a negative effect on life. Acceptance that others didn't always understand was often necessary for survivors. For instance, when experiencing a lack of support from family members, one person stated "I understand because they can't really handle it, sometimes I get frustrated with them, but other times I just say that's the way it is and let it go." On the other hand, supportive relationships facilitated the process towards life enjoyment.

Survivors who had access to childhood cancer and survivor camps and/or community centers were able to use these resources to seek others and attain support. Half of the participants took part in childhood cancer and survivor camps, and described it as central to their lives and their relationships. One participant stated, "Talking to others with the same experiences, who had the same story, and sharing what we've been through really changed my life. I opened up about it and it's been the best ever since."

Other types of community centers provided access to supportive others as well. For example, one participant said, "I've been going to a community center and there are older people that have strokes and things, and it's nice to get out and talk to them." This participant also accessed a cancer organization and stated, "Through a cancer group, I talk to this woman...who has gone through similar experiences. It feels like there's other people who have gone through the same thing and sometimes it's good to have someone listen to you."

Other environmental resources utilized by survivors included assistive aids and treatments. For instance, participants with learning disabilities used learning aids such as software to record university lectures, and those with mobility issues used crutches or wheelchairs. Medication helped some survivors to manage lasting impacts, such as suppressing seizures.

The use of environmental resources, however, depended on their availability and accessibility to participants. As well, supportive relationships and personal knowledge varied by individual. However, when these resources were available, survivors were able to benefit from them. Through the successful management of the impacts and effects of having had cancer, participants were able to experience a sense of life enjoyment/satisfaction. When asked how they would describe their current QOL, participants expressed a sense of joy and satisfaction with their lives. For example, one participant stated, "I love my life. I love who I am, and I want to be who I am."

Emergent Theory: Managing Impacts and Effects toward Good QOL

The development of the process of managing impacts and effects has led to a substantive theory of what childhood cancer survivors go through with regard to their QOL. The past illness experience leads to lasting impacts as well as an affected life. However, an affected life is also influenced by the existence of lasting impacts. Either or both of the lasting impacts and affected life make up the context for which managing impacts and effects occur, as was described above. Use of the management system has an impact back on life effects. To carry out the managing of impacts and effects, survivors utilized personal coping strategies and/or relational and environmental resources. The result of this process emerged as life enjoyment, or good QOL. This process provides an

understanding of how these survivors cope with impacts and effects of their past illness experience. Survivors are able to enjoy good QOL by undergoing this management process.

Discussion

This study addressed two specific questions: (a) How do childhood cancer survivors define the concept of QOL and (b) What processes do childhood cancer survivors go through regarding their QOL?

Defining QOL

For some study participants, good QOL meant living similarly to the average person, or having the ability to perform day-to-day tasks or manage life's problems, while half revealed simply that good QOL is achieved from enjoying life. These definitions reflect the point of view that QOL may be best understood as a subjective evaluation by a person of the overall degree of positivity in his/her life. Indeed, there is increasing consensus that QOL may be most appropriately defined in terms of overall satisfaction with one's life (Moons et al., 2006; Seitz et al., 2011). While there may never be complete agreement about how to conceptualize, measure, and study a concept as abstract as QOL, an approach that views QOL as a subjective phenomenon may provide a better fit with a client autonomy model where clients are viewed as the experts with respect to their own life quality (Dijkers, 1999).

Most study participants expressed a strong sense of satisfaction with life. Participants described undertaking strategies and utilizing resources to overcome unfavorable circumstances and achieve good QOL, indicating that multiple interacting factors can lead to changes in QOL over time. In the current study, the primary domains of human functioning identified by the WHO (1996) as important to QOL were used to broadly guide the interviews: physical, psychological, and social. The major strategies and resources that emerged for managing impacts and effects were tied to these domains. The strategy of adopting a positive outlook is a psychological/spiritual process, living a healthy lifestyle is a strategy focused on physical and emotional health, and seeking out relationships with others is a social process strategy. In addition, utilizing personal and environment resources, such as knowledge, relationships, and the greater community for support and growth emerged as essential to survivors' life quality. This finding suggests that these personal, relational, and environmental domains are all important aspects of life that can influence survivors' overall QOL. An individual's QOL is not just affected by physical well being, but many other factors as well; and these factors are in constant interaction (McDougall, Wright, & Rosenbaum, 2010).

QOL Processes

Individual illness experiences led to varying outcomes for each survivor. Many were faced with ongoing follow-up appointments, worry, permanent physical changes, developmental changes, knowledge of illnesses and death, and/or learning disabilities. Over time, participants experienced these changes as long-term lasting impacts. In

addition to these impacts, their lives were affected by many other factors, such as reintegration to school and other social environments, feeling different socially, and/or having affected relationships.

These findings support both the existing qualitative and quantitative literature. Researchers have found that over 60% of survivors suffer from one or more late effects of their past illness (Pemberger et al., 2005; Sharp, Kinahan, Didwania, & Stolley, 2007). For example, survivors have been shown to experience fatigue, aches, and pain (Zebrack & Chesler, 2002), be aware of their mortality (Parry & Chesler, 2005), worry over recurrence of their cancer (Prouty, Ward-Smith, & Hutto, 2006), and feel uncertain about their future (Zebrack & Chesler, 2002). Other studies have also found that survivors feel that they do not fit in with others (Boydell, Stasiulis, Greenberg, Greenberg, & Spiegler, 2008), have trouble going back to school (Boydell et al., 2008), and have a need for special education (Van Dijk, Imhof et al., 2007).

Managing impacts and effects, the core category, emerged as the way that survivors dealt with the negative outcomes of having had cancer. This process reflects a major theme that has been identified in past qualitative research in children with cancer, that of “constructing a new normal” (Woodgate, 2000), characterized by some researchers as adopting a new daily routine and a new worldview (Clarke-Steffen, 1993, 1997). This process began in childhood when the participants were diagnosed with cancer. Participants identified personal coping strategies (adopting a positive outlook, living a healthy lifestyle, seeking others) and personal/environmental resources as the primary means to manage lasting impacts of childhood cancer and/or an affected life. These findings also find support in the literature. Parry and Chesler, in their 2005 qualitative study, reported that many survivors avoid health risks, watch their diet, and exercise. Carswell and colleagues (2008) also reported that survivors were less likely to smoke and binge drink than population controls.

Parry and Chesler (2005), in a qualitative study, found that survivors chose not to worry, but rather to focus on positive outcomes, as well as to interpret events in a positive way. Similarly, in a second qualitative study, Karian, Jankowski, and Beal (1998) found that survivors were optimistic, exhibited a positive attitude, and viewed life as precious and believed it should not be taken for granted. Still, other studies have found that survivors see their lives as particularly valuable (Maggiolini, Grassi, & Adamoli, 2000), have a high level of determination (Boydell et al., 2008), and a greater appreciation for life (Van Dijk, Huisman et al., 2007), because of their past illness experiences.

Interacting socially with other survivors was also reported as important to survivors in the literature, demonstrating that sharing stories and experiences with survivors who have been in similar situations can be very comforting and healing (Zebrack, Oeffinger, Hou, & Kaplan, 2006). Parry and Chesler (2005) also reported that survivors make a point of creating time for relationships, and derive enjoyment from these relationships.

This study has led to the emergence of a substantive theory that identifies the ongoing interrelated processes of positive personal coping, and environmental supports that survivors use to manage the impacts and effects of having had cancer. The use of these processes ultimately serves to enhance and maintain their life quality, thus providing some insight into why some survivors have rated their overall QOL, and specifically, their emotional well-being as equal to, or better than, others who have not

survived cancer. We have chosen to refer to the emerging theory as *Interrelated Processes toward QOL Theory*.

Potential Service Delivery and Research Directions

The findings of this study cannot be generalized. However, the personal accounts of the childhood cancer survivors interviewed for this study may help health professionals to better understand how some survivors of childhood cancer view and approach their lives over time. Participants revealed that they strove toward achieving and maintaining good QOL by enhancing their physical health, psychological outlook, social relationships and community participation, despite the challenges they had to face due to their past illness. Woodgate (2000), in a critical review of qualitative research related to children's experiences with cancer, noted that numerous studies indicate children with cancer do attempt to adjust their lives to the cancer experience, and do not approach it from a deficit-centered perspective. However, a study by Boydell and colleagues (2008) highlighted the tendency of health, education, and other professionals to define the needs of childhood cancer survivors and to view them as vulnerable individuals who have difficulty managing their own lives. Professionals are encouraged to adopt a strengths-based, as opposed to a needs-based, approach to service delivery (Chung, Burke, & Goodman, 2010; Phipps, 2007) that will support survivors as they call upon their own personal strengths to help them reframe their lives and develop a positive viewpoint, and to seek opportunities for community reintegration and participation. Moreover, it is important for professionals to understand that each survivor has a unique perception of what QOL means, and that service delivery should be based on individual assessment (Shepherd & Woodgate, 2010).

The results of this study can help inform future qualitative studies and quantitative studies in this area. Participants for this study were recruited through advertisement postings on community bulletin boards in large cities, university campuses, within cancer organizations, and on the Internet. Recruitment was therefore limited to those who have access to these areas and/or the Internet. The participants in this study might differ from those recruited in other ways. For example, half of the participants in this study were involved in cancer camps, which might not be the case if study participants had been recruited through postings in rural communities. The participants in this study might also differ from those not willing to take part in research studies. Other researchers may want to conduct his work with different samples of survivors. Future qualitative research might also attempt to identify differences between survivors who take part in research, and those who do not. This might require an assessment of the peers or families of survivors. Other qualitative work might inquire further into the role that the specific factors such as self-determination, spirituality, or community participation play in the QOL of survivors.

As noted, quantitative work in this area has most often measured QOL in terms of functional outcomes. A subjective approach, where QOL is measured in terms of survivors' life satisfaction has only just begun to emerge (Seitz et al., 2011). Quantitative researchers are encouraged to undertake longitudinal studies that measure QOL in terms of perceived QOL or life satisfaction, and to examine the relative and related contributions of personal, relational, and environmental factors to individuals' perceived

QOL over time (McDougall et al., 2010; McDougall, Wright, Schmidt, Miller, & Lowry, 2011).

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Acknowledgments

The authors would like to thank the individuals who participated in this study and so thoughtfully shared their experiences.

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Article Citation

Tsonis, M., McDougall, J., Mandich, A., & Irwin, J. (2012). Interrelated processes toward quality of life in survivors of childhood cancer: A grounded theory. *The Qualitative Report*, 17(Art. 89), 1-18. Retrieved from <http://www.nova.edu/ssss/QR/QR17/tsonis.pdf>
