Health-Related Quality of Life of Young Adult Survivors of Childhood Cancer: A Review of Qualitative Studies

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Purpose: The occurrence of late effects, combined with traditional growth and developmental issues, can significantly affect the health-related quality of life (HRQOL) of young adult survivors of childhood cancer (YASCC). Limited HRQOL measurement tools have been developed or validated for YASCC. The purpose of this study was to identify the domains of HRQOL that are unique to YASCC by conducting a systematic review of qualitative studies. Specifically, we compared the findings to the classical framework of HRQOL that was developed for survivors of adult-onset cancer and identified specific domains not being assessed in existing HRQOL instruments for YASCC. **Methods:** We searched qualitative studies published in peer-reviewed journals from 2000 to 2010 in the PsychINFO, PubMed, and EBSCOhost databases. A set of keywords and inclusion/exclusion criteria were utilized to identify eligible studies with a focus on survivorship and HRQOL issues of YASCC. **Results:** Sixteen studies met the inclusion/exclusion criteria and were investigated in this study. Six important domains of HRQOL were identified (physical, social, psychological, spiritual, fertility/sexual, resilience, and body appearance) with several sub-domains. **Conclusion:** Use of the classical HRQOL framework and existing instruments is not comprehensive enough for YASCC. Adding unique domains to the classical framework and existing instruments will make them valuable tools for measuring the HRQOL of YASCC and increase health professionals' ability to identify if and when psychosocial services are needed for this unique population.

Introduction

FOR THE LAST THREE DECADES, the 5-year survival rate of childhood cancer has improved substantially in the United States, from less than 50% in the 1970s to approximately 80% today.¹ It is estimated that nearly 12 million Americans are cancer survivors² and more than 330,000 are survivors of childhood cancer, with 24% of those having survived for more than 30 years since diagnosis.³

Childhood cancer survivors are at significant risk of developing late effects, defined as significant health problems that can be life threatening and result from cancer itself and/or cancer treatment. It has been reported that approximately

75% of young adult survivors of childhood cancer (YASCC) experience late effects.⁴ Unlike side effects that occur during or immediately following cancer treatment, late effects may appear several years after a cancer diagnosis and successful treatment. For YASCC, common late effects include neurocognitive, psychological, cardiopulmonary, endocrine, and musculoskeletal impairment, as well as recurrent or secondary cancers.⁵

The presence of late effects can impair the health-related quality of life (HRQOL) of YASCC, defined as the effect of treatment and/or disease on people's daily functioning and well-being.⁵ Concepts commonly measured under the HRQOL rubric include: somatic symptoms, physical

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capability, psychological problems, social activities, and cognitive functioning, as well as the broad concept of "life satisfaction."⁶

A classical framework of survivor-specific HRQOL was developed by the City of Hope research group two decades ago.⁷⁻⁹ This framework recognizes the effect of cancer and its treatment on the physical, psychological, social, and spiritual well-being of cancer survivors. Based on this framework, the research group developed the Quality of Life—Cancer Survivors (QOL-CS)⁹ instrument using adult cancer survivors who received a bone marrow transplant. However, this classical framework and the derived measurement tool were not developed to account for the unique developmental and growth issues that older adolescents and young adults experience as they transition from childhood.^{10,11} For example, adolescents and young adults have concerns pertaining to body image and sexual identity, making future life decisions (e.g., career, higher education, or family), establishing their identity, and spending less time with parents and more time with peers and intimate partners.¹¹ It is important to recognize these issues because children who are diagnosed and treated for chronic illnesses such as cancer may encounter difficulties in achieving such developmental and growth milestones,¹² consequently leading to unique impairments in psychosocial development¹³ or HRQOL during adulthood.^{12,14} Empirical evidence also suggests that the QOL-CS instrument is not an optimal measure of HRQOL for YASCC.¹⁵ For example, Zebrack and Chesler tested this instrument in a population of YASCC and reported some limitations, including poor internal reliability of the distress subscale, different perceived content/ factorial structure captured by the instrument, and poor recall due to the young age at which some of the survivors had cancer.¹⁵

In addition to the QOL-CS instrument,⁹ the Quality of Life Adult Cancer Survivors Scale (QLACS)¹⁶ and the Impact of Cancer Scale (IOC-S)¹⁷⁻²⁰ are also designed for cancer survivors. The QLACS encompasses both generic domains (physical pain, negative feelings, positive feelings, cognitive problems, sexual problems, social avoidance, and fatigue) and cancer-specific domains (financial problems resulting from cancer, distress about family, distress about cancer recurrence, appearance concerns, and benefits of cancer) and is intended for survivors of adult-onset cancer. Given that the instrument was developed for survivors of adult-onset cancer, similar to the QOL-CS instrument, the QLACS instrument may fail to measure HRQOL adequately in the YASCC population. The only scale specifically intended for YASCC is the IOC-S, which includes the domains of life challenges, body/health, talking with parents, personal growth, thinking/memory problems, health literacy, socializing, financial problems, sibling concerns, and relationship concerns. The authors suggest, however, that the IOC-S be used as a complement to other HRQOL instruments rather than serve as an independent measure of HRQOL.¹⁹

It is important to note that previous studies of HRQOL in YASCC largely relied on quantitative data collected by existing instruments.^{21,22} Theoretically, quantitative methods are useful for comparing HRQOL across subgroups of cancer survivors given the established framework or instruments with pre-specified domains of HRQOL (e.g., physical, psychological, and social functioning).^{21,22} In contrast, qualitative methods allow for a more thorough exploration of the unique

HRQOL issues for YASCC that have traditionally been neglected in quantitative instruments. In other words, qualitative methods may facilitate a greater understanding of HRQOL for this population by allowing the researcher to identify and explore the domains of HRQOL that are relevant to this population. Moreover, qualitative data are also useful for informing instrument development.

The purpose of this study was to identify domains of HRQOL for YASCC that are important but neglected in the classical City of Hope framework⁷⁻⁹ and the domains of other HRQOL instruments for cancer survivors by conducting a systematic review of qualitative studies published in the past 10 years. The comparisons between our findings to the classical framework and the domains of existing HRQOL instruments will help researchers develop and refine HRQOL measurement tools in a way that is developmentally appropriate for YASCC.

Methods

We searched articles using the following databases for systematic review: PubMed, PsycINFO (powered by EBS-COhost), and Academic Search Premier (powered by EBS-COhost). The first author (CN) and a research assistant conducted independent searches with a comprehensive list of keywords to identify the articles. Keywords utilized for the search were "childhood cancer," "neoplasm," "survivor," "young adult," "quality of life," and "qualitative." We used the following inclusion/exclusion criteria to select articles that were (1) published between the years 2000 and 2010, (2) written in English, (3) used qualitative methods, and (4) focused on the population of YASCC (with whatever age range the author identified as "young adults"). It is important to note that these YASCC were diagnosed with pediatric cancer and were young adult-aged survivors by the time of the study interview. We excluded articles that did not describe the fundamental methods of the qualitative research, such as data collection methods or analytic and reporting strategies. We excluded studies published prior to 2000 because we wanted to provide a current perspective on the HRQOL of YASCC.

The first author and a research assistant read the abstracts of the articles pulled from various sources. If an abstract was selected as eligible, the first author and a research assistant independently read the full text of the respective article to confirm that it met inclusion criteria. Discrepancies were adjudicated by consensus, or failing this, by the senior author (IH).

We created an evidence table to abstract characteristics of the articles systematically using a standard methodology.²³ Specifically, we included the year of publication, the country where the study was conducted, the study design, the sample size, the approach used to conduct interviews, the process used to synthesize and analyze the data, and any questions/scripts utilized to collect data. We also abstracted characteristics of subjects in aggregate, including gender, race/ethnicity, age at interviews, age at diagnosis, time since diagnosis, and type of cancer.

The themes of HRQOL identified by each study were reviewed and the similar findings were grouped and presented. We utilized the City of Hope framework⁷⁻⁹ as an initial guide to assist in organizing the content into the overarching domains of HRQOL. We documented the themes of HRQOL

extracted from each article, then mapped the results into the City of Hope framework which includes physical, psychological, social, and spiritual well-being. We identified HRQOL concerns of YASCC that are not currently included in the City of Hope framework. Specific themes deemed important to YASCC but not included in the classical framework were categorized and presented alongside the classical framework.

Results

Characteristics of the studies

Sixteen studies that met our inclusion/exclusion criteria are included in this systematic review. Characteristics of included studies are summarized in Table 1. The majority of the studies included both males and females.^{24–34} Three studies did not indicate the gender distribution,^{35–37} and the remaining two studies reported the inclusion of either all females³⁸ or all males.³⁹ The age of participants included in the studies ranged from 13 to 38 years old at the time of interview. Six studies reported the participants' time since diagnosis,^{26,27,29,31,32,34} which ranged between 1 and 36 years, and one study³⁶ indicated only that participants were at least five years post-diagnosis. Most studies consisted of survivors of various cancer diagnoses, although two focused on only one specific cancer type (brain cancer or leukemia)^{24,35} and one did not indicate the cancer type.²⁹

One study used a mixed (qualitative and quantitative) methods design,²⁷ although the quantitative results are not included in this review; the remaining studies used only qualitative methods. Methods to collect data primarily consisted of individual interviews and/or focus groups, although one study used Photovoice³³ and one study used a series of online sessions with the same group of participants.³⁸ The majority of the studies utilized Grounded Theory⁴⁰ for data analysis.^{25,28,31–33,36–39}

HRQOL issues for YASCC

Domains and sub-domains of HRQOL that we identified in the present review are presented in Table 2. Consistent with the City of Hope framework^{7–9} and the QOL-CS tool,⁹ we found that physical, psychological, social, and spiritual issues are reported by YASCC. However, other unique domains and sub-domains of HRQOL for YASCC such as fertility/sexual functioning, resilience, and body appearance were also identified and are presented as follows.

Theme 1: Physical functioning. Although YASCC reported a host of physical problems, physical issues do not appear to be an overwhelming burden compared to other domains of HRQOL. YASCC reported increased vulnerability to common illnesses such as allergies and dental problems,³⁶ poor vision,^{26,36} hearing loss,²⁶ short stature and balance problems,^{26,35,36} arthritis, sensitive skin and underproductive thyroid,²⁴ deficits in endocrine and motor-sensory functioning, and semi-paralysis.²⁶ Survivors also suffered from chronic diseases and symptoms such as diabetes, high blood pressure, and weight loss,²⁹ as well as fatigue^{26,30} and chronic back and bone pain.³⁶

Theme 2: Fertility/sexual functioning. YASCC reported significant concerns regarding their fertility status. Green *et al.*

found that although the majority of male survivors asserted that they did not become emotionally upset upon learning about their potential infertility, some reported feeling that their masculinity was compromised.³⁹ Fertility status also affected survivors' intimate relationships with partners.³⁴ Many expressed concern that their potential infertility could deter a future mate,³⁹ and Zebrack *et al.* found that survivors had experienced or feared rejection from their partner due to their potential infertility.³⁴ Consequently, survivors were hesitant to share their infertility concerns with their intimate partners. Survivors also noted that becoming pregnant allowed them to feel normal,³⁴ although some survivors feared passing cancer to their offspring.^{31,34,36}

Theme 3: Body appearance. Many YASCC were concerned about their body appearance and changes. For example, survivors experienced changes in hair loss,^{26,35,37} stature,^{26,35} and weight³⁷ and acquired scars that served as reminders of their cancer experience.^{28,35,37} Survivors indicated that their appearance affected how peers perceived them, such that the more "normal" they appeared, the more they felt accepted.³⁵ Body appearance affected survivors' self-image, self-esteem, and feelings of competence.³⁵ In fact, some females reported eating disorders following treatment, and both males and females noted concern regarding their ability to meet gender norms.³⁷

Theme 4: Social relationships—friendship. Although YASCC greatly desire to become part of the mainstream or peer groups,^{28,35} they reported difficulty in fitting in and consequently experienced feelings of loneliness and isolation.³⁵ Survivors noted how missing out on developmentally important milestones caused them to be either more³⁸ or less mature³³ than their peers, which for some consequently affected their ability to assimilate with peer groups.³⁸ YASCC also reported being stigmatized by their peers due to their physical impairments,²⁶ and some purposely avoided treatment to hide their disease.^{26,37} Although fitting in was difficult for most survivors, Enskar and Bertero found that survivors reported some positive and stronger relationships with friends as a result of their cancer experience.²⁸

Impact on family. YASCC noted that the cancer experience also affected their family and their relationship with family members. For example, survivors noted the effect of cancer on their family's finances and insurance status, which consequently led them to feel guilty.³³ Mothers of survivors often put careers on hold to serve as primary caretakers during their child's illness.²⁴ Some siblings of YASCC felt jealous and were sometimes neglected by their parents.^{24,28} In studies with Taiwanese survivors of brain cancer, survivors noted difficulty in, and expressed chronic fear about, not being able to fulfill the expected social and cultural role of caring for their younger siblings.^{26,27}

Despite hardship on the family, many YASCC developed closer and stronger relationships with family members through the cancer experience.^{28,29,32,36} Survivors reported receiving emotional and physical support from their parents who acted as facilitators to their care.²⁵ However, in some cases, the increased family bond may have contributed to impaired autonomy for the survivor. For example, Latino and non-Latino survivors in Casillas *et al.*'s study noted that their family perceived them as "medically vulnerable" adults and thus led

TABLE 1. CHARACTERISTICS OF INCLUDED STUDIES OF HRQOL IN YASCC

Study	Sample (n)	Gender distribution	Age at interviews (range)	Type of cancer	Study origin	Race/ethnicity of participants	Theory/model used
Boydell <i>et al.</i> (2008) ³⁵	14	n/a	17–29	Brain tumor	Canada	Caucasian (n = 33), Chinese (n = 1), East Indian (n = 1), Filipino (n = 1), Caucasian (n = 10) Latino (n = 1)	Dickelmann's seven-stage approach
Brown <i>et al.</i> (2008) ²⁴	11	7 males/4 females	19–24	Leukemia	United States	Caucasian (n = 10) Latino (n = 1)	Consensual qualitative research
Cantrell <i>et al.</i> (2009) ³⁸	6	All female	21–30	CML, breast cancer, Ewing sarcoma, lymphoma, ALL, thyroid cancer	United States	n/a	Grounded theory
Casillas <i>et al.</i> (2006) ³⁶	57	n/a	18–37	AML, ALL, Wilms tumor, NHL, lymphoma, PNET, RMS, embryonal cancer	United States	Non-Latino (n = 30) Latino (n = 27)	Grounded theory
Casillas <i>et al.</i> (2010) ²⁵	27	12 males/15 females	15–30	Leukemia, brain/CNS, lymphomas, soft tissue sarcomas, other	United States	Latino	Grounded theory
Chen <i>et al.</i> (2008) ²⁶	7	6 males/1 female	13–22	Germ cell tumors, astrocytoma	Taiwan	Chinese	Giorgi's phenomenological methodology
Chou <i>et al.</i> (2009) ²⁷	98	61 males/37 females	18–21	Brain tumor, leukemia	Taiwan	Chinese	n/a
Drew (2007) ³⁷	32	n/a	18–28	ALL, AML, leukemia (unspecified), brain tumor, HL, NHL, Ewing sarcoma, osteosarcoma, germ cell tumor, RMS, other	Australia	n/a	Grounded theory
Enskar <i>et al.</i> (2010) ²⁸	7	1 male/6 females	20–23	HL, Ewing sarcoma, lymphoma, ALL	Sweden	n/a	Grounded theory
Green <i>et al.</i> (2003) ³⁹	15	All male	19–32	ALL, NHL, T-cell ALL, Wilms tumor, ALCL, HL, osteosarcoma, RMS, Ewing sarcoma, CGL, ERMS	England	n/a	Grounded theory
Jones <i>et al.</i> (2010) ²⁹	9	7 males/2 females	14–21	n/a	United States	Latino	n/a
Langeveld <i>et al.</i> (2000) ³⁰	35	29% male/71% female	18–38	ALL, lymphoma, Wilms tumor, brain tumors, other solid tumors	The Netherlands	n/a	n/a
Parry (2003) ³¹	23	10 males/13 females	17–29	Leukemia, lymphoma, Wilms tumor, bone/soft tissue, CNS tumors	United States	Caucasian	Grounded theory and reflexivity
Parry <i>et al.</i> (2005) ³²	50	25 males/25 females	17–29	Leukemias, lymphomas, Bone/soft tissue, Wilms tumor, CNS tumors	United States	Caucasian (n = 47), Other (n = 3)	Grounded theory
Yi <i>et al.</i> (2010) ³³	6	2 males/4 females	20–33	ALL, germinoma brain tumor, osteosarcoma, brain tumor	United States	Mexican (n = 2), Hispanic (n = 2), Hispanic-Indian (n = 1), Persian American (n = 1)	Grounded theory
Zebreck <i>et al.</i> (2004) ³⁴	32	18 males/14 females	19–37	Neuroblastoma, leukemia, HD, Wilms tumor, other	United States	Caucasian (n = 20), Latino (n = 12)	Grounded theory

ALCL, anaplastic large-cell lymphoma; ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; CGL, chronic granulocytic leukemia; CML, chronic myeloid leukemia; CNS, central nervous system; ERMS, embryonal rhabdomyosarcoma; HD, Hodgkin disease; HL, Hodgkin lymphoma; HRQOL, health-related quality of life; NHL, Non-Hodgkin lymphoma; PNET, primitive neuroectodermal tumor; RMS, rhabdomyosarcoma; YASCC, young adult survivors of childhood cancer.

TABLE 2. IMPORTANT HRQOL FINDINGS OF INCLUDED STUDIES PERTAINING TO YASCC

Domains/sub-domains	Examples of important findings
<i>Physical</i>	Increased vulnerability to common illnesses ³⁶ Survivors experienced fatigue ^{26,30}
<i>Fertility/sexual functioning</i>	News of potential infertility caused some male survivors to feel that their masculinity was compromised ³⁹ Survivors' uncertainty regarding their fertility status caused strain in intimate relationships ³⁴ Survivors noted that becoming pregnant allowed them to feel normal ³⁴
<i>Body appearance</i>	Appearance affected survivors' self-image, self-esteem, and feelings of competence ³⁵ Male and female survivors were concerned about their appearance and its consistency with masculine/feminine norms ³⁷ Some females reported weight loss/gain and subsequent eating disorders ³⁷
<i>Social relationships</i>	
Friendship	Survivors had difficulty fitting in and experienced loneliness and isolation ³⁵ Survivors reported being overly mature or immature compared to peers ^{33,38}
Impact on family	Survivors reported that their siblings were jealous and neglected by the parents ^{24,28} Survivors developed a closer relationship with their family ^{28,29,32,36}
<i>Psychological</i>	
Fear and uncertainty	Survivors were fearful of their cancer returning and developing a second cancer ^{27,31} Feelings of uncertainty made survivors reluctant to dream about their future ³⁸
Negative feelings/thoughts	Survivors had bad memories of their cancer experience ³³ Survivors experienced emotional thinking and emotional outbursts of sadness or anger ²⁸
Cognitive impairment	Brain tumor survivors experienced short-term memory loss, impaired spatial processing, etc. ²⁶ Cognitive impairment impacted survivors' academic experiences and daily activities ^{26,35}
<i>Spiritual</i>	Survivors experienced increased faith ^{29,33,36} Survivors rationalized the meaning of their surviving and gave meaning to their experience ^{26,29}
<i>Resilience</i>	
New sense of identity	Survivors identified as a "survivor" rather than a "victim" ^{32,33} Survivors were faced with reinventing their new self by integrating their cancer experience ³⁸ Survivors wanted to pursue careers in the medical field or helping professions ^{24,33}
Achieving normalcy	Survivors desired to be normal again ^{35,38} Being "normal" was different from pre-cancer "normal" ³⁸ Survivors noted that being normal included having the freedom to feel grumpy or dissatisfied with life, despite others' expectations ³⁸

them to be dependent.³⁶ Similarly, another study found that some YASCC felt their families were too overprotective, which prevented them from fully experiencing life.³³

Survivors with children expressed that their cancer experience had left them greatly valuing family life, leading them to spend more time with their children.^{24,34} Many of those without children expressed an interest in eventually getting married and having a family.^{24,34}

Theme 5: Psychological—fear and uncertainty. Feelings of fear and uncertainty were common among YASCC. Survivors were fearful of their cancer returning,^{27,31} developing a secondary cancer, passing cancer to their children, infertility,³¹ experiencing disability, and being unable to perform role expectations.²⁷ Survivors in Casillas *et al.*'s study experienced anxiety when attending long-term follow-up visits because they feared receiving news of cancer recurrence.³⁶ In a study by Cantrell and Conte, survivors expressed a desire to plan for and dream about their future, but prevailing feelings of uncertainty prevented them from doing so.³⁸

Negative feelings and thoughts. YASCC reported negative feelings and thoughts associated with their cancer experience. For example, survivors in Yi and Zebrack's study reported

having bad memories of their cancer treatment.³³ Enskar and Bertero found that survivors engaged in emotional thinking and experienced emotional outbursts of sadness or anger that related to the cancer experience.²⁸ For some fatigued survivors, their mood was negatively affected and sometimes led to feelings of depression.³⁰ Some survivors reported a loss of self, which included "loss of self-efficacy, self-esteem, and hope for the future" and some survivors used negative modes of rebounding such as "dependency, denial reality, and surviving in whatever way possible."²⁷

Cognitive impairment. Brain tumor survivors oftentimes experienced cognitive difficulties such as short-term memory loss, impaired spatial processing, and difficulties in reading, writing, and mathematics.^{26,35} These cognitive problems affected their academic experiences³⁵ and daily activities.²⁶

Theme 6: Spiritual. YASCC reported increased faith as a result of their cancer experience,^{29,33,36} which helped them cope with their problems.^{29,33} Survivors reported using faith, hope, and an existential perspective in an attempt to balance their feelings of uncertainty with certainty.³¹ They developed a greater appreciation for life,^{29,36} which was sometimes caused by an increased awareness of their vulnerability and

mortality³² or by feelings of uncertainty.³¹ Survivors also reported rationalizing their cancer experience²⁹ and the meaning of surviving²⁶ to form better relationships and priorities, reduce risky behaviors, and become kinder and more mature.²⁹ Feelings of uncertainty provoked survivors to focus on living in the present rather than the past,³¹ and some commented that their survival was a “religious miracle.”³³

Theme 7: Resilience—new sense of identity. Despite the struggles faced by survivors, YASCC overwhelmingly demonstrated resilience in their personal growth and a positive orientation toward their future. YASCC expressed that cancer was not just a part of their past but rather that the experience changed their lives and identity forever.³⁷ Survivors were faced with reinventing their new self with the integration of their cancer experience.³⁸ The integrated self included “hope, self-esteem and self-efficacy, autonomy, being loved and being valued, perseverance, self-control, and adaptability.”²⁷ Survivors also reported an increased self confidence,³⁶ maturity,^{28,29,32,38} and ability to manage problems and overcome hardships.^{32,33}

With a new sense of identity, some survivors no longer perceived themselves as victims^{32,33} and instead gained independence by taking care of themselves and their illness²⁶ and actively engaging in a healthier lifestyle.^{24,32} YASCC also felt their cancer experience had positively affected their career and educational plans.^{24,32} Many survivors expressed altruism^{24,36,38} and wanted to pursue careers in the medical field²⁴ or helping professions.³³ For some survivors, helping others allowed them to feel less guilty about surviving their cancer.³⁸

Achieving normalcy. Survivors expressed the desire to return to living a “normal” life again, especially since they missed out on many normal experiences during the phase of treatment.^{35,38} However, they commented that being normal post-treatment was different than normal prior to their cancer experience. For example, survivors had to reenter everyday life (e.g., school, work) but without their prior treatment regimen that provided structure in their life.³⁸ There was a paradox in survivors’ desire to be normal because although survivors wanted others to verify and acknowledge their cancer past, they also wanted to be treated as normal.³⁸ In some cases survivors did not seek extra needed help in school because they wanted to be perceived as normal.³⁵ Survivors noted that being normal included having the freedom to feel grumpy or dissatisfied with life, despite others expectations.³⁸

Differences in thematic content across race/ethnicity and culture

Conventional health-related studies often preclude participation from marginalized and underserved groups.^{41,42} Findings from our review suggest there are some differences in the themes identified by race/ethnicity and culture. Casillas *et al.* conducted the only study that evaluated results by ethnicity using a comparison group.³⁶ They explored the differences between Latino and non-Latino survivors and concluded that although the majority of the themes were shared across both groups, non-Latino survivors reported impaired sibling relationships while Latino survivors did not report any family impairment. The study’s authors interpreted these results in light of *familismo*, defined as “a

heightened concern with family resulting in an increased bond with all family members,” which is often seen in the Latino culture. However, several studies included in our review reported an increased family bond as a result of cancer,^{28,29,32,36} making it difficult to ascertain whether these experiences are associated with the Latino culture or a direct effect of the cancer itself.

Cultural issues were observed in other studies as well. For example, cultural issues emerged in Yi and Zebrack’s study, which focused on cancer survivors of Mexican, Hispanic, Hispanic-Indian, and Persian American ethnicities.³³ Several unique themes were identified in this study, such as the significance of food and the role of traditional remedies throughout the cancer experience, religion, and the inability to engage in rituals (e.g., Ramadan or quinceañera). Moreover, Taiwanese survivors discussed the effect of cancer on their ability to care for younger siblings, which can be significant within the Taiwanese culture.²⁶ Future studies are encouraged to explore the effect of cultural issues on HRQOL, since evidence in this area is limited.

Discussion

To our knowledge, this study is the first systematic review of qualitative studies that suggests the need for a comprehensive framework to measure HRQOL for the YASCC population. Although reviews have been conducted on HRQOL issues for YASCC, these reviews were largely based on studies of quantitative design and were inclusive of studies conducted before the 21st century.^{43,44} The present study highlights the unique contribution of qualitative methodology in the identification of HRQOL issues for YASCC and serves as an important supplement to the previous studies of quantitative design. The results are useful for revising the classical framework of HRQOL and related measurement instruments when applied to the YASCC population.

Refining the classical framework

Figure 1 shows the suggested revised framework of HRQOL based on our findings. Our results show the need for the addition of three new domains for HRQOL of YASCC: body appearance, resilience, and fertility/sexual functioning. Previously, body appearance was included in the social well-being domain.^{7–9} However, we found that body appearance transcends into multiple domains of HRQOL^{28,35,37} and consequently should be an additional domain in its own right. Another significant theme for this population was resilience, evident in survivors’ ability to rebound and experience personal growth. Given the profound effect of resilience on the HRQOL of YASCC, we recommend an additional domain for resilience.

In the current City of Hope framework, infertility is included in the physical well-being domain and sexual functioning is included in the social well-being domain,^{7–9} with each issue measured by a single item. Our results, however, suggest that fertility concerns and sexual functioning are beyond the scopes of physical and social well-being alone, and are substantial enough issues for YASCC to warrant their own domain. Although our findings were limited in regards to sexual well-being, we attribute this issue to the sensitive nature of the topic. Quantitative studies have also demonstrated the significance of sexual functioning among YASCC. For

FIG. 1. City of Hope cancer survivor-specific HRQOL framework and suggested additions of the body appearance, resilience, and fertility/sexual concerns domains for the YASCC population.

example, Zebrack *et al.* found that although sexual functioning did not appear to be a significant burden for survivors overall, 42.7% of their sample reported having at least one symptom that was problematic.⁴⁵ Moreover, males believed their life in the future would be better if they had less sexual dysfunction. Puukko *et al.* found that female survivors were significantly less likely “to have experienced sexual intercourse, less likely to masturbate, and less likely to have talked with friends about sexual topics” when compared to age-matched healthy controls.⁴⁶ Taken together, these findings lead us to believe that sexual functioning is an influential and worthy component of HRQOL for YASCC.

Comparison of findings to existing instruments

Our findings revealed both similarities and discrepancies in the domains presented in the existing survivor-specific instruments such as the QLACS¹⁶ and IOC-S.^{17–20} Both instruments incorporate items covering social, psychological, spiritual, and physical domains. Moreover, both instruments also incorporate items covering body appearance concerns, resilience, and sexual functioning. However, the QLACS does not address fertility concerns, in contrast to our findings and the IOC-S. Furthermore, although our findings have overlap with the domains of the instruments, our results suggest that

the existing instruments lack some important and unique concerns of YASCC. For example, survivors noted concerns regarding their ability to meet gender norms and the risk of passing cancer onto their children; neither existing instrument incorporates these findings. In line with our qualitative evidence, two reviews of quantitative studies demonstrated that the domains included in the existing HRQOL instruments for YASCC are merely relevant to physical, psychological, and social functioning.^{21,43}

Future directions

Although our results suggest a revision to the classical HRQOL framework and commonly used instruments, future qualitative studies and surveys are encouraged to verify our recommendations. Being able to measure HRQOL adequately is integral to meeting the Institute of Medicine’s recommendations for psychosocial health services for cancer patients.⁴⁷ Appropriate use of HRQOL instruments is important for shared decision making between survivors and healthcare providers, and can guide the design of interventions to improve daily functioning and well-being. Specifically, measurements of HRQOL can allow providers to assess functioning prospectively and identify when and what psychosocial services are needed so that survivors can be referred

for appropriate services and systematically monitored for changing health needs. A recent meta-analysis also suggested that the measurement of HRQOL in routine use can help identify future adverse psychosocial and health issues, including death.⁴⁸ In addition, although limited studies explored HRQOL issues specific to gender or distinct cultural populations, our results indicate potential differences, indicating the need for more studies in this area.

Study limitations

Although effort was made to include studies of high quality, some limitations were still evident and largely pertained to the studies' samples. First, we only reviewed studies conducted in the past 10 years (2000–2010). We therefore potentially omitted studies that included other themes of HRQOL. However, we believe that studies from earlier years would add only limited information, since we found saturation across the 16 studies we reviewed. Second, we included two studies^{26,29} with subjects younger than the typical young adult age of 15–39 years used by the National Cancer Institute and the 2006 Adolescent and Young Adult Oncology Progress Review Group.⁴⁹ We decided to review these two studies because the existing qualitative studies on HRQOL for YASCC were limited, and because the youngest participants in these studies were only 1–2 years younger than the typical young adult age. Third, our selected studies include subjects with very heterogeneous characteristics in regard to gender, races/ethnicity, and cancer diagnoses, which may have limited our comparisons of HRQOL across subgroups. However, we did find the unique themes of HRQOL behind specific racial, ethnical, and cultural subgroup of YASCC. Finally, there was inconsistency in the definition of “survivorship” and in survival time across studies. For example, Casillas *et al.*³⁶ included long-term survivors, which they defined as five or more years post-diagnosis, whereas Enskar and Bertero²⁸ included survivors defined as those with at least three years of post-treatment event-free survival. It is possible that survivors may experience alterations in HRQOL across time. However, we did not identify any conflicting results across studies, so the inconsistency in how authors defined “survivor” did not appear to weaken our findings. Although the present study has some limitations, we believe the limitations are minimal and that the study contributes greatly to the existing literature on HRQOL of YASCC.

Conclusion

The present review outlines important and unique domains of HRQOL for YASCC and suggests a revised framework. HRQOL is recognized as an important health outcome for cancer survivors as treatment advances are made and mortality rates decline. Although the YASCC population experiences impairments in HRQOL, they overwhelmingly demonstrate resilience. We suggest that the HRQOL measurement tools for the YASCC population should encompass well-being in the physical, social, psychological, spiritual, resilience, body appearance, and fertility/sexual functioning domains. The suggested revised framework allows for the development of comprehensive measures healthcare providers can use to assess HRQOL over time and identify needed services. We believe our empirical findings will bridge the knowledge gap in understanding the important themes of

HRQOL in YASCC and help extend the conventional theoretical models of HRQOL in childhood cancer survivors.

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