HEALTH AND SUPPORTIVE CARE NEEDS OF CANCER SURVIVORS

IDENTIFYING THE HEALTH AND SUPPORTIVE CARE NEEDS OF ADOLESCENT AND YOUNG ADULT SURVIVORS DIAGNOSED WITH CANCER: A MIXED METHODS STUDY

By ELENA TSANGARIS, BSc.

A Thesis Submitted to the School of Graduate Studies in Partial
Fulfillment of the Requirements for the Degree Master of Science

McMaster University

McMaster University MASTER OF SCIENCE (2012) Hamilton, Ontario

TITLE: Identifying the health and supportive care needs of adolescent and young adult survivors diagnosed with cancer: a mixed methods study
AUTHOR: Elena Tsangaris, BSc. (McMaster University)
SUPERVISOR: Dr. Anne F. Klassen
NUMBER OF PAGES: xii, 179

ABSTRACT

Background: Current cancer care models in Canada fail to address the unique needs of adolescents and young adults (AYA) diagnosed with cancer, due to the dichotomous age restrictions of these models. Under the current system, adolescents aged 15 to 17 years are treated in regional pediatric hospitals, while young adults aged 18 to 25 years are treated in regional adult hospitals. The inability of either model of care to meet the needs of this cohort leads to complex issues. The purpose of this study was to conduct a mixed methods analysis to investigate the spectrum of health and supportive care needs (HSC) of AYA survivors with cancer.

Methods: A concurrent nested mixed methods (CNMM) design was used. For this study, the major method was the qualitative descriptive (QD) method, and the systematic literature review (SLR) was the minor method. In the qualitative study, a purposive sample of AYA survivors aged 15 to 25 years were recruited from Hamilton's regional pediatric and adult cancer programs. Interviews were conducted and were digitally recorded and transcribed verbatim. Line-by-line coding was used to establish codes and categories. Relationships within and across these codes and categories were examined through constant comparison. Patients were interviewed until no new categories or themes emerged. For the SLR, a comprehensive search strategy was developed and then CINAHL, Cochrane Central, EMBASE, Medline, PsycInfo and PubMed were searched from their date of inception to October 2011. A similar search strategy was used for each database. Abstract and title screening was performed by two screeners who worked independently. Discrepancies of opinion were resolved after each screening level. The full text of all potentially relevant papers were obtained and examined by two reviewers. A citation review from all articles that met the inclusion criteria was conducted. One reviewer extracted results and a second reviewer checked all extracted data. Furthermore, findings from the qualitative study and the SLR were synthesized to develop a comprehensive understanding of the HSC needs of AYA survivors with cancer.

Results: For the SLR, 760 citations were identified, of which 11 met the inclusion criteria. An additional publication was identified through the citation review of included articles. For the qualitative study, a total of 20 interviews were conducted: 12 patients were diagnosed during adolescence and eight during young adulthood. Nine patients were male and 11 were female, and represented 12 different types of cancers. Among the most commonly reported HSC needs for AYA survivors with cancer from both studies, were social wellbeing, information-sharing and communication and service provision. The qualitative study revealed prominent needs for improved health care facilities, while psychological/emotional needs were commonly reported in studies retrieved for the SLR.

Conclusion: This study has identified a comprehensive set of HSC needs of AYA survivors with cancer. AYA patients with cancer expressed fundamental needs that must be addressed in order to ensure optimal care delivery and outcomes. Comparison of findings from the qualitative study and the SLR, along with findings from the cancer needs questionnaire for young people and a documentary, reveal several overlapping themes (e.g., entertainment for teens) and several novel themes (e.g., collaboration between the hospital and other services) emerging from the qualitative study. Study results will be used to inform the potential development of a new healthcare program for AYA patients in the Hamilton Health Sciences (HHS).

ACKNOWLEDGMENTS

First of all I would like to express my heartfelt appreciation to my thesis supervisor, Dr. Anne Klassen, for her continued guidance and support throughout this journey, and to Ms. Jessica Johnson who has been my partner in crime throughout this entire process. I cannot thank you both enough for enlightening me with your expertise and for being such esteemed advisors and support systems.

A special thank you to the members of my thesis committee; Dr. Graeme Fraser, Dr. Ronald Barr and Dr. Denise Bryant-Lukosius, for there continued patience, advice and encouragement. It has been an absolute pleasure and honor to work with such a knowledgeable, vibrant and compassionate group. Also, thank you to Dr. Rebecca Johnson, for agreeing to be external reviewer for my thesis.

I would also like to send out my sincerest thank you to the participants in the qualitative study who shared their intriguing and inspiring stories with me. It has been an immense pleasure working with you all, and I have learned so much.

Thank you to Ms. Lorraine Carroll, Ms. Kristina Vukelic and Ms. Kristine Bonnell for being such a terrific team and providing me with any program support. Also, my sincere thank you to McMaster Child Health Research Institute and Juravinski Cancer Centre for funding this study.

Lastly but certainly not least, I would like to dedicate this thesis to my mother, father and sister, and thank them for their life-long love and support. I love you all dearly.

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

LIST OF APPENDICES

MASTER LIST OF ABBREVIATIONS

AYA – refers to adolescents and young adults

CASP – refers to critical appraisal skills program

CNQ-YP – refers to cancer needs questionnaire for young people

CNMM – refers to concurrent nested mixed method

HHS – refers to Hamilton health sciences

HSC – refers to health and supportive care

IPA – refers to information preference for adolescents

QD – refers to qualitative description

OSAP – refers to Ontario student assistance program

RAP – refers to regional action partnership

REB – refers to research ethics board

SEER – refers to Surveillance Epidemiology and End Results program

SLR – refers to systematic literature review

DECLARATION OF ACADEMIC ACHIEVEMENT

Contribution: Ms. Elena Tsangaris performed all data collection, analysis and the write-up of the thesis. Ms. Jessica Johnson is a study co-investigator and assisted in data collection and analysis. Dr. Ronald Barr is a study co-investigator and committee member, and assisted in the development of the study design, analysis and write-up of the thesis. Dr. Denise Bryant-Lukosius is a study co-investigator and committee member, and assisted in the development of the study design, analysis and write-up of the thesis. Dr. Graeme Fraser is a primary investigator and committee member, and assisted in the development of the study design, analysis and write-up of the thesis. Dr. Rebecca Johnson is an external committee member and assisted in the write-up of the thesis. Dr. Anne Klassen is a primary investigator and committee member, and assisted in the development of the study design, analysis and write-up of the thesis.

CHAPTER 1

Introduction

1.1 Cancer in adolescents and young adults

Cancer is diagnosed in over 2,000 adolescents and young adults (AYA), aged 15 to 29 years old, in Canada annually, and accounts for approximately two percent of all cancers combined.[1-3] The most common cancer categories reported in this age group include lymphomas, melanoma, sarcomas, leukemia, brain tumors and cancers of the breast, thyroid, ovaries, testis, and colon.[4] Lymphomas are common in both the 15 to 19 year old and 20 to 29 year old age brackets. However, some cancers are more common in certain age groups than in others. For instance, leukemia, sarcoma and brain tumors are the more common cancers seen among adolescents aged 15 to 19 years, and melanoma, thyroid cancer and testicular cancer are more common in young adults aged 20 to 29 years.[4] The Canadian Cancer Society's 5-year survival calculations (1997-2004) for all cancers in AYAs aged 15 to 29 years old was estimated to be approximately 83%.[1,5] Meanwhile, survival for children, aged zero to 14 years remains slightly lower at 82%.[1,6] Despite the low occurrence of cancer in AYAs, poor outcomes and poor quality of life are evident for this cohort, and impose detrimental effects on society and the economy. Poor outcomes can be attributed to: the lack of guidelines for access to care,[6,7] the biologically diverse nature of the disease,[6] and the limited research aimed at understanding the cancer continuum and its impact on the various aspects of the AYAs developmental trajectory (i.e. social, psychological, physical).[5]

The multifaceted nature of cancer and its impact on the personal and social life of AYAs impose significant barriers to achieving optimal outcomes for these patients.[3,8,9] Adolescence and young adulthood are critical developmental phases in which individuals begin to form new relationships and identities.[10,11] A diagnosis of cancer during this vital developmental stage interferes with normal developmental tasks of AYAs and can disrupt their educational and/or occupational trajectories, social support systems and relationships.[10,12] Oversights on how these variables impact the progress of AYAs diagnosed with cancer significantly impedes on the health care provider's ability to provide quality care and further improve overall survival, outcomes and quality of life for these patients.[2]

1.2 Definition of adolescents and young adults

A universal definition for AYA has yet to be established. Though the lower and upper age range for adolescents has been widely accepted as 15 to 19 years of age, [7,13,14] the upper age limit definition for young adults remains highly variable. According to the Canadian Cancer Society[1] and the Surveillance Epidemiology and End Results (SEER) Program[15] the upper age limit for young adults has been defined as 29 years while the Progress Review Group in the United States defined the upper age limit as 39 years.[1,16,17] Further to this, in Europe, Eurocare[10,18] and the National Institute for Health and Clinical Excellence[19] in England has defined the upper age limit for YA as 24 years[14,16,19,20] Agreement on an upper age limit within Canada is critical to ensure consistent, rapid and adequate access to care for AYAs, thus will contribute to improving their outcomes and quality of life.[10,16]

1.3 Definition of access to care

Albritton and Eden (2008) define access to care as follows: the least delay between the first signs of symptoms and the start of treatment, expertise of care providers, availability of evidence-based therapy and clinical trials, and provision of resources and support services appropriate to meet the needs of the patient.[21] Suboptimal access to care for AYAs is widely due to the failure of current models of care in Canada to meet the needs of this cohort and provide suitable services.[21]

In Canada, individuals diagnosed with cancer from birth to 17 years of age are referred to pediatric cancer centers that function under family-centered models of care while individuals 18 years or older are referred to adult cancer centers that function under a disease-focused model of care.[3,6,12] Yet evidence from the Canadian Cancer Registry has indicated that, despite the availability of a pediatric model of care, only 30% of adolescents (age 15 to 17 years) are treated at pediatric oncology centers, with the remainder being treated in adult cancer centers.[3,22]

Pediatric centers reportedly possess little expertise in management of AYAs, but offer benefits such as greater access to clinical trials, peer support and intensive treatment.[3] A lower likelihood for enrollment in clinical trials and longer waiting times for healthcare procedures has been associated with treatment of AYAs in adult cancer centers.[3,22]

Evidence indicates that pediatric specific clinical trials, offered in pediatric centers only, are more appropriate for cancers in AYA than clinical trails offered in adult centers.[22] Despite this fact, only ten to 20% of adolescents with cancer in Canada are offered the opportunity to participate in clinical trials. The lack of participation is widely attributed to the scarcity of suitable trials to treat the types of cancers commonly occurring in AYAs, poor sample sizes to achieve statistical power, and the potential that AYAs may be less inclined to participate in a clinical trial.[3]

Furthermore, AYAs are more likely than children to experience delays in diagnosis and initiation of treatment. Evidence from a Canadian study has identified that delays in diagnosis and onset of treatment in adolescents aged 15 to 19 years is significantly longer than in children.[23] This delay may be a result of poor detection of symptoms related to cancer, or delays in seeking medical attention when symptoms arise. Findings reveal that delays are more prominent among patients referred to adult cancer centers, as opposed to those referred to children's hospitals.[3] In addition, outcomes for adolescents with cancer have been shown to be more promising when treated in pediatric versus adult centers.[22] Findings from two recent studies from Germany and Italy identified a potential survival advantage for treatment of older patients at pediatric centers compared with adult centers.[24,25,26]

Evidently, treatment settings for AYAs with cancer vary as a consequence of the ambiguous age cutoff for AYAs, the low frequency of cancer in this cohort, and the lack of specialization for treating AYAs. Consequently, patient care may be compromised by the lack of expertise and inadequate infrastructure (e.g., resource availability) to provide access to clinical trials, both of which are critical components to better manage this cohort.[3] The development of an AYA-specific cancer unit containing in-patient and outpatient services may provide invaluable specialized multidisciplinary care to this cohort by combining experienced surgeons, and specialized oncologists, with supportive care teams (e.g., social workers and psychologists) with expertise in caring for AYAs.[3]

1.4 Canadian Partnership Against Cancers' Task Force on Adolescents and Young Adults with Cancer

In 2008, the Canadian Task Force on AYAs with Cancer was established. The goals of this Task Force are to improve outcomes and health-related quality of life for AYA survivors with cancer diagnosed during childhood, adolescence or young adulthood. The aims of the Task Force are as follows; to ensure immediate and equitable access to care for AYA Canadians; to optimize health outcomes; and to improve AYA quality of life during and after active treatment.[27]

As part of the Task Force's efforts, a survey was conducted to evaluate current practices and resources available to AYAs with cancer in all pediatric, and a sample of adult, cancer centers in Canada. Findings from this survey revealed minimal resources and expert staff in both types of centers, along with negligible collaborative efforts, if any, between pediatric and adult centers to enable adequate care to AYAs with cancer.[2] These findings support the need for closer collaboration between medical and pediatric oncologists. Furthermore, adoption of a model that brings together expertise to care for AYA cancer patients within the same facility might better suit AYAs needs and address some of the challenges of treatment and supportive care. This new model may improve clinical outcomes, quality of life, and improve patient satisfaction with care.[2] Improved care for this group will be economically and socially beneficial, and will allow individuals to achieve their full potential as productive, functioning members of society.[8]

The Task Force organised an international workshop (March, 2010) to examine priorities for providing optimal care to AYAs in Canada involving more than 100 stakeholders (e.g., from hospitals, cancer agencies, government, advocacy organizations, researchers, and patients). The proceedings were published in a supplement of *Cancer* with a separately published paper outlining recommendations from the workshop based on the six broad recommendations aimed to support age-appropriate, disease-specific and expert medical care including psychosocial, survivorship and palliative care.[8] A second workshop, held March 2012, mapped out a pan-Canadian AYA action framework with objectives for change and evaluation in the areas of advocacy, clinical and supportive care, education and research, and prevention and screening.[8] An essential workshop outcome was the establishment of Regional Action Partnership (RAPs) representing every part of Canada. These RAPs will assist in putting into action the framework for implementation of the recommendations for improved outcomes for AYA with cancer.

Innovative models of care systematically designed to better meet the needs and improve outcomes of AYA patients have not yet been developed or tested in Canada. Conceptually, the notion of AYA-specific cancer units has been endorsed by the AYA Task Force because these appear better suited to meet the distinctive needs of this population, and may facilitate research efforts in contrast to the fragmented nature of existing care models.

To date, the development of AYA cancer programs has been ad hoc rather than systematic. It is not clear whether such approaches impact upon critical determinants of health and health outcomes in AYA patients because existing programs have not been rigorously evaluated. At the conclusion of the Task Force workshop, it was decided that, moving forward, each RAP would determine the best model of AYA care for their local jurisdiction.

1.5 Study rationale

Recently, cancer research has expanded to include not only adult and pediatric, but also AYA cancer. Reasons for this shift are to attempt to understand the multifaceted nature of cancer, and its impact when diagnosed during AYA.[1,10,16,17,28,29] Current research suggests that the health and supportive care (HSC) needs for this cohort are not adequately met.[2] More specifically, research presented by the Task Force has indicated that the current cancer care models in Canada do not provide adequate systems of care in which to deliver optimal treatment and support to AYAs. As a first attempt to decipher the limitations of the current models of care in Canada, the Task force has developed a list of recommendations that aim to target the needs for age-appropriate, disease-specific and expert medical care. Proceedings from the recent Task Force workshop announced the establishment of RAP’s, developed to help implement these recommendations throughout Canada.

Discussion on how best to implement the recommendations by the Task Force is currently underway in Ontario. More specifically, a planning group has been established in Hamilton, Ontario to prepare for the likelihood that the comprehensive restructuring currently ongoing at HHS will accommodate a new AYA oncology program. The HHS is uniquely positioned to create an AYA oncology program, as it encompasses a regional adult cancer centre and a children’s oncology program within a general hospital.

Establishing an AYA-specific program, may be more appropriate to address the developmental needs of AYAs with cancer.[2] Development of such a program could improve barriers engrained within current models of care, and improve provider expertise.[30] In order to understand the multifaceted nature of cancer and its impact on patients after being diagnosed, a mixed method study to identify the HSC needs of AYA survivors with cancer was conducted. The term survivor was used in accordance with the definition by Fitzhugh Mullan (1985), in conjunction with the founding of the National Coalition for Cancer Survivors (1986).[31] For this study, survivor was thus defined as *"anyone who has ever had cancer from the moment of diagnosis to the balance of his or her life, regardless of the ultimate cause of death."* Results from this needs assessment will be used locally to inform the potential development of the AYA-specific program being planned in the HHS.

1.6 Theoretical framework and supportive care needs

The theoretical framework used to guide this study builds upon the construct of human needs, initially described by Fitch (2000) as the Supportive Care Needs Framework (Figure 1 and 2).[32] According to Fitch (2008), supportive care is *"based upon, and matched with, an individual's needs within the context of his or her unique situation."* A diagnosis of cancer may interfere with an individual's ability to meet his or her physical, psychological/emotional, social, and spiritual needs.[32,33] Though all patients with cancer entering the cancer care system require basic supportive care services to satisfy their HSC needs, others require more intensive interventions. Fitch (2000) defines supportive cancer care as

> *The provision of the necessary services as defined by those living with or affected by cancer to meet their physical, social, emotional, informational, psychological/emotional, spiritual and practical needs during the pre diagnostic, diagnostic, treatment and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement.*

Age, gender, socio-economic status, education, religion, language, culture, and preferences are variables to be considered when tailoring supportive care services.[33] Rudimentary supportive care services are essential to fulfill patient HSC needs. Hence, designing services directed towards a specific cancer cohort is critical, and changes should be evidence-based and include the patients' perspectives.

1.7 Needs and needs assessment

The definition of needs by Foot (1996) was used to guide the present study. Foot defines a need as *"a requirement for some action or resource that is necessary, desirable, or useful to attain optimal well-being."*[34] A needs assessment is a formal and methodical attempt to study needs in order to determine and close the gap between 'what is' and 'what should be.'[35] Needs assessments can increase communication and networking, thus improving coordination between services. Needs assessments can be used to guide policy and program development, determine service needs and utilization, identify gaps in service provision, and establish an appropriate program that addresses the issues identified.[36-39] Research methods for conducting needs assessments are plausible through quantitative or qualitative approaches. Quantitative approaches enable the identification of the extent and importance of HSC needs, while qualitative studies enable in-depth understanding of the intricacy of individuals' needs within the context of their lives.[40]

1.8 Chapter summary

This mixed-methods study is a needs assessment to identify the HSC needs of AYA survivors with cancer. It provides insight into the importance of understanding the HSC needs for this cohort. This chapter began with a description of AYA cancer and its burdens, followed by key definitions of AYA, and access to care. The context is then set for how this study fits within the work of the AYA Taskforce, and local efforts to develop an AYA model of care. The chapter concludes with a description of the theoretical framework used to guide this study and a definition of needs and needs assessments.

Chapter 2 outlines the purpose, research questions, and study design methods for data collection and analysis. Chapter three reports the study findings, including those of a systematic literature review (SLR), to identify the heath and supportive care needs of AYA cancer survivors, and the qualitative analysis of HSC needs for AYA cancer survivors. Chapter four provides an in-depth discussion of the study findings. The thesis concludes with a description of the study strengths and limitations, followed by implications of the findings and recommendations for designing needs-based supportive care services for AYA cancer survivors. The chapter ends with the next steps, including future research, dissemination plans and the overall conclusion.

CHAPTER 2

Methodology

This chapter provides a detailed description of the study methodology. The chapter begins with a description of the problem addressed by the thesis, the study purpose and research questions. This introduction is followed by a description of study methods used to conduct a SLR and a qualitative description study to understand AYA needs. The chapter concludes with a rationale for selecting the methodologies along with an appraisal of the strengths and limitations of each methodology.

2.0 Declaration of problem

The HSC needs for AYA survivors with cancer are poorly addressed within the current Canadian cancer care models, resulting in poor outcomes, poor quality of care, and shortcomings in communication and collaboration between health care providers and services.[16,30] The development of an AYA oncology program was a proposed strategy to alleviate these limitations. The specialized oncology program will restore the quality of care necessary to treat AYAs, and serve to bridge gaps between pediatric and adult models of care.

As an initial step to the development of an AYA-specific program at the HHS, a needs assessment was conducted to inform its development. Understanding the HSC needs from the patient perspective, through qualitative interviews, is a critical first step to developing a program that will effectively address AYA needs and enable optimal service delivery, outcomes and quality of life. Furthermore, a SLR was conducted concurrently, to understand the scope of needs currently reported in the literature.

2.1 Study aim and purpose

The purpose of this research study was to identify the HSC needs of AYA survivors with cancer that were treated within the Hamilton region. This mixed-methods study was undertaken to gain a comprehensive understanding of the HSC needs from the patient's perspective, providing information that could be used to inform the development of an AYA model of care in the HHS.

2.2 Research question

The research question addressed in this study was: what are the complete health and supportive care needs (met and unmet) of AYA survivors with cancer?

2.3 Mixed methods study design

A concurrent nested mixed methods (CNMM) design was employed. The CNMM design uses two discrete methods in which one method is secondary; yet supportive, to the other.[41] The CNMM design provides a more comprehensive approach to addressing the research question.[41]

For the present study, qualitative and quantitative methods were used. The primary method was qualitative and the secondary method was quantitative. Qualitative description (QD) was the qualitative method selected because it enabled us to describe the perceptions and experiences of the participants directly using the participant's language.[42] A SLR accompanied the qualitative study to provide a more comprehensive understanding and description of the research topic. Data collected from both methodologies were compared in the data interpretation phase of the project.[42,43,44]

2.4 Developing themes and subthemes in the quantitative and qualitative studies

Initial codes and categories of needs for the qualitative study were developed based on the Supportive Care needs Framework and a literature review. Fitch (2008) reports several supportive care needs of patients who are suffering with a life-threatening illness, which are outlined in Figure 2.[34] These needs were used in the study as the categories and sub-categories for the development of the initial codebook for coding the qualitative interviews. After several interviews were conducted, categories of needs were modified to match closely with the words and descriptions of the study participants. Categories and sub-categories for the SLR were derived in a similar manner. Initially, descriptions of needs were taken directly from each publication. Once data was extracted, the codes and categories developed for the qualitative study were used to code both datasets, the qualitative and the SLR, to group needs in a manner that would allow us to establish pertinent themes and relationships between the two studies. Refined categories and sub-categories from the qualitative study and SLR were then used to code a documentary entitled *"Wrong way to hope" and a* Cancer Needs Questionnaire for Young People (CNQ-YP) to examine relationships between findings from the qualitative study and the SLR, the documentary and the CNQ-YP.

2.5 Quantitative methodology: systematic literature review

2.5.1 Search strategy

CINAHL, Cochrane Central, EMBASE, Medline, PsycInfo and PubMed were searched from their date of inception to October 2011. The research team, alongside a medical librarian, developed a comprehensive search strategy to capture relevant publications that investigated the HSC needs of AYA survivors with cancer (a detailed search strategy is available in Appendix B). A similar search strategy was used for each database. Needs identified by Fitch (2008) in the Supportive Care Needs Framework guided the development of the search strategy.[34] The seven categories of needs described by Fitch (2008) were the primary search terms relating to needs.[34] These needs categories include psychological needs, social needs, spiritual needs, informational needs, physical needs, emotional needs and practical needs. Additional terms were then developed to ensure a comprehensive search that would identify all relevant publications.

Abstract and title screening was performed by two screeners who worked independently. Discrepancies of opinion were resolved after each screening level (Figure 3). The full text of all potentially relevant papers was obtained and examined independently by two reviewers. The following inclusion criteria were employed: (i) the study sample focused on adolescents and/or young adults; (ii) the study sample was diagnosed during adolescence and/or young adulthood (defined as between the ages of 11 and 44 years old for the SLR, based on the range of participants investigated in the included papers); (iii) the study sample included survivors with cancer; and (iv) the study used a qualitative and/or quantitative approach to evaluating needs. The search was not restricted to English language articles because of the anticipated scarcity of studies surrounding this research topic. Studies that investigated AYAs among other patient groups, but did not report findings separately for AYAs with cancer were excluded from analysis. Furthermore, abstracts, dissertations, editorials, and reviews were excluded.

We conducted a citation review from all included articles to evaluate the quality of the search, and ascertain the inclusion of all relevant literature. One reviewer extracted results from eligible publications and a second reviewer checked the extracted data against each paper.

2.5.2 Appraisal of study quality

Included studies were critically appraised for validity and applicability. Criteria provided by the Critical Appraisal Skills Program (CASP)[45] was used for the evaluation of qualitative studies (Appendix C), and criteria from the STROBE statement[46] used to assess the quality for quantitative studies (Appendix D). Evaluation of quality for each publication was based on how rigorously methodologies were followed. The quality of each paper was arbitrarily categorized as high, medium or low, depending on the number of design issues presented in the study. High quality was assigned when no significant design issues were found; that is, when 'Yes' was assigned to more than 50% of the items required by the STROBE or the CASP (e.g., 18 out of the 34 checklist items required by the STROBE statement or, six out of the ten items required by the CASP statement). Medium quality was assigned when publications met 50% of the criteria provided by STROBE and CASP, and low quality was given when substantial design errors were identified, i.e., when less then 50% of the criteria were met.

2.6 Qualitative methodology: qualitative description

2.6.1 Study design

Qualitative description (QD) by Sandelowski (2000) was the qualitative approach employed.[42] QD follows a method of investigation that aims to describe the perceptions and experiences of the participants.[47] QD studies have traditionally been used to describe participants' views or experiences. [48] This approach is inductive and a suitable method for identifying a problem generating hypotheses and developing concepts.[42,47]

2.6.2 Study setting

Study participants were recruited from two sites, including the pediatric and adult cancer centers in Hamilton, Ontario. The two sites are the only cancer centers within the Hamilton area that offer a diverse patient population, and are the primary treatment sites for two study investigators who commissioned and collected initial participant consent. The participating sites are the primary referral centers for individuals diagnosed with cancer and serve the majority of the pediatric and adult cancer cohorts in the Hamilton, Burlington, Niagara, Haldimand, Norfolk and Brant regions.

2.6.3 Sampling strategy

A maximum variation sampling strategy was employed (Table 1).[49,50,51] Maximum variation sampling allows for the documentation of diverse variations of study participants and identification of common patterns of the phenomenon under study.[52] This sampling approach ensured that cases believed to be information-rich were obtained, allowed the phenomenon to be accurately described, and helped assure rigor in the study findings.[42,49]

2.6.4 Study participants

A pediatric oncologist from McMaster Children's Hospital, and an adult hematologist from Juravinski Cancer Centre approached eligible participants via telephone or in person during clinic visits, and asked if they were interested in participating in the study. Another study investigator recruited one participant via telephone. Eligible participants were those diagnosed between 15 to 25 years of age, who could speak and understand the English language. Survivors with a significant cognitive impairment were excluded from the study.

After verbal consent was obtained, the research team was notified and provided with the participants’ contact information. A member of the research team contacted the participants via telephone to set up an interview date and time at the convenience of the participants and their location of choice. All study participants were reimbursed fifty dollars as a symbol of appreciation from the research team for their participation.

2.6.5 Data collection

A study research assistant with expertise in qualitative research conducted the first six interviews. To learn the methods of qualitative research, I listened to, and transcribed the six interviews. I then conducted a pilot interview, which was not included for analysis, but was evaluated by the research assistant who provided feedback. I then conducted the remaining fourteen interviews.

A semi-structured interview approach was used. An interview guide (Appendix I) and preliminary codebook (Appendix J) were devised based on the Supportive Care Needs Framework (Figure 1 and 2) and were used to guide the interviews. Fitch (2008) reports seven supportive care needs of patients who are suffering with a life-threatening illness. These needs were used in the study as the categories or sub-categories for the initial codebook, and were used to guide the development of relevant questions for the interview guide. For instance, to target social relationship needs, participants were asked how supportive their family and/or friends were throughout their cancer experience, and whether they attended any support groups before or after treatment. Probes were used to encourage in-depth discussion of feelings and experiences of participants. Interview questions were open-ended to encourage participants to talk about issues in greater depth.[53] Questions that related to the needs of AYA cancer survivors, from the perspective of the patient, were addressed in terms of the following topics: client/family centered care needs, physical needs, psychological/emotional needs, coping needs, health behavior needs, social needs, informational needs, health facility needs and any other needs thought to be relevant to participants. Fitch (2008) reports most of these categories, as part of the Supportive Care Needs Framework for patients with life-threatening illness, excluding the need for client/family-centered care, health behavior needs and any health facility needs. Study team members devised these new categories in order to address fundamental aspects of the studies objectives. Prior to starting the interview, the interviewees were asked to read and sign consent or assent depending on their age (patients aged 15 years signed an assent form) (Appendix H). The interviews commenced by having the participant confirm consent on tape. Interviews began with having the participants describe their experiences prior to and immediately after their diagnosis of cancer and the start of treatment. Interviewers probed participants to express positive and negative aspects of their experience and assured participants that their reports would not be shared with other members of the research or clinical team. All interviews were digitally recorded. Each in-depth interview was conducted in private, at the most convenient time and location for the participant, and lasted an average of 75 minutes. Interruptions, disturbances or distractions of recording were minimized throughout the interview. Recording equipment was double-checked after the commencement of each interview and was monitored throughout to ensure no information was lost.

Demographic data were collected on the date of the interview using a data collection sheet (Appendix K). Information collected included the following: participants current age, age at diagnosis, age at the end of treatment, comorbidities, gender, diagnosis, treatment, education level, ethnicity, living status (e.g., with parents, partner etc.), relationship status, relapse, and occupation. Descriptive information on the parents or caregivers of the participants were also collected and included their working status, occupation, level of education, marital status, and annual household income of the family. These data were entered into Excel and double-checked to ensure accuracy of the data.

2.6.6 Data management and analysis

Either a professional transcriptionist or myself transcribed the interviews verbatim. Problems in the quality of the transcribed documents were double checked for accuracy by myself by listening to the audio files again. Any information that may lead to positive identification of study participants or healthcare providers was removed from the transcript documents.

I closely followed the method for data collection, coding and analysis as outlined by Sandelowski (2000). A preliminary codebook was devised a priori, based on the Supportive Care Needs Framework.[52] Data collection and analysis took place concurrently, which allowed me to revise the interview guide, gather new data and refine emerging codes and categories.[54] Analysis involved moving line-by-line through each transcript, applying codes from the preliminary codebook and developing new codes, which were then added to the codebook in an ongoing manner. Initial codes were devised to reflect words/statements used directly by research participants.[42] The codes created were ones that remained close to participant descriptions as in the manner used in QD and were not interpretive.[42] During the entire coding process, codes were organized and refined using the constant comparison method, which involved comparing codes within and across codes and categories. This led to the development of categories, themes and subthemes.[42] Interviewing continued until no new codes and categories emerged. QSR NVivo 8 software is a computer-assisted data management program and was used to code, store, and manage the data.[55]

2.6.7 Provisions to ensure rigor in the qualitative methodologies

Throughout analysis, my own perceptions and biases played a pivotal role in making sense of participant statements. During content analysis, I reflected on the impact of my gender, age, social class, professional status, life experiences and role as a researcher throughout data collection. I am a middle-class young adult female who is a Master's of Science candidate. I have experience working with pediatric cancer populations in urban and rural settings and have a keen interest in a broad range of cancers and cancer research. My current goals are to continue my education in an attempt to expand my knowledge base to its fullest capacity. To ensure that participant statements were accurately represented, I needed to bracket any previous knowledge or insights gained from my prior experiences working with other pediatric cancer cohorts, and any of my preconceived thoughts.

As described by Morse (2002), the verification strategies used to ensure rigor in this study include (i) addressing methodological coherence by ensuring that the research question matches the methods, and that the methods match the data and the analytic procedures; (ii) ensuring that the sample is appropriate, by including participants who best represent, or have knowledge of, the research topic; (ii) collecting and analyzing data concurrently, to form a mutual interaction between what is known and what one needs to know; (iv) thinking theoretically, ensuring that ideas emerging from the data are reconfirmed in the new data collected, which will give rise to new ideas that, in turn, will be verified by data already collected; and (v) developing theory by reflection between a micro evaluation of the data and a macro conceptual understanding of theory.[56]

To further promote trustworthiness of the findings, credibility, confirmability and transferability were used.[54,57,58] Credibility was supported through the use of data triangulation and peer debriefing.[54] For this study, data triangulation involved building evidence for a code or theme from interview transcripts, the literature, a documentary *and the* CNQ-YP.[41] Comparison of findings to the documentary and the CNQ-YP was a vital step in confirming and validating qualitative and quantitative findings. Furthermore, data triangulation of the documentary and the CNQ-YP allowed for more in-depth interpretations and analysis of study results in the data interpretation phases of the study. Peer debriefing involved the review of interview transcripts and emerging categories of needs by a second member of the research team upon meeting to discuss and confirm the relevance and novelty of the new category.[54,57] Confirmability requires unbiased research procedures and results, and congruence on the meaning, relevance and accuracy of findings derived from data analysis.[57,59,60] Confirmability was achieved through the same triangulation methods described.[59] Achieving an adequate sample size, data saturation, and maintaining the desired qualitative approach ensured rigor was maintained.[54,57] Transferability, the acquisition of a *"thick description"* of findings to enable transfer of the findings to other contexts, was addressed by providing clear descriptions of the context, selection and characteristics of participants, data collection and analysis.[58]

2.6.8 Provisions to protect human subjects

Ethics approval for the study was obtained from the Research Ethics Board (REB) of the participating centers and was conducted in accordance with the Tri-Council Policy Statements *"Ethical Conduct for Research Involving Humans."* All participants provided written informed consent for participation. The consent form included information explaining the research project. Participants were assured that any information provided would not be identified individually in any verbal or written reports of the study and that information collected during the study would be kept confidential and used only for the purposes of the study. Participants were informed that they could withdraw from the study at any time for any reason with no effect on the care received.

Confidentiality was assured by assigning participants a personal study number and using that number on the interview data and by keeping the consent forms separate from the interview data. Identifying information was removed to protect participant confidentiality. In accordance with the Personal Health Information Protection Act (2004) contact information, demographic information and audio files were transferred to password-protected electronic files. Interviews were then deleted from recording devices, and all written documents were stored in locked cabinets, available only to the principal investigator.

2.7 Rationale for chosen methodology

One of the key advantages to using QD is its ability to mesh well with quantitative data in a mixed methods approach. Proper use of QD enables beneficial synthesis and modification of data from qualitative needs assessments or mixed method studies.[47] QD aims to provide rich, straightforward descriptions of experiences, and allows one to stay close to the data during data analysis.[61]

QD differs from most traditional qualitative methods such as ethnography, grounded theory and phenomenology, which aim to provide thick description, develop theories or derive interpretative meaning of experiences respectively.[61] Further to this, QD differs from interpretive description, an applied health services approach, in that interpretive description provides in-depth descriptions and understandings of a concept while QD stays closer to the data and the language of the participants to provide descriptions of participant experiences.[61]

2.8 Chapter Summary

This chapter outlined the problem, purpose, aims and research questions that were addressed in this study. The study methods were described in detail in relation to the research design, setting, sample, recruitment, and data collection strategies. Finally, a rationale for the chosen methodologies was provided.

CHAPTER 3

Results

This chapter summarizes the results of the SLR and the qualitative needs assessment. The chapter begins with an overview of the demographic characteristics of the samples for each study in the SLR. Specific findings of needs and variables associated with needs reported in the literature are described. Following this description, demographic characteristics of the study sample for the needs assessment are reported, along with the needs and variables of needs identified.

3.0 Systematic literature review

A total of 760 abstracts and titles were retrieved from the literature search. Among them, 11 publications met the inclusion criteria. One additional publication was identified through a citation review of all included articles (Figure 3). In total, 12 articles were included in the analysis.[62-73] No publications were omitted after critical appraisal for quality of each study using the CASP and the STROBE statement, as no study scored below 50% for quality as per the checklist items. Six publications undertook a qualitative approach to data collection and analysis; five publications used quantitative methods; and one, used mixed methods to study needs. Among the publications using qualitative methods, three [62,63,64] conducted focus groups, one[65] used face-to-face qualitative interviews, one[66] used a combination of focus groups followed by in-depth interviews, and one used pre-testing, a determinative evaluation that assesses perceptions such as comprehension and attitudes towards concepts in the early stages of material development.[67]

Among the five studies using strictly quantitative methods, three [68,69,70] used an online survey. These surveys were not previously validated and were developed by the researcher.

In two studies [71,72] a validated instrument was used to investigate needs. One study[71] used the Information Preferences for Adolescents (IPA) measure, an 18-item scale that measures informational needs and concerns. The second study[72] used the Cancer Needs Questionnaire for Young People (CNQ-YP), a scale that investigates needs for structure of care, process of care, relationships, information, daily living, psychological/emotional needs and school/occupation. At the time of the study, the CNQ-YP was in its unpublished form and consisted of 108 items. This scale has since been psychometrically evaluated, displaying strong factor structure, internal consistency and test-retest reliability.[74] The final measure consists of 70 items and measures six variables: treatment environment and care, feelings and relationships, daily life, information and activities, education, and work.[74]

3.0.1 Study characteristics

Study characteristics of each included publication are described in Appendix E. Studies investigating the HSC needs of AYA survivors with cancer are from three developed countries, USA (7), Australia (3), and UK (2). Sample sizes ranged from six to 1088 participants. The age at study entry and diagnosis varied between 11 to 44 years of age. The most prominent type of cancer investigated was lymphoma, followed by leukemia.

3.1 Systematic literature review categories of needs

A total of 54 needs were identified in the 12 papers and were categorized into six main themes as follows: facility needs, information-sharing and communication needs, physical and daily living needs, psychological/emotional needs, service provision needs, and social needs. Facility needs refer to any needs relating to the physical design and décor of the hospital, and/or the amenities offered by the hospital facility. Information-sharing and communication needs refer to the quality of information patients received, or that patients felt was not adequately addressed during their cancer experience. Physical and daily living needs refer to any needs for maintaining optimal health, functionality and managing symptoms. Psychological/emotional needs refer to needs to help deal with various emotions, to feel normal, or provide spiritual support to the patient. Service provision needs refers to any needs relating to the delivery of care such as client-centered care delivery, accessibility to services, wait times, coordination of care, client safety and the availability of a multidisciplinary team. Lastly, social needs refers to any needs relating to participation in social roles and social support. Detailed definitions of needs categories and sub-categories are reported in Appendix A. Needs reported by Fitch (2008) in her Supportive Care needs Framework were used to guide initial development of categories and sub-categories for the codebook and interview guide used in the qualitative interviews.[34] The definitions of needs were developed from the qualitative interviews and remained close to the words and statements of participants. The codebook developed for the qualitative study was also used to code findings from the SLR. Categories and sub-categories were further refined, as necessary; to reflect additional needs from the SLR. This ensured the credibility of the comparison between findings from the qualitative study and the systematic review.

The most common theme reported from the SLR was that of information-sharing and communication [62-67,69-72,73] and the least common were facility needs. Participants frequently reported needs for information on cancer treatment and diagnosis. More specifically, participants required information on sexual function and discussions on the side effects of treatment (Appendix E).

3.1.1 Information-sharing and communication needs

Eleven studies reported an information-sharing and communication need.[62-67,69-72,73] A total of 23 different types of information-sharing and communication needs were reported, which were categorized as follows: cancer treatment and diagnosis, mode of information, information delivery, seeking information, talking about cancer and other needs (e.g., information on available services for young people, exercise) (Appendix F).

The most commonly reported information-sharing and communication needs were for information on cancer treatment and diagnosis.[62-65,67,69,70-72,73] More specifically, information on sexual function (e.g., effect of cancer on sexuality and reproduction, fertility/infertility)[63-65,69-71,73] and other treatment side effect[62, 69-72] were the most prominently reported sub-themes under this category. In one study, participants reported that their need for medical staff to raise questions about fertility had been unmet. Participants who had concerns about fertility reported having to raise these issues themselves.[63] In another study,[64] participants identified needs for more timely information on fertility, which they felt was not adequately met.[64]

In four studies,[62,65,69,70] participants discussed mode of information and described a preference for information in electronic form (e.g., Internet websites).[62,65,69,70] Other information needs included having information about the services available for young people,[62,69,70,72] diet and nutrition (e.g., what type of food to eat) during[11] and following[65,70] treatment, and practical matters (e.g., financial support, and insurance issues).[62,65,71]

3.1.2 Psychological/emotional needs

Ten studies[62-65,67,69-72,73] reported a psychological/emotional need (Appendix F). Four different categories of needs were reported as follows: autonomy, feeling normal, self-consciousness and counseling support. The most common need among participants was for psychological support services.[62-65,67,69-72,73] Participants in four studies[63,64,69,70] reported the need for counseling and guidance to deal with fears of recurrence,[64] leaving the acute health system[64] or issues of sexuality and intimacy.[69,70]

Autonomy was highly regarded by participants in four studies.[62,63,67,73] In all instances, participants expressed a need to gain back their independence lost after being diagnosed with cancer.

3.1.3 Service provision needs

Nine studies[62,63,65,66,67,69,70,72,73] reported a service provision need (Appendix F). Eight categories of needs were identified as follows: availability/accessibility, client (AYA) centered care, client safety, coordination, the availability of a multidisciplinary team and other (e.g., choice of treatment days).

Among several studies, the most commonly reported need was for the availability of a multidisciplinary team offering a wide range of services.[65,69,70,73] Multidisciplinary services requested included access to a personal trainer,[65] social worker,[63] adoption services,[69,70] child care,[69,70] complementary/ alternative health services,[69,70] and infertility treatment services.[69,70,73]

Various types of service needs were also reported in two studies. In both studies, participants reported an unmet need for adoption services, complementary/alternative health care services, and infertility treatment services.[69,70] Interestingly, in both studies, the majority of participants reported that the need for adoption services had been unmet, and that they had an unmet need for infertility treatment services.

3.1.4 Social needs

Eight studies[62,63,65-67,71,72,73] reported social needs, which were categorized as follows: companionship, participation in social roles and social support (Appendic F). In several studies, participants reported needing support from family and/or friends[62,67,73] or peers with cancer.[65,67,73] In some studies, participants reported the need for strategies to better deal with not being able to hang out or do the same things as their friends[72,73] while, in other studies, participants reported the need for assistance in transitioning back into school following their treatment, or not being able to keep up with school while on treatment.[63,66,71]

3.1.5 Physical and daily living needs

Four studies reported a physical or daily living need.[65,69,70,73] Two different types of needs were reported and categorized as follows: health maintenance and practical needs. In one study[65] participants reported the need for various interventions to remain active, eat healthy or promote relaxation.[65] In three studies,[69,70,73] a practical need was expressed (Appendix F), including the need for financial[73] or transportation[69,70] support.

3.1.6 Facility needs

Three studies[63,66,72] reported several hospital facility needs that participants felt were not adequately met (Appendix F). Three categories of facility needs were identified including amenities, entertainment, and food and drink. A common theme among all three studies that focused on adolescents[5] or young adults,[63,66] was the need for an AYA ward in which they could be cared for among individuals that are similar in age.[63,66,72] In a focus group study that investigated the physical, psychological/emotional and social needs of adolescent cancer patients, participants reported that their inpatient experience of being treated with much older or younger patients was distressing.[63]

3.2 Systematic literature review variables associated with reported needs

A total of nine studies[63,62,66,68-72,73] measured at least one of 13 variables related to HSC needs (Appendix G). The most commonly reported variables were age,[68-70] and age at diagnosis.[63,68-70] Information-sharing and communication and service provision needs were the most frequently reported categories of needs among the identified variables. Here, we summarize the most frequently reported variables and their associated needs.

3.2.1 Information-sharing and communication needs

Of the nine studies investigated at least one of 13 variables related to information-sharing and communication needs (Appendix G),[62,63,66,68-72,73] age,[68-70] and age at diagnosis[68-70] were the most commonly related variables to the need for information about sexual health[68-70] and diagnosis.[63,68,70] Younger respondents and those diagnosed at younger ages reported a significantly greater need for information about sexual health[68-70] and diagnosis.[63,70] In one study, participants who were diagnosed between 25 to 29 years of age reported a significantly greater need for information on sexual health than those who were diagnosed between 15 to 24 year and 30 to 35 years of age.[69]

3.2.2 Service provision needs

Twelve variables of service provision needs were identified (Appendix G). Older adults, males, and those diagnosed at older ages ranked the need for access to multiple medical opinions highest.[68] Meanwhile, females,[69,70] younger participants,[68,69] and those diagnosed at younger ages,[68] attributed higher rankings to the need for fertility treatment services,[68-70] scheduling treatment to fit their lifestyles[68-70] and adoption services[69,70]

3.2.3 Psychological/emotional needs

Six variables relating to a psychological/emotional need were identified (Appendix G). The most common variables were age (10 to 44 years old) and age at diagnosis (15 to 35 years old).[68-70] The need for available support services to participants was most commonly reported in six studies.[68-72,73] Younger participants, aged 18 to 29 years old,[70] reported needing available support services, such as mental health counseling or alcohol abuse counseling, more frequently than their older counterparts who were aged 30 to 40 years.[70]

3.2.4 Social needs

Six variables of social needs were identified (Appendix G). The opportunity to meet other young adult cancer survivors, with similar diseases, was ranked highly among females and respondents diagnosed at a younger age.[68] Additionally, the need for assistance in getting back to work, guidance about future school or career paths and help dealing with not being able to participate in regular social roles were reported more frequently by participants who were five years or more since treatment.[72] In one study, the younger respondents reported the need for encouragement to pursue social activities significantly higher than older respondents.[68]

3.3 Summary of systematic literature review findings

The SLR retrieved 12 relevant publications investigating HSC needs of AYA survivors with cancer. Findings from the SLR reveal that information-sharing and communication needs were most commonly studied. Psychological/emotional needs, service provision needs and social well-being needs were also frequently studied in the publications. Identified needs from the SLR will be compared to findings from the qualitative interviews in a subsequent section.

3.4 Qualitative study

Between September 2011 and January 2012, eligible participants were contacted and recruited for study participation. A total of 30 potential participants were contacted, and 20 were recruited for interviewing. Reasons for non-participation included lack of interest (n= 3), the person was too sick to participate (n= 1) and we were unable to contact the patient after at least three attempts (n= 6). Non-study participants were mostly male (n= 7) and had various types of cancers.

In one interview, the recording device failed and therefore, rendered part of the interview incomplete. In another, the interviewee did not want the interview to be tape-recorded; however, the interview proceeded and detailed notes were taken. Overall, 20 participant interviews were conducted by January 2012.

3.4.1 Demographics

Table 2 provides a summary of study participants and their demographic characteristics. Current age at the time of recruitment ranged from 15 to 29 years, and age at diagnosis was between 15 to 25 years. A total of 11 females and nine males were recruited. All participants were treated within the Hamilton Health Sciences but mainly resided in neighboring communities. Most participants were Caucasian, had a high school education or less and lived with their parents or caregivers.

Seven categories of needs were identified from patient interviews and included the following: collaboration needs, facility needs, information-sharing and communication needs, physical and daily living needs, psychological/emotional needs, service provision needs, and social needs (Appendix L). Important quotes from participants, for each need category, are reported in Appendix M. Pertinent findings from the qualitative study are described below in order of the most prominent to least prominent category of needs.

3.5 Qualitative study categories and variables of needs

3.5.1 Facility needs

Facility needs refer to any needs relating to the physical design or décor of the hospital, and/or the amenities offered by the hospital facility. A range of needs was described and related to the following: bathroom facilities, outdoor areas, patient kitchen, hospital room and teen ward. An important category of needs that emerged was that of amenities. Amenities refer to tangible aspects of the hospital environment that participants have liked to be incorporated into the facility or to be improved.

Fifteen participants said that they would prefer an AYA ward. One participant said the following:

> *A ward would be nice if it was like, more of your age group. They are like very young people, so it would be nice to see more people like your own, like separated into like your own age groups.*

Most participants reported a desire to be treated in an area among people who were similar in age, type of disease or gender. A common reason for wanting to be treated among similar patients, as expressed by participants, was to be in proximity to individuals that they could relate to. In some instances, participants reported that they had been placed in a room with an individual of the opposite sex, which made them feel uncomfortable. These participants would have preferred to share a room with someone who was the same gender. Sharing a ward with someone who had a less severe disease frustrated some participants who felt that the level of care received was poor compared to the care provided to the patient with the less-severe disease. Older participants mentioned that they preferred to not be placed in a room with a younger patient because they could not relate to them.

A related and frequently reported theme was the need for access to entertainment and an entertainment room. A large proportion of participants (n=15) wanted access to the Internet, a variety of movies and TV channels, gaming systems, board games, and AYA outings into the hospital experience. Participants requested that activities be appropriate for age and accessible at any time. One comment on the need for Internet was as follows:

> *To have Internet where you could hookup to Facebook and stuff like that would be a major thing because Facebook to teens is pretty much a teen's life; that's how they communicate with their friends.*

As mentioned, some participants (n=8) also requested an entertainment room to be available within the hospital unit. Most suggested a lounge area where individuals can interact, while others suggested a computer or movie room.

The need for a private hospital room (n=8), a patient kitchen area (n=7) and private bathroom facilities (n=5) were also frequently reported among participants. Two adolescent female participants also reported a need for the bathroom facilities to be located in proximity to their hospital room, while the remaining three participants requested that they have a private washroom, as opposed to one that is shared among two or more patients. The need for a patient kitchen to be able to store their own food, or to make their own food while in the hospital, was also frequently reported (n= 7). Furthermore, participants who reported a need for a private hospital room were both male and female.

Eight participants wanted improvements made to the design or décor of the facility. Such improvements included providing a more pleasant décor, an outdoor facility or sunroom area, or balconies and windows. In most instances, participants stated that they would prefer brighter paint colors in the facility and an outdoor area that would allow them to escape the hospital atmosphere and get some fresh air.

Lastly, the need for better quality food that was accessible and more varied was crucial to several participants. In all instances, participants wanted the cafeteria to be closer in proximity to their hospital room. Some requested that a cafeteria or vending machines be placed directly on the ward, while others needed the cafeteria to be closer in proximity, but not necessarily on the ward itself. Food quality was also a key issue. In all instances, participants reported that they were disgusted by the food in the hospital and would have liked the quality to be improved. One participant stated: *"the food is horrible. It's absolutely horrible. I know they can't have a kitchen there, which you can make food off the go, but they got to do something."*

3.5.2 Social needs

Support from family and/or a friend was by far the most commonly reported need, which was mentioned by 18 participants. Most participants reported having a strong social and family support system. One participant stated: *"I had lots and lots of family support. So it was, it was kind of nice because I would have someone new come in each day and time sort of went by."* However, some participants reported that they would have liked more support from a family member or a friend. In concurrence with this theme, 12 participants reported the need for support from peers with cancer. This need was consistent with the reported need to be in proximity to friends while on treatment.

In some cases, participants had support from peers with cancer and felt that it was helpful. One participant stated:

> *It's good when you have people outside of your family and your friends who are going through the same thing, who are like, yeah, you can do this! Like, we're doing it too, and you hear their experiences, and that kind of feeds, you know, your drive and, you don't feel so different.*

Others, who did not have support from peers with cancer, reported that it would have been useful to talk to someone they could relate to, or who has gone through a similar experience. In such cases, participants preferred to talk to someone with the same type of cancer, age or gender. This finding was also consistent with the reported need for support groups.

Support from school was also crucial, and was mentioned by ten participants. In most cases, participants wanted support from schools in order to set up a program that would allow continued participation while on treatment. One participant stated:

> *When I tried to ask the professors and whoever it was if I could get like special accommodations, something like even if I had to write in my own room, at least I could take my time. If there*

> *wasn't a set time limit and like if I wasn't stuck in a room with other students where I would be disturbing them. I tried to ask them if they could do something like that but they said they couldn't do that unless it's a permanent disability.*

A social need refers to any need pertaining to family relationships, community acceptance, involvement in relationships and social roles, and coping with changing relationships with friends and family members. Three main categories of social needs emerged from the study and include companionship, participation in social roles and social support.

The ability to participate in usual social roles was the second most commonly reported need. Themes that emerged under this category were as follows: the need to be able to, or continue with, participation in regular activities, school, work and physical activities. Several participants reported the need to continue with, or get back to, school, work or extracurricular activities. One participant stated:

> *"It's kind of annoying because I've been stuck at home with nothing to do for the past year now and I thought okay you know at least this semester stuff would be, you know, things would be different I could go back to school at least for two courses. Even if it's like two times, a week at least I have something to focus on.*

Some participants reported that they needed to continue with school while on treatment in order to graduate on time, while others, who were forced to leave school, were eager to get back to school to complete their education.

Participants reporting the need for companionship were more likely to report feeling isolated compared to those who did not report the need for companionship. Some participants stated that they missed out on going out partying with friends, while others felt isolated due to apparent changes in relationships with friends. For example, one patient stated:

> *All my friends are doing their thing at school and I wasn't a part of that…and then, all my friends became better friends, and then when I stepped in, it was just like kind of different.*

3.5.3 Service provision needs

Several sub-categories related to healthcare service needs were identified from the participant interviews and included the following: availability/accessibility, client (teen) centered care, client safety, coordination, a multidisciplinary team and wait times. Availability/accessibility needs refers to the extent to which services are available and accessible in a timely manner. Six participants reported a need pertaining to availability/ accessibility. Common themes were the need for access to various service providers (e.g., social worker, doctors/specialists etc.) in person or via e-mail. Shorter wait time during clinic visits was also a prominent theme mentioned by nine participants.

Client (AYA) centered care needs means the involvement of clients in the planning and delivery of services. Eighteen participants reported a need for client centeredness with the most common sub-category of needs as follows: friendly and supportive staff (n=6), knowledgeable and qualified staff (n=5), staff that they could trust or relate to (n=8), staff that pays more attention to and takes their time with, patients (n=8) and staff that treats them like a teenager/young adult (n=5). As one participant said; *"Some of the nurses…I know it's hard to keep a good demeanor all day, but just sometimes they need to be a little* *nicer, perkier we'll just call it."* Female participants most commonly reported needs for friendly and supportive staff or knowledgeable and qualified staff.

Client safety refers to the prevention of actual or potential harm to the client through the provision of a service. Three participants reported a client safety need. Some suggestions for improving client safety were to provide medicinal marijuana, better manage treatment-related symptoms, and for nurses to be attentive and meticulous when treating patients. Some patients who used marijuana during treatment reported its success at temporarily alleviating pain. Also, in relation to the need for nurses to be more attentive and meticulous, one participant felt that senior staff should better manage student nurses so that patients could feel safer.

Several participants also reported a need for coordination of care. Coordination of care refers to the provision of services that are continuous, integrated and organized around the client. Communication between doctors and services (n=5) and the need to deal with one health care professional (n=3) were common sub-themes. Similarly, six participants also reported the need for a multidisciplinary team. Specific team members that were frequently requested by participants include a social worker, the availability of multiple physicians to reduce the wait times, physiotherapists and rehabilitation services.

3.5.4 Information-sharing and communication needs

Information-sharing and communication needs refer to the need for information to reduce confusion, anxiety and fear, inform decision-making, and assist in skill acquisition. In order to reduce confusion, 11 participants expressed the need to be able to ask questions. In some instances participants reported that their need to ask questions of health care providers had been unmet. Furthermore, even if they were offered the opportunity to ask questions, they felt that their questions would likely be ignored rather than addressed. Questions about their cancer diagnosis and treatment, such as side effects, effectiveness of treatment and preserving sperm for future use, were commonly sought along with questions about alcohol use while on treatment, the use of drugs or other risky behaviors, such as the right time for getting a tattoo. In all cases, participants stated that they would like their questions to be answered when asked, or to be offered relevant information before having to ask for it.

Several participants mentioned the need for health care providers to provide certain types of information. Fifteen participants reported a need for information on cancer treatment and diagnosis. The most commonly requested information was on treatment processes, followed by information on diagnosis (n=8), side effects (n=6) and sexual function (n=2). One participant stated the following:

> *They just don't have information. Its too generalized. Like you walk in you'd see lymphoma, breast cancer, lung cancer. Its like you feel that, what, you're going to explain to me, what this person has, in three lines in a pretty brochure it's not, it doesn't do anything. Sure it's informative but it's very general. This is a pamphlet you take when you first get diagnosed but it doesn't help, like you'll get some information.*

Additionally, 17 participants described their preferred mode for receiving information. Written information (n=10) was the most commonly reported mode of information delivery, followed by information from peers with cancer (n=9), online information in the form of Internet websites (n=2) and verbal information (n=2). Gender was related to the need for online or verbal information. Females requested online information, while males' preferred verbal communication. Concomitantly, 14 participants reported a need relating to the way in which health care providers deliver information. These include the need to discuss difficult news in a caring way (n=4), explain things in a way that the participant could understand (n=7), to be provided with detailed and consistent information (n=4) and to be spoken to honestly (n=3).

3.5.5 Psychological/emotional needs

In this study, psychological/emotional needs are defined as the ability to cope with the illness, its consequences, and understanding the meaning and purpose of life. This category had the greatest number of reported needs. Six participants expressed the need for spiritual support, stating that they sought out spiritual prayer as a means to get through their cancer experience. *One participant stated:*

> *At one point they thought I had like very little like time to live. So I needed spiritual guidance so I sought out a chaplain, like I always, if I need help I get the help kind of thing.*

A few participants also reported that they used prayer and support from spiritual leaders to find meaning in their cancer experience. Several participants also requested improved access to other psychological support services, such as access to a psychologist or social worker to help them deal with fears, the impact of cancer, an uncertain future, and life changes after cancer.

The need to gain back independence was among the themes that emerged under psychological/emotional needs. Two individuals reported wanting to gain back the independence they had lost after being diagnosed with cancer. *One comment from a participant was the following:*

> *When you are in a place like a hospital, it's almost like a jail because you can't go out. A lot of your independence and your freedom is taken away from you. Um, so I just, yeah, really honed in on doing what I had to do to get out of there.*

Another common theme among participants was the need to feel normal and to deal with their feelings of self-consciousness. Often, when they spoke about their cancer, patients expressed that they felt different and/or that their friends treated them differently. Participants stressed that they wanted to be treated normally and to feel normal. In a related theme, participants expressed the need to use various strategies to conceal physical changes, such as a wig, hat, exercising to gain muscle strength and, in one instance, a female participant was contemplating plastic surgery to remove scars from surgery in order to deal with the apparent physical changes of her disease.

3.5.6 Physical and daily living needs

A physical and daily living need was defined as the need for physical comfort, freedom from pain, optimal nutrition, and the ability to carry out usual day-to-day activities. Health maintenance, practical and symptom management needs were the sub categories emerging under the physical and daily living needs category. In most cases, participants reported the need for continued participation in physical activity and healthy eating while on treatment. Symptom management was also a common theme reported by eight participants. One of the most commonly reported symptom management strategies was the use of marijuana. Participants used marijuana as an attempt to alleviate pain or to boost their appetite. Prescription medications were also used to alleviate pain, nausea and fatigue.

Furthermore, 17 participants reported the need for some form of practical support. The most frequently expressed need was for financial support. The need for financial coverage through work benefits, insurance, fundraisers or other organizations was often expressed. One participant, who was a student, wanted financial support to continue with school without having to worry about working to pay for medications and other illness-related services. Others described a need for financial support for gas, sperm banking and uninsured medication.

Transportation assistance was a common theme among 7 participants. Some participants stated that they used the transportation services available through the hospital, but wished that these services were more flexible to allow for last minute calls or more family members. Lastly, five participants (all of whom were female) reported a need for assistance to complete house chores. In one instance, a participant reported the need for help with cooking meals and personal care (e.g., drying hair, showering). For women living independently or with their families, house chores consumed a large proportion of their daily routine. It was seen as critical to obtain support to ensure that daily chores are completed, which in turn would re-introduce some degree of normalcy, thus allowing these women to focus on improving their health status.

3.5.7 Collaboration needs

Collaboration refers to any instance in which the participants reported a need for partnerships between different services and providers that are external to the hospital. A total of four participants reported a need for collaboration. Among them, two participants reported a need for collaboration between their school and the hospital. Participants reported that correspondence with the two services was difficult, and they would have preferred a liaison to facilitate communication between the school and the hospital.

Two participants, who were in university at the time of their diagnosis and treatment, requested further collaboration between universities and the Ontario Student Assistance Program (OSAP). In both instances, participants experienced difficulty with OSAP, asserting that OSAP continued with normal procedures even though the participants had dropped out of their courses. One participant felt that schools should inform OSAP of any interruptions to a student's education so that the student would be entitled to OSAP upon returning to school.

Lastly, in another instance, one participant requested collaboration between the pharmacy at their treatment center and a local pharmacy closer to home. This participant had difficulty retrieving prescription medication from a near-by pharmacy as a result of the lack of communication between pharmacies.

3.6 Qualitative vs. quantitative findings

Findings from the SLR and the qualitative study are compared below. Several consistencies and inconsistencies exist among the themes emerging from the two studies and are summarized in Table 3.

One of the most salient social needs identified in both studies was the need for support from family and/or friends,[62,67,73] and peers with cancer.[65,67,73] In both the SLR and the qualitative studies, most participants had a strong support system from family and friends, and participants felt that this support was useful in getting through their cancer experience. Participants from both studies also reported that they would have liked more support from peers with cancer. Those who were lucky enough to have such support reported that talking to someone going through the same experience was beneficial.

The need to get back to school or keep up with school and work were also consistent themes among findings from both the SLR and the qualitative study. In both studies, some participants reported needing more support so that they could continue with school, while others reported the need for assistance in getting back to work. Some participants also reported that helping them find suitable jobs, based on their capabilities, would be beneficial.

Information-sharing and communication was also among the most common categories in both studies. A total of six sub-categories of needs were identified, of which four (cancer treatment and diagnosis, mode of information, seeking information, talking about cancer) were identified in both the SLR and the qualitative study. One additional information need, asking questions, was identified in the qualitative study. Providing information on cancer treatment and diagnosis, that is detailed and easy to understand, was frequently reported by the majority of AYA individuals. Information on sexual function[63-65,69-71,73] and side effects[62,69-72] seemed to be most frequently reported by participants who were identified in studies from the SLR, while information on treatment process, diagnosis and side effects were most relevant to participants from the qualitative study. Consistently, various modes for delivery of information was requested to be available upon the patient's request. The SLR revealed that most participants preferred information in electronic form.[63,65,69,70] However, the qualitative findings reveal that written information was more commonly requested, followed by information from peers with cancer, online information and verbal communication.

All service provision sub-categories were consistent among findings from both the SLR and the qualitative study. The availability of a multidisciplinary team was vital to some participants in both studies. Accessibility to a diverse healthcare team, such as those found in pediatric centers, was important to some AYAs. Some suggestions of potential team members from the SLR include access to a personal trainer,[65] social worker,[63] adoption services,[69,70] child care,[69,70] complementary/alternative health services,[69,70] and infertility treatment services.[69,70,73] Participants from the qualitative study also requested a social worker, along with multiple physicians, physiotherapists and rehabilitation services. Consistent client (AYA) centered care needs identified in both studies were the need for friendly staff who are knowledgeable and qualified, and who participants felt can be trusted. Important client (AYA) centered care themes that were identified only in the qualitative study include having staff members who are attentive, who take more time to care for their patients, and treat their patients in accordance with their age.

Needs to incorporate support services were prominent psychological/emotional needs emerging from the SLR and qualitative study respectively. A common theme emerging from the SLR and the qualitative study was the need for counseling support,[62-65,67,69-72,73] while in the qualitative study, spiritual support was also frequently reported. Participants in four studies[63,64,69,70] from the SLR reported the need for counseling and guidance to deal with fears of recurrence,[64] leaving the acute health system,[64] or issues of sexuality and intimacy,[69,70] while participants from the qualitative study report the importance of having support from a spiritual leader in order to find meaning in, and gain acceptance of their cancer experience.

Two consistent themes emerged under the physical and daily living needs category between the SLR and qualitative study. These include health maintenance and practical needs. In the qualitative study, an additional theme, symptom management, was also reported. Commonly reported sub-themes of needs that relate to remaining active, eating healthy or promoting relaxation were also reported.[65] In addition, the incorporation of more sources for financial support[73] or convenient transportation services[69,70] was identified in both studies.

Though facility needs were less commonly reported among studies in the SLR, some overlapping sub-themes emerged between the SLR and qualitative study. Participants from both studies reported the need for an AYA ward in which they could be cared for among individuals who are similar in age.[63,66,72] This is consistent with the reported social need to have support from peers with cancer. Also, the theme for collaboration was identified only among participants from the qualitative study. Some participants felt that enhanced collaboration between services would be beneficial to patients and allow for smooth transitioning processes.

3.7 Chapter summary

This chapter outlined several noteworthy findings from the SLR and the qualitative study. Furthermore, a comparison of findings from both studies was also provided. Among the most commonly reported HSC needs for AYA survivors with cancer from both studies, were social wellbeing, information-sharing and communication and service provision. The qualitative study revealed prominent needs for improved health care facilities, while psychological/emotional needs were commonly reported in studies retrieved for the SLR. Findings from both studies will be further analyzed and compared to a documentary, the CNQ-YP and literature in the subsequent section.

CHAPTER 4

Discussion

This chapter offers a summary and synthesis of study results. Through a SLR and participant interviews, we have provided a comprehensive list of HSC needs for AYA survivors with cancer. Data from this study can be used to develop a focused program that aims to address these needs.

Following a discussion of the usefulness of the Supportive Care Needs Framework in understanding AYA HSC needs will be a discussion on pertinent findings from the SLR and the qualitative study, and a comprehensive comparison between study findings, a documentary and the CNQ-YP. This will be concluded with a discussion of novel needs from the qualitative study.

4.1 Utility of the Supportive Care Needs Framework

Fitch (1994) has developed a conceptual supportive care needs framework for cancer care; designed to conceptualize the various service delivery needs, which has been used to organize findings from the SLR and the qualitative study.[75] This framework was useful in designing the initial interview guide and coding framework for this study. This approach to the development of the codebook was appropriate because of the framework’s ability to capture a wide range of relevant needs at the different developmental stages of AYAs. However, certain categories of needs that emerged from this study, and appear to be relevant to AYAs, were not captured in Fitch’s framework. These categories include collaboration needs, facility needs, and service provision needs. Therefore, although Fitch’s framework provides a sound basis for evaluating HSC needs of AYAs; modifications to the framework may be necessary to better capture additional pertinent needs to this cohort.

4.2 Systematic literature review

The SLR has amalgamated evidence of HSC needs in survivors with cancer from 12 studies. Through this search, we have identified a range of needs categories that have been used in this study to examine findings.

The focus of the SLR was to identify published studies that used quantitative or qualitative approaches to investigate the HSC needs of AYAs from a patient's perspective. Through the search, we determined that no existing study had comprehensively evaluated the HSC needs of AYA survivors with cancer. However, the SLR did identify HSC needs that have been well-researched (e.g., information-sharing and communication needs, and psychological/emotional needs)[62-67,69-72,73] and those where more research is required (e.g., facility needs, physical and daily living needs).[63,65,66,69,70,72,73] Furthermore, several variables relating to HSC needs such as age, age at diagnosis and gender, were identified in the literature.[62,63,68-69,71]

Understanding the HSC needs of AYA survivors with cancer is critical to ensure quality of care delivery and optimal outcomes for these patients.[8] Given the limited number and narrow scope of publications identified through the search, we recognize that there may be a number of HSC needs that have yet to be captured or elaborated. In order to develop a comprehensive understanding of HSC needs of survivors with cancer, a qualitative study to provide a more in depth examination of needs, from the perspective of the patient, was also necessary.

4.3 Qualitative study

In this study, we examined patient perspectives of the HSC need of AYAs diagnosed with cancer. The most commonly reported needs were related to facility needs, social needs, service provision needs and information-sharing and communication needs. In line with previous studies, the results from this study indicate that AYA survivors with cancer experience several challenges throughout their cancer care trajectory and indicate several unmet needs. Improving the care provided to this cohort may be critical to alleviating the burdens of care and ensuring optimal patient outcomes.

One of the most negative experiences for AYAs who participated in the qualitative study was the poor physical structure of, and resource availability within, the health care facility. Participants felt that the journey they embark on after being diagnosed with cancer was derailed by the poor design and resource availability during their stay in the hospital. Most frequently, participants expressed that they would have enjoyed having additional entertainment, and an entertainment room that is geared towards AYAs.

Communication with friends during the hospital stay was also identified as essential for optimizing the social experience of AYAs. However, several participants expressed that this need had been unmet due to the limited, if not absent, access to Internet Wi-Fi during their hospital stay. Socializing with friends is critical to maintaining optimal quality of life for AYAs. Because present day communication involves access to friends through Internet sites such as Facebook and other social networking sites, restricting access to the Internet can lead to the patient feeling isolated, and may impose a substantive negative impact on their healthcare experience and social life.

Participants also expressed the need for an AYA ward where they would benefit from interactions with individuals their own age, gender or diagnosis. Confining AYAs to a particular area will likely improve their overall cancer experience and health outcomes as a result of feeling supported. This need was accompanied by an expressed need for improving the design and décor of the interior facility, reporting that they would have liked a more pleasant environment. Some suggestions included brighter colors, more windows or balconies and appropriate designs that appeal to AYAs. Evidently, altering the physical environment of the hospital, to better suit the needs of AYAs, may be a crucial first step in the development of an AYA program, as such changes may provide more positive outcomes for this cohort. Various studies in the literature also support the need for an AYA ward. In some studies, participants suggested that opportunities should be provided to AYAs so that they can establish relationships with peers, develop their identity and achieve optimal well-being.[10,76,77]

The cancer experience affects the social lives of AYAs. Maintaining relationships and having support from family and friends were reported to be instrumental to maintaining a favorable cancer experience. Some participants were burdened by diminished family dynamics (among extended family members) or loss of long-term friendships, which significantly impacted their QOL. This report from participants from the qualitative study on diminishing relationships, are consistent with various studies in which the inability of AYA cancer survivors to maintain normalcy in their social lives has been shown to significantly impacts social relationships.[78-80] Maintaining social relationships throughout the cancer experience appears to be critical to AYAs ability in dealing with the situation. It may be beneficial for the development of convenient and accessible programs that will aid in maintaining or improving dynamics between families and friends during such a difficult time. In addition, ensuring that patients are connected to other peers of the same age may be critical to boost the patient's confidence and ensure they are supported throughout their cancer trajectory. Current literature supports our findings on the need to maintain social relationships. An article by Zebrack (2011) identified that in order to achieve healthy development for AYAs, healthy peer relationships are necessary.[10] Other studies identify family support to be the most vital contributor to positive adjustment,[81] and family functioning as the best predictor of distress.[82]Others identify the roles of friends to be significant.[73,83]

Furthermore, participants from the qualitative study also indicated that they were distraught by their sudden loss of independence and the inability to participate in regular social roles (e.g., school, work, activities and going out with friends), which also impacted their ability to cope. Concurrent with these findings, Zebrack (2011) also identifies that AYAs commonly report feeling alienated because they are missing out on normal AYA experiences (e.g., dating, leaving home and establishing independence, going to college, pursuing gainful employment, getting married, or having children).[10,84]

Communication between services was identified as an important theme for AYAs. Enhancing collaboration between services may minimize current limitations to patient care delivery by reducing patient-service correspondence and enhancing communication between services. As a result, the burden of a patient having to coordinate between activities, while focusing on improving their health may be significantly reduced. For example, communication to deal with various school issues was crucial to some participants. In one instance, the participant’s entitlement to their OSAP was compromised due to the lack off communication between the school and OSAP officials. Therefore, to ensure that individuals will be entitled to their OSAP after treatment completion, it is critical that schools be informed of the necessary procedures to accommodate their students needs and ensure that all parties are informed of interruptions in regular procedures.

Study participants also reported several information-sharing and communication needs. Participants from the study required more detailed information about the treatment processes and their diagnosis. In several instances, participants reportedly had the desire to know what is to be expected, in order to prepare for what is to come. This was consistent with some participants' need to seek information from external sources, such as the Internet or various organizations, and their need to discuss experiences with peers who have gone through and experienced cancer. According to study participants, most would prefer this information in the form of written documents that are tailored to their own experiences. Furthermore, participants who received verbal information expressed that they would prefer this to be delivered in a more caring manner, and in a way they and their families could understand.

Concurrent with findings by Zebrack (2011) participants from the qualitative study also struggled with the issue of if, when, and how to share information about cancer with their friends, peers and partner.[10] Also, one participant from the qualitative study was concerned with when, how, and how much they should tell their partner about their cancer history, and feared how their partner would react.[10]

AYAs also needed the opportunity to participate in discussions and decision-making for their illness, and in several instances, participants expressed that time alone with health care providers to discuss sensitive matters (e.g., sexual health), would be helpful. Only one participant expressed that they would rather the information about their illness be directed to their parents, thus consistent with the importance of maintaining and supporting the participant's independence and sense of control over their health. Furthermore, participants indicated that they would have liked more control over who found out about their cancer and preferred to be the ones to share their diagnosis and experiences with family and friends.

Suggestions to improve client (AYA) centeredness were commonly expressed by participants. Issues that appear to be vital in improving the quality of care delivery for this cohort include having friendly encounters with staff, access to knowledgeable and qualified staff, and staff to take their time with participants and whom they feel that they can trust. Substantial wait times for appointments, treatment, and scans imposed significant burden to the AYAs experience. Thus, reducing wait times for appointments is important to this cohort. This need is consistent with the expressed needs to coordinate multiple appointments within one day, and coordination and communication between doctors and services. Poor health care provider communication may be detrimental to the progress of these patients and burden treatment adherence and contribution to long-term follow up care.

Planning interventions to address the various AYA needs may be critical to improve outcomes for these patients. One such intervention is currently underway in the U.S. and is known as the Cancer Treatment Summaries and Survivorship Care Plans. This plan is being developed to improve coordination of care in the survivorship phase.[85,86,87] However, this initiative is still young, and more evidence is needed to understand its impact. A study such as the Cancer Treatment Summaries and Survivorship Care Plans may be necessary in Canada to address the specific needs of the Canadian AYA cohort.

4.4 Comparison of qualitative and quantitative findings to the Cancer Needs Questionnaire for Young People (CNQ-YP) and the documentary *"Wrong way to hope"*

Findings from the qualitative study and SLR were compared with results from the Cancer Needs Questionnaire for Young People (CNQ-YP)[74] and a recent documentary entitled *"Wrong way to hope."*[88] Results identified by the CNQ-YP and documentary were instrumental in advancing AYA research. Given the depth of the interviews conducted in the qualitative study, a critical step was to compare findings of the SLR and the qualitative study to the CNQ-YP and the documentary in order to identify any novelties in the findings of the present study. After I coded the CNQ-YP and the documentary according to the coding framework developed for the SLR and qualitative study, similarities and differences between each study and the documentary were easily identified, and relationships were deduced. The results of these comparisons are summarized below and in Appendix N.

The CNQ-YP is a psychometrically evaluated measure developed to capture the needs of AYA cancer survivors in Australia. This scale consists of 70 items and measures six variables: treatment environment and care, feelings and relationships, daily life, information and activities, education, and work.[74] Though a small sample size was used to validate the questionnaire, the CNQ-YP has indicated strong factor structure for the six variables measured, and indicated strong internal consistency and test-retest reliability.[74]

"Wrong way to hope" is a Canadian documentary produced and acted in by Mike Lang, a cancer survivor.[88] The goal of this documentary (2010) was for a group of eight AYA cancer survivors to embark on a journey to share their cancer experiences and insights.[88] Participants were aged 23

to 36 years (age at diagnosis between 16 and 32 years old), three females and five males, who were diagnosed with several different types of cancers (cervical cancer, rhabdomyosarcoma and osteosarcoma combined, Hodgkin lymphoma, esophageal cancer, endodermal sinus tumor, brain tumor and acute lymphoblastic leukemia).[88] Through this documentary, issues such as fears, uncertainties, and emotional and physical challenges were addressed from the perspectives of eight survivors.[88]

Comparison of findings from the CNQ-YP and the documentary to the Supportive Care Needs Framework reveals limited correlations after coding the CNQ-YP and the documentary using the coding framework developed for this study. When comparing the CNQ-YP to the Supportive Care Needs Framework, only four of the main themes emerged from the CNQ-YP. These include information needs, physical needs, psychological/emotional needs and social needs. When evaluating the findings from the documentary, only psychological/emotional needs and social needs were consistent between the documentary and the Supportive Care Needs Framework. This is important to note because findings from our studies were consistent with the Supportive Care Needs Framework but also revealed additional categories that may require a revision of the Supportive Care Needs Framework or the development of a new AYA framework.

When comparing findings from the qualitative interviews to the CNQ-YP and the documentary, the CNQ-YP revealed consistent themes pertaining to facility needs, information sharing and communication needs, physical and daily living needs, psychological/emotional needs, service provision needs and social needs. The documentary revealed three consistent themes and includes psychological/emotional needs, service provision needs and social needs.

Consistent with results from the qualitative study and the SLR, items in the CNQ-YP and participants from the documentary expressed the desire to maintain autonomy throughout the cancer experience. Furthermore, psychological/emotional support to deal with fears and uncertainties was found to be critical to this cohort. Coordination of care, such as improving patient transition experiences (e.g., from being healthy to having cancer), social support, and the need to go out with friends, were consistent themes across all studies and the documentary. One participant from the documentary stated: *"the transition I think is too abrupt."*

Consistency in various types of needs was also identified among the qualitative study, the SLR and the CNQ-YP, particularly relating to facility needs. These include the need for various types of entertainment and an entertainment room within the hospital that has activities appropriate for AYAs. Improving the quality of the food was also a consistent sub-theme across the qualitative study, the SLR and the CNQ-YP.

Information-sharing and communication themes also overlapped among the qualitative study, the SLR and the CNQ-YP. Participants revealed that it would be beneficial to receive information on their cancer treatment and diagnosis. Often expressed needs were for information on their cancer and treatment side effects. In addition, the need for information in online, verbal, or written form was also pertinent but varied across participants. Other suggestions from participants from the qualitative study include the delivery of information from health care providers in a way that can be understood by the patient and their families, and to be spoken to honestly. In some instances, seeking information from outside sources appeared to be a salient factor among study participants, along with encouraging patient education, involvement in discussion and decision-making and time alone with doctors to discuss sensitive matters. Furthermore, participants from these studies felt it was important to have the opportunity to talk about their cancer to family and friends. Other variables that were consistent among these studies, and appear to be relevant to this cohort include financial support, transportation assistance, strategies to deal with feelings of self-consciousness issues, encountering friendly and supportive staff, client safety, a multidisciplinary team, improved wait times and the ability to participate in social roles.

The need for spiritual support and encountering staff members who the participants felt they could trust or relate to were consistent with findings from the qualitative study, the CNQ-YP and the documentary, and the SLR and documentary respectively. In concurrence with the theme for spiritual support, one participant from the documentary stated:

> I *don't think I ever could have found out who I really was apart from my relationship with God. That's been one thing that stayed constant throughout my entire life, but especially my cancer experience, was that I knew that I had a God who loved me, who wanted the best for me and no matter what happened to me, that would never change.*

4.5 Novel needs from the qualitative study

Several novel needs were identified through the qualitative study that were not identified in the SLR, CNQ-YP or the documentary (Appendix N). No other studies had investigated or identified the need for collaboration between services, i.e., between the hospital and school. In addition, facility needs such as private hospital rooms, bathroom facilities, outdoor areas, and a patient kitchen were not identified in other studies but were mentioned by seven of the participants in the qualitative study. They also provided concrete suggestions for improving the design and décor of the physical facility. Lastly, some studies previously reported the need for better quality food; however,[63,72] other needs such as accessibility of food services, and providing a variety of food options, were not previously reported. Participants prefer a variety of food options or accessible cafés or vending machines with food to purchase.

Various information-sharing and communication needs were also novel. Participants reported the need to be able to ask questions or be provided the opportunity to ask questions to health care providers, and for their questions to be addressed. In some instances, participants noted that their questions were never answered or were ignored by health care professionals. Also, participants felt that health care providers were insensitive to their situation and preferred that information be delivered in a caring and consistent manner.

Physical and daily living needs that were novel among the qualitative study cohort include the need for legal advice, home care, and strategies to manage symptoms. One participant from the study wanted to seek out legal advice from professionals to ascertain the likelihood of cancer stemming from their line of work. This was the only participant to mention such a need; however, it is important to ensure that participants are aware that such services are available. Also, novel strategies to manage symptoms that were specific to this cohort include the use of marijuana. This is crucial because previous findings suggest that drug use is more likely during AYA,[11] therefore, offering clean medicinal marijuana through pharmacies may benefit these patients and reduce the use of street drugs that are potentially potent and harmful.

Lastly, some service provision needs have been identified from the qualitative study but have not been previously reported in the SLR, CNQ-YP or documentary. One service provision need was having health care providers who take their time and pay more attention to patient needs. In addition, participants from the study also deemed the need for improved methods for appointment bookings as relevant. Therefore, it is critical that findings from the qualitative study be amalgamated with other study findings in order to improve the quality of care delivered to AYA survivors with cancer and improve outcomes. Furthermore, findings from the study may be used to improve the CNQ-YP, thus ensuring a comprehensive tool is available to evaluate the needs of this cohort in the future.

4.6 Chapter summary

This chapter has outlined pertinent needs identified in the qualitative study, SLR, CNQ-YP and documentary and deduced several important relationships. AYA survivors with cancer expressed fundamental needs that must be addressed in order to ensure optimal service delivery and outcomes for these patients. The final chapter of this thesis will outline important strengths, limitations, and implications of this study and provide various recommendations, future research plans and, plans for dissemination.

CHAPTER 5

Strengths, Limitations, Implications, Recommendations, Future Research, Plans for Dissemination and Conclusion

In this chapter, we summarize the various strengths and limitations of this mixed-methods study. Furthermore, we summarize some of the key implications of the study results, plans for future research and plans for dissemination. Lastly, we provide a conclusion of study findings.

5.1 Strengths and limitations of the study

To the best of our knowledge, the present study is the first mixed methods study conducted to generate a comprehensive understanding of the HSC care needs for AYA survivors with cancer in Canada and the world. Study findings document concrete needs, rather than hypothetical needs, expressed by patients' themselves through qualitative interviewing. They represent the views of AYA survivors with cancer treated at a regional pediatric and adult cancer center. Given the overlap between the findings and literature, the study findings may be transferrable beyond the study population.

A significant strength was the use of a CNMM design in which qualitative methods were dominant. This mixed methods design is a useful framework to add strength and rigor to the complex issues facing AYA survivors with cancer.[42] The quantitative study provides a descriptive approach to understanding the HSC needs of AYA survivors with cancer presently known through literature. Numerous methodological initiatives were implemented to ensure rigor in the qualitative study findings such as ensuring that the research question matched the methods; that methods matched the data and analytic procedures; the recruitment of an appropriate sample; collecting and analyzing data concurrently, and reconfirming data in subsequent interviews are essential. Furthermore, employing criteria outlined by Lincoln and Guba (1991) (dependability, credibility, confirmability and transferability) further enabled us to establish methodological rigor.[57] Findings from the qualitative study provided insights into the current state of the problem from the perspectives of survivors.

The Supportive Care Needs Framework was useful for developing the research questions, focusing the analysis and interpreting results. The needs described by Fitch (2008) in this framework were used to guide the development of the initial codebook and interview guide. Furthermore, definitions of needs, as reported by Fitch, were useful guides when extracting the needs reported by study participants in the qualitative interviews.

A possible limitation to the study, when using a qualitative approach, is that my preconceived notions or experiences may influence data collection and analysis. In order to address this limitation, bracketing was employed to become aware of any of my preconceived notions or influences from my prior experiences working with cancer patients, so that they do not interfere with data analysis. Furthermore, credibility was addressed through the use of data saturation, data triangulation, and peer review.[55] One researcher reviewed coding and the primary investigator validated the content analysis and critically reviewed findings.[42,54] In an attempt to waive this limitation, a study co-investigator who was distanced from the data and thus had no predispositions when reviewing the data, verified analysis. A high level of consistency in coding was achieved between the second reviewer and myself. Any discrepancies were discussed in person until consensus was reached. The sample size was small but appropriate for the qualitative method, and data saturation was achieved. Similar strategies were used to ensure credibility of coding used for extraction of needs from the documentary and the CNQ-YP.

5.2 Implications of study findings and recommendations

Current models of cancer care delivery for AYA patients are fragmented due to their failure to assimilate HSC services. According to Fitch (2008) supportive care must correspond with an individual's unique needs in order to be effective. Study results indicate that current models of cancer care delivery for AYAs are lacking in their ability to meet pertinent AYA needs such as collaboration needs, facility needs, information sharing and communication needs, physical and daily living needs, psychological/emotional needs, service provision needs and social needs.

In order to successfully meet patient needs, the development of a program focused on addressing the needs of individuals, communities, or cultures, is essential. Results from this study may be used to inform the development of such a program and improve healthcare services to better meet the HSC needs of this cohort. The study findings suggest the need for better assessment and management of HSC needs for AYA survivors with cancer. Knowledge gained from this study may guide healthcare providers on how to provide more responsive, emotionally sensitive, and client-oriented care for this patient population.

Study findings reveal the need for improved communication between the patient and healthcare provider. Enabling communication between the two parties will allow the patient more flexibility in expressing concerns, and provide resources for health care professionals to enhance the outcomes of patients.

The need for better assessment and management of HSC needs of AYA survivors with cancer was also identified in this study. Knowledge gained from this study may help physicians, nurses and other healthcare providers to provide more responsive, emotionally sensitive, and client-oriented care for this vulnerable population. Initiating a conversation with patients about the impact and meaning of being diagnosed with cancer may provide a better understanding of the patient's health needs.[33]

Findings from this study may also provide pertinent information to be considered by health care decision makers and planners, may be a useful tool in planning the development of a new AYA program.

5.3 Future research

This mixed methods study is a comprehensive needs assessment that identifies the HSC needs of AYA survivors with cancer. The quantitative methodologies were used to gain a broader understanding of patient needs, yet did not allow us to infer why, or how, current health care services are failing to address AYA patient and survivor needs. This is because several studies identified in the systematic literature review used quantitative methods to identify AYA needs, had a small sample size, or focused their study on measuring one or few AYA needs categories. The qualitative interviews complemented the quantitative analysis to alleviate any methodological or study limitations, and led us towards a more comprehensive needs assessment. The qualitative study provided data from a large sample of patients and investigated several HSC needs of AYAs. The present study will assist in developing strategies to address these needs and fill gaps in the current cancer care system. To our understanding, a similar study that was conducted in Toronto Ontario is currently awaiting publication. It will be interesting to see whether differences exist among patients treated at a neighboring city.

Given the large amount of additional data revealed from this study, when compared to the CNQ-YP, it may be necessary to expand the qualitative study and use the data collected to either develop a new measure that better addresses the needs of AYAs from the Canadian perspective or to revise the CNQ-YP to better address these needs.

Furthermore, future qualitative research from the family's perspective may be necessary to further identify the HSC needs, which younger participants may not have elaborated, such as financial burdens or emotional impacts on families. In addition, research from the perspective of the health care providers will be critical to understand the strengths and limitations they face in addressing the HSC needs of this cohort and the limitations placed by the current health care systems. This will ensure that the restraints and needs of all parties involved will be addressed in the development of an AYA program.

Future comparisons of the patients', families' and health care providers' needs to ensure optimal care delivery and health outcomes of survivors will be critical to developing a suitable health care setting in which all parties' needs are accurately being met.

5.4 Plan for dissemination of results

Study results will be shared at national and international conferences. In particular, the study has been accepted for a poster presentation at the McMaster Child Health Research Trainee Day in Hamilton, Ontario in June 2012 and the 44th Congress of the International Society of Pediatric Oncology, in London, UK, in October 2012. In addition, study findings will be presented to various stakeholder groups such as the Canadian Partnership Against Cancer's

Task Force on Adolescents and Young Adults with Cancer. Abstracts for oral and/or poster presentations at other conferences will be submitted. Various manuscripts will be prepared for publication in peer-reviewed journals.

5.5 Conclusion

This study has identified a comprehensive set of HSC needs of AYA survivors with cancer. AYA survivors with cancer expressed fundamental needs that must be addressed in order to ensure optimal outcomes. The most common needs were related to facility needs, social needs, information-sharing communication needs and service provision needs. Study results will be used to inform the planning process to develop a new healthcare program for AYA patients in Hamilton Health Sciences (HHS).

REFERENCES

1. Canadian Cancer Society. Canadian cancer statistics special topic: cancer in adolescents and young adults. Toronto, Ontario, Canada: Canadian Cancer Society, 2009

2. Ramphal R, D'Agostino N, Klassen A, McLeod M, De Pauw S, Gupta A. Practices and resources devoted to the care of adolescents and young adults with cancer in Canada: a survey of pediatric and adult cancer treatment centers. Journal of Adolescent and Young Adult Oncology, 1(3); 140-144, 2012

3. Da P, Ellison LF, Barr RD, Semenciw R, Marrett LD, Weir HK, Dryer D, Grunfeld E. Canadian adolescents and young adults with cancer: opportunity to improve coordination and level of care Canadian Medical Association Journal, 183(3); e187-e194, 2011

4. Bleyer A, Barr R, Hayes-Lattin B, Thomas D, Ellis C, Anderson B. The distinctive biology of cancer in adolescents and young adults. Nature Review, 8(4); 288-298, 2008

5. Soliman H, Agresta SV. Current issues in adolescent and young adult cancer survivorship. Cancer Control Journal, 15(1); 55-62, 2008

6. Fernandez CV, Barr RD. Adolescents and young adults with cancer: an orphaned population. Pediatrics and Child Health, 11(2); 103-106, 2006

7. Albritton KH, Bleyerb WA. The management of cancer in the older adolescent. European Journal of Cancer, 39(18); 2584–2599, 2003

8. Fernandez C, Fraser GAM, Freeman C, Grunfeld E, Gupta A, Mery LS, De Pauw S, Schacter B. Principles and recommendations for the provision of healthcare in Canada to adolescent and young adult–aged cancer patients and survivors. Journal of Adolescent and Young Adult Oncology, 1(1); 53-59, 2011

9. Eiser C, Kuperberg A. Psychological support for adolescents and young adults. (pp. 365-374) In: Bleyer WA, Barr RD (Eds). Cancer in adolescents and young adults. New York: Springer, 2007

10. Zebrack BJ. Psychological, social, and behavioral issues for young adults with cancer. Cancer, 117(10 suppl.); 2289–2294, 2011

11. Morgan S, Davies S, Palmer S, Plaster M. Sex, drugs, and rock 'n' roll: caring for adolescents and young adults with cancer. Journal of Clinical Oncology, 32(32); 4825-4830, 2010

12. Decker CL. Social support and adolescent cancer survivors: A review of the literature. Psycho-Oncology, 16(1); 1–11, 2007

13. Alston RD, Rowan S, Eden TO, Moran A, Birch JM. Cancer incidence patterns by region and socioeconomic deprivation in teenagers and young adults in England. British Journal of Cancer 96(11); 1760–1766, 2007

14. Pollock BH, Birch JM. Registration and classification of adolescent and young adult cancer cases. Pediatric Blood and Cancer, 50(5 suppl.); 1090–1093, 2008

15. Bleyer A, O'Leary M, Barr R, Ries LAG (eds): Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975-2000. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD, 2006

16. Barr R. Adolescents, young adults, and cancer: the international challenge. Cancer, 117(10 suppl.); 2245–2249, 2011

17. National Cancer Institute. Closing the gap: research and care imperatives for adolescent and young adults with cancer. Report of the Adolescent and Young Adult Oncology Progress Review Group. NIH Pub. No. 06-6067. Bethesda, MD: National Cancer Institute, 2006

18. Gatta G, Capocaccia R, De Angelis R, Stiller C, Coebergh JW. Cancer survival in European adolescents and young adults. European Journal of Cancer, 39(18); 2600-2610, 2003

19. National Institute for Health and Clinical Excellence. Guidance on cancer services: improving outcomes in children and young people with cancer. National Collaborating Centre for Cancer, 2005

20. National Collaborating Centre for Cancer. Guidance on cancer services, improving outcomes in children and young people with cancer. London, UK: National Institute for Health and Clinical Excellance, 2005

21. Albritton KH, Eden T. Access to care. Pediatric Blood and Cancer, 50(5 suppl.); 1094–1098, 2008

22. Klein-Geltink J, Shaw AK, Morrison HI, Barr RD, Greenberg ML. Use of paediatric versus adult oncology treatment centres by adolescents 15–19 yeas old: The Canadian Childhood Cancer Surveillance and Control Program. European Journal of Cancer, 41(3); 404–410, 2005

23. Klein-Geltink J, Pogany L, Mery LS, Barr RD, Greenberg ML. Impact of age and diagnosis on waiting times between important healthcare events among children 0–19 years cared for in pediatric units: The Canadian Childhood Cancer Surveillance and Control Program. Journal of Pediatric Hematology Oncology, 28(7); 433–439, 2006

24. Paulussen M, Ahrens S, Juergens HF. Cure rates in Ewing tumor patients aged over 15 years are better in pediatric oncology units. Results of GPOH CESS/EICESS studies. Proceedings for the American Society of Clinical Oncology, 22: abstract 3279, 2003

25. Ferrari A, Gronchi A, Casanova M, Meazza C, Gandola L, Collini P, Lozza L, Bertulli R, Olmi P, Casali PG. Synovial sarcoma: a retrospective analysis of 271 patients of all ages treated at a single institution. Cancer, 101(3); 627–634, 2004

26. Ferrari A, Gronchi A, Casanova M, Meazza C, Gandola L, Collini P, Lozza L, Bertulli R, Olmi P, Casali PG. Rhabdomyosarcoma in adults. A retrospective analysis of 171 patients treated at a single institution. Cancer, 98(3); 571–580, 2003

27. Canadian Partnership Against Cancer Corporation. Adolescents and young adults with cancer. Available from: http://www.cancerview.ca/cv/portal/Home/TreatmentAndSupport/TSProfessionals/Adolescents_Young_Adults/AYAcancer_ca?_afrLoop=874103186963000&_afrWindowMode=0&_adf.ctrl-state=y01mud8tc_75, 2012

28. Schmidt, C. Lack of progress in teen and young adult cancers concerns researchers, prompts study. Journal of National Cancer Institute, 98(24); 1760–1761, 2006

29. Bleyer, A. Young adult oncology: The patients and their survival challenges. Cancer Journal for Clinicians, 57(4); 242–255, 2007

30. Ferrari A, Thomas D, Franklin ARK, Hayes-Lattin BM, Mascarin M, van der Graaf W, Albritton AH. Starting an adolescent and young adult program: some success stories and some obstacles to overcome. Journal of Clinical Oncology, 28(32); 4850-4857, 2010

31. Mullan F. Seasons of survival: reflections of a physician with cancer. New England Journal of Medicine. 1985; 313(4); 270–273, 1985

32. Fitch, M. I. Supportive care for cancer patients. Hospital Quarterly, 3(4); 39-46, 2000

33. Fitch, M. I. Supportive care framework. Canadian Oncology Nursing Journal, 18(1); 6-14, 2008

34. Foot, G. Needs assessment in tertiary and secondary oncology practice: a conceptual and methodological exposition [Ph.D. dissertation]. Newcastle: University of Newcastle, 1996

35. Kaufman R, English FW. Needs assessment: concept and applications. Englewood Cliffs, N.J.: Educational Technology Publications, 1979

36. Warheit G, Bell R, Schab J. Needs assessment approaches: concepts and methods. DHEW Publication No. ADM 77-472. Washington, DC: U.S., 1977

37. Windsor RA, Baranowski T, Clark G, Cutter G. Evaluation of health promotion and education programs. Palo Alto, CA: Mayfield, 1984

38. Fishman D, Neigher W. Needs assessment: an overview. In G. Landsberg, W. Neigher, R. Hammer, C. Windle, & J. Woy (ed.) Evaluation in practice. Washington, DC: U.S., 1979

39. Siegel LM, Attkisson CC, Carson LG. Need identification and program planning in the community context. In C.C. Attkisson, W.A. Hargreaves, M.J. Horowitz, & J.E. Sorenson (ed.), Evaluation of human services programs. New York: Academic Press, 1978

40. Macnee, C.L. To what types of patients do theses research conclusions apply. Who was in the study? In understanding nursing research: reading and using research in practice (pp. 101-105). Philadelphia, Lippincott Williams & Wilkins Publishers, 2004

41. Creswell, J. W. & Piano Clark, V. L. Designing and conducting mixed methods research. Thousand Oaks, CA: Sage Publications, Inc., 2007

42. Sandelowski, M. Whatever happened to qualitative description? Research in Nursing and Health, 25(4); 334-340, 2000

43. Miller, W. L., & Crabtree, B. F. Primary care research: a multimethod typology and qualitative road map. In B. F. Crabtree & W. L. Miller. Doing qualitative research (pp.3-28). Newbury Park, CA: Sage Publishing, 1992

44. Wolcott, H.F. Transforming qualitative data: description, analysis, and interpretation. Thousand Oaks, CA: Sage, 1994

45. Critical Appraisal Skills Program (CASP). 10 questions to help you make sense of qualitative research. Public Health Resource Unit, England, 2006

46. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP; STROBE initiative. The strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. Annals of Internal Medicine, 147(8); 573-577, 2007

47. Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description – the poor cousin of health research? Medical Research Methodology, 9; 52, 2009

48. Daly J, Willis K, Small R, Green J, Welch N, Kealy M, Hughes E. A hierarchy of evidence for assessment qualitative health research. Journal of Clinical Epidemiology, 60; 43-49, 2007

49. Kuzel A. Sampling in qualitative inquiry. In B. F. Crabtree & W. L. Miller (Eds.). Doing qualitative research. (2nd ed.). (pp. 33-45). Thousand Oaks, CA: Sage, 1999

50. Creswell J. W. Qualitative inquiry and research design: choosing among five traditions. Thousand Oaks, CA: Sage Publications, Inc., 2007

51 Sandelowski M. Sample size in qualitative research. Research in Nursing & Health, 18(2); 179-183, 1995

52. Miles M., & Huberman, A. Qualitative data analysis: an expanded source book. (2nd ed.) Thousand Oaks, CA: Sage Publishers, 1994

53. Bazeley P. Qualitative data analysis with NVivo. Thousand Oaks, CA: Sage, 2007

54. Sandelowski M. Rigor or rigor mortis: the problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2); 141-144, 1993

55. Creswell, J.W. Research design: Qualitative, quantitative and mixed methods approaches. Thousand Oaks, CA: Sage Publications, Inc., 2003

56. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. International Journal Qualitative Methods, 1(2); 1-19, 2002

57. Lincoln Y S, Guba E. Naturalistic inquiry. Beverly Hills: Sage, 1985

58. Sandelowski M. The problem of rigor in qualitative research. Advances in Nursing Science, 8(3); 27-37, 1986

59. Richards L. Handling qualitative data: a practical guide. Thousand Oaks, CA: Sage, 2005

60. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Education Today, 24(2); 105-112, 2004

61. Giorgi A. Description versus interpretation: competing alternative strategies for qualitative research. Journal of Phenomenological Psychology, 23(2); 119-135, 1992

62. David CL, Williamson K, Tilsley DW. A small scale, qualitative focus group to investigate the psychosocial support needs of teenage young adult cancer patients undergoing radiotherapy in Wales. European Journal of Oncology Nursing, 16(4); 375-9, 2012

63. Palmer S, Mitchell A, Thompson K, Sexton M. Unmet needs among adolescent cancer patients: a pilot study. Palliative and Supportive Care, 5(2); 27–134, 2007

64. Thompson K, Palmer S, Dyson G. Adolescents & young adults: issues in transition from active therapy into follow-up care. European Journal of Oncology Nursing, 13(3); 207–212, 2009

65. Rabin C, Simpson N, Morrow K, Pinto B. Behavioral and psychosocial program needs of young adult cancer survivors. Qualitative Health Research, 21(6); 796–806, 2011

66. Wilkinson J. Young people with cancer – how should their care be organized? European Journal of Cancer Care, 12(1); 65–70, 2003

67. Blumberg BD, Lewis MJ. Developing materials to meet the educational needs of adolescents with cancer. Oncology Nursing Forum, 10(1); 35-39, 1983

68. Zebrack B, Mills J, Weitzman TS. Health and supportive care needs of young adult cancer patients and survivors. Journal of Cancer Survivorship, 1(2); 137–145, 2007

69. Zebrack B. Information and service needs for young adult cancer patients. Supportive Care in Cancer, 16(12); 1353–1360, 2008

70. Zebrack B. Information and service needs for young adult cancer survivors. Supportive Care in Cancer, 17(4); 349–357, 2009

71. Decker C, Phillips, Haase JE. Information needs of adolescents with cancer. Journal of Pediatric Oncology Nursing, 21(6); 327-334, 2004

72. Millar B, Patterson P, Desille N. Emerging adulthood and cancer: how unmet needs vary with time-since-treatment. Palliative and Supportive Care, 8(2); 151–158, 2010

73. Zebrack B, Bleyer A, Albritton K, Medearis S, Tang J. Assessing the health care needs of adolescent and young adult cancer patients and survivors. Cancer, 107(12); 2915-2923, 2006

74. Clinton-McHarg T, Carey M, Sanson-Fisher R, D'Este C, Shakeshaft A. Preliminary development and psychometric evaluation of an unmet needs measure for adolescents and young adults with cancer: the Cancer Needs Questionnaire - Young People (CNQ-YP). Health and Quality of Life Outcomes. 30(10); 1-11, 2012

75. Fitch, MI. Providing supportive care for individuals living with cancer (Task Force Report). Toronto: Ontario Cancer Treatment Research Foundation, 1994

76. Elad P, Yagil Y, Cohen LH, Meller I. A jeep trip with young adult cancer survivors: lessons to be learned. Supportive Care in Cancer. 11(4); 201-206, 2003

77. Canada AL, Schover LR, Li Y. A pilot intervention to enhance psychosexual development in adolescents and young adults with cancer. Pediatric Blood and Cancer, 49(6); 824-828, 2007

78. Ishibashi A. The need of children and adolescents with cancer for information and social support. Cancer Nursing, 24(1); 61–67, 2001

79. Felder-Puig R, Peters C, Matthes-Martin S, et al. Psychosocial adjustment of pediatric patients after allogeneic stem cell transplantation. Bone Marrow Transplantation, 24(1); 75–80, 1999

80. Hinds P, Martin J. Hopefulness and the self-sustaining process in adolescents with cancer. Nursing Research 37(6); 336–340, 1988

81. Levin Newby W, Brown RT, Pawletko TM, Gold SH, Whitt JK. Social skills and psychological adjustment of child and adolescent cancer survivors. Psychooncology, 9(2); 113-126, 2000

82. Hill JM, Kornblith AB, Jones D, et al. A comparative study of the long term psychosocial functioning of childhood acute lymphoblastic leukemia survivors treated by intrathecal methotrexate with or without cranial radiation. Cancer, 82(1); 208-218, 1998

83. Zebrack B, Chesler M, Kaplan S. To foster healing among adolescents and young adults with cancer: what helps? what hurts? Supportive Care in Cancer, 18(1); 131-135, 2010

84. Zebrack B, Hamilton R, Wilder-Smith A. Psychosocial outcomes and service use among young adults with cancer. Seminars in Oncology 36(5); 468-477, 2009

85. Smith SL, Singh-Carlson S, Downie L, Payeur N, Wai ES. Survivors of breast cancer: patient perspectives on survivorship care planning. Journal of Cancer Survivors, 5(4); 337-44, 2011

86. Hahn EE, Ganz PA. Survivorship programs and care plans in practice: variations on a theme. Journal of Oncology Practice, 7(2); 70–5, 2011

87. Cancer Program Standards (CPS) 2011 Project. American College of Surgeons Cancer Programs. Available from: http://www.facs.org/cancer/coc/cps2011.html, 2012

88. Lang M. (Director). Wrong way to hope: an inspiring story of young adults and cancer. Canada: Hands.On.Films, 2010

Figure 1: Supportive Care Needs Framework (Adapted from Fitch 2008)

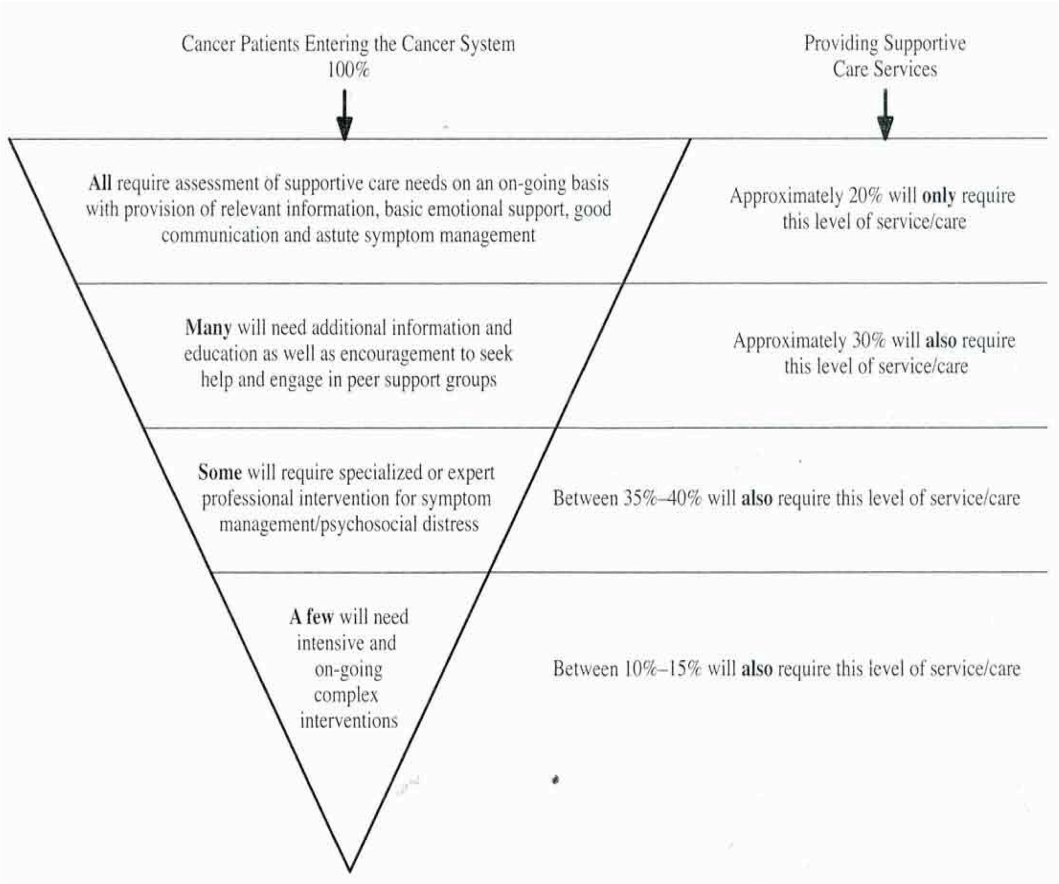

Figure 2: Supportive Care Needs Framework for patients with life-threatening illness (Adapted from Fitch 2008)

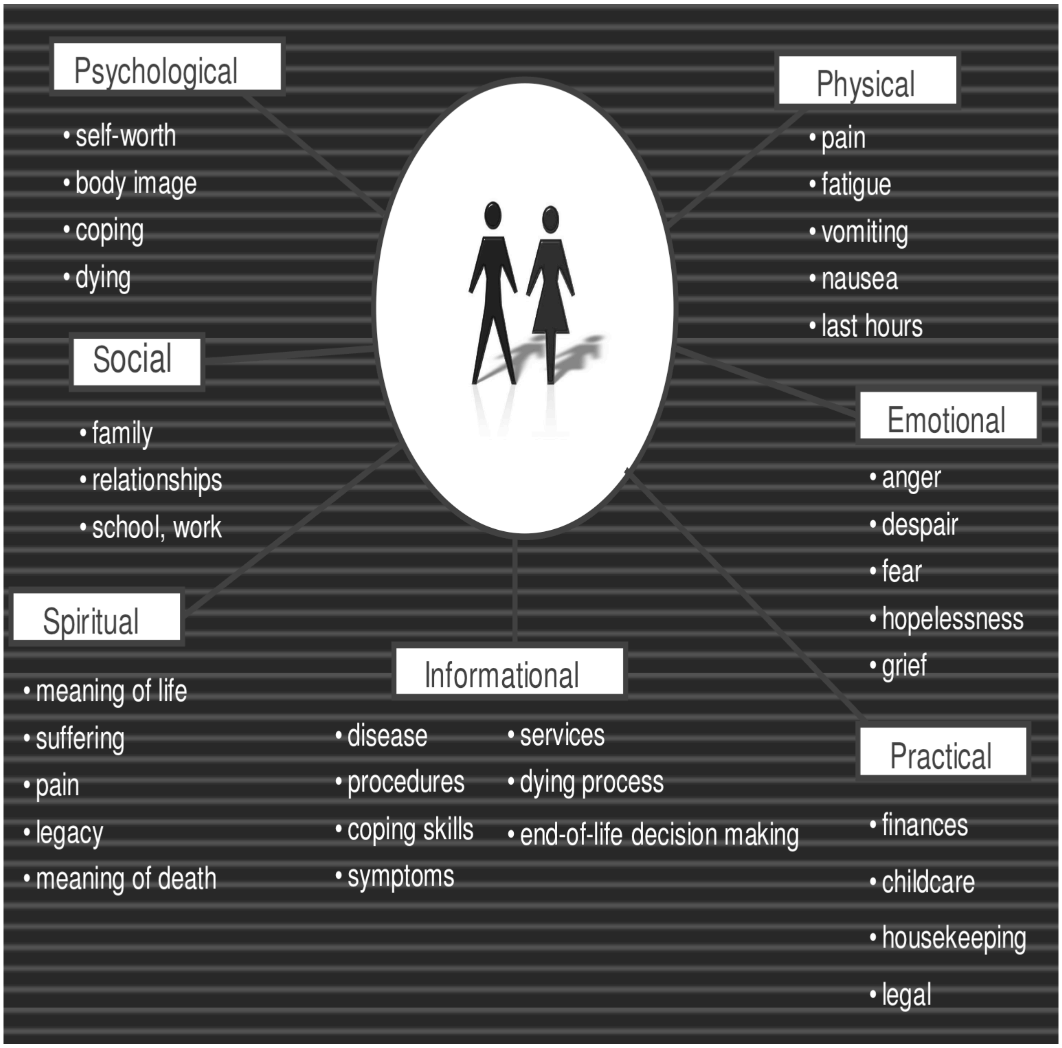

Figure 3: Exclusion process for the systematic literature review

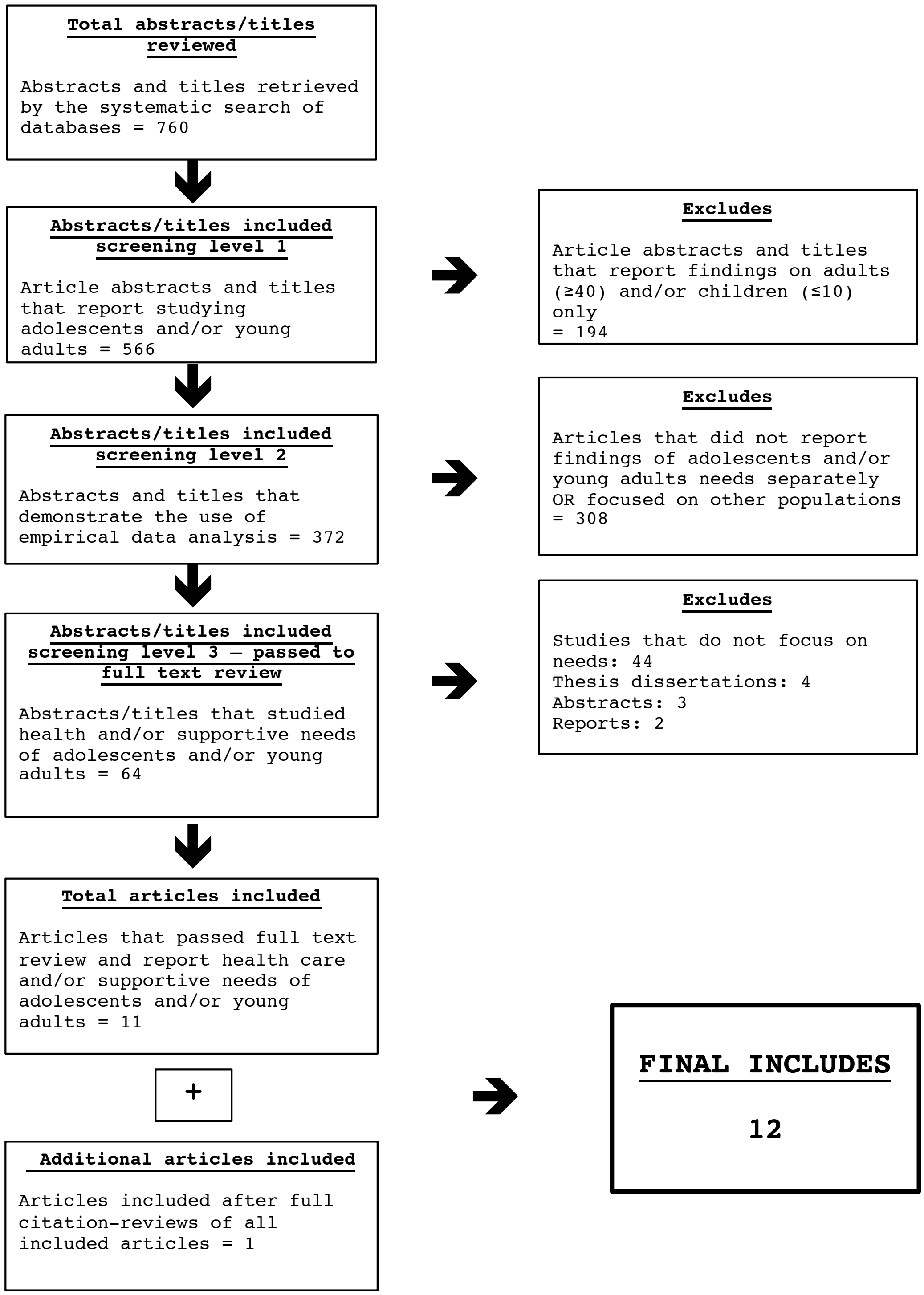

Table 1: Sampling matrix for qualitative interviews

a. Initially planned

Treatment phase				**Post-treatment follow-up**			
Current age: 15-18 years		**Current age: 19-25 years**		**Current age: 15-18 years**		**Current age: 19-25 years**	
Male	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
2	2	2	2	2	2	2	2

b. Final

Treatment phase				**Post-treatment follow-up**			
Current age: 15-18 years		**Current age: 19-25 years**		**Current age: 15-18 years**		**Current age: 19-25 years**	
Male	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
2	2	2	1	2	3	3	5

Table 2: Qualitative study participant demographics

Characteristic	**Number of participants**	**Percent (%)**
Current age		
- Adolescent (15-18)	9	45
- Young adult (19-25)	11	55
Age at diagnosis		
- Adolescent (15-18)	12	60
- Young adult (19-25)	8	40
Gender		
- Male	9	45
- Female	11	55
Treatment stage		
- On	7	35
- Off	13	65
Ethnicity		
- Caucasian	16	80
- Other	4	20
Type of treatment		
- Chemotherapy only	5	25
- Combination (chemotherapy, radiation and/or surgery)	15	75
Relapse		
- Yes	2	10
- No	18	90
Comorbidity		
- Yes	3	15
- No	17	85

Characteristic	Number of participants	Percent (%)
Diagnosis		
- Acute lymphoblastic leukemia	4	20
- Astrocytoma	1	5
- Bone cancer	2	10
- Brain tumor	1	5
- Burkitts lymphoma	1	5
- Colon cancer	1	5
- Ewings sarcoma	2	10
- Hodgkins lymphoma	4	20
- Non-Hodgkins lymphoma	1	5
- T-cell lymphoma	1	5
- Testicular cancer	1	5
- Thyroid cancer		
Patient education level (completed)		
- Less then high school	1	5
- High school	11	55
- College	1	5
- Bachelor	6	30
- Masters	1	5
Patient living status		
- Parents/caregiver	15	75
- Partner	4	20
- Friends	1	5
Patient working status		
- Yes	8	40
- No	12	60

Characteristic	Number of participants	Percent (%)
Patient relationship status		
- Single	5	25%
- In a relationship/married	8	40%
- Unknown	7	35%
SES		
- <$20,000	6	30
- $40,000-$49,000	1	5
- $60,000-$69,000	1	5
- Unknown	12	60
Parent relationship status		
- Married	14	70
- Divorced	5	25
- Unknown	1	5
Mother education level		
- Less then high school	2	10
- High school	5	25
- College/university	9	45
- Unknown	4	20
Father education level		
- Less then high school	2	10
- High school	5	25
- College/university	10	50
- Unknown	3	15

Table 3: Consistent and inconsistent themes emerging from the qualitative and quantitative studies

Category	**Sub-category**	**Qualitative study**	**Quantitative study**
Collaboration	Hospital-hospital	Yes	No
	Pharmacy-pharmacy	Yes	No
	School-other services	Yes	No
Facility	Amenities	Yes	Yes
	Design/décor	Yes	No
	Entertainment	Yes	Yes
	Food/drink	Yes	Yes
Information sharing and communication	Asking questions	Yes	No
	Cancer treatment and diagnosis	Yes	Yes
	Mode of information	Yes	Yes
	Information delivery	Yes	No
	Seeking information	Yes	No
	Support independence	Yes	Yes
	Talking about cancer	Yes	Yes
Physical and daily living	Health maintenance	Yes	No
	Practical	Yes	Yes
	Symptoms	Yes	No
Psychological/emotional	Autonomy	Yes	Yes
	Feeling normal	Yes	Yes
	Self conscious	Yes	Yes
	Spiritual support	Yes	No
	Support	Yes	Yes
Service provision	Availability/accessibility	Yes	Yes
	Client (AYA) centered care	Yes	Yes
	Client safety	Yes	Yes
	Coordination	Yes	Yes
	Multidisciplinary team	Yes	Yes
	Wait times	Yes	Yes
Social	Companionship	Yes	Yes
	Participation in social roles	Yes	Yes
	Support	Yes	Yes

APPENDIX A

Final coding framework - definition of needs

Category	**Sub-categories**	**Definition**
Collaboration	Hospital-hospital, pharmacy-pharmacy, school-other services	Linkages and partnerships that are to be established among different service delivery systems, networks and providers to enable effective planning and the implementation of a high-quality integrated service
Facility	Amenities, design/décor, entertainment, food/drink, other	Location and environment (e.g., amenities, entertainment) of the hospital or clinic, such as having privacy, and nearby accommodation
Information-sharing and communication	Asking questions, cancer treatment and diagnosis, mode of information, information delivery, seeking information, talking about cancer, other	Information to reduce confusion, anxiety and fear, to inform decision-making, and to assist in skill acquisition
Physical and daily living needs	Health maintenance, practical, symptoms	Physical comfort and freedom from pain, optimum nutrition and ability to carry out one's usual day-to-day functions
Psychological/ emotional	Autonomy, feeling normal, self conscious, spiritual support, support	Ability to cope with the illness experience and its consequences, the meaning and purpose in life and the need to practice religious belief
Service provision	Availability/accessibility	Extent to which services are available and accessible (e.g., geographically, physically, affordability) in a timely manner
Service provision	Client (AYA) centered care	Extent to which the planning and delivery of services involves clients, is positive, acceptable and responsive to their needs and expectations, and respectful of privacy, confidentiality and differences (e.g., cultural, socioeconomic)
Service provision	Client safety	Actual or potential harm to the client through the provision of a service, that can be prevented, avoided, reduced or minimized through integrated risk management activities

Category	**Sub-categories**	**Definition**
Service provision	Coordination	Provision of services that are continuous, integrated and organized around the client (e.g., within and across service settings and over time)
Service provision	Multidisciplinary team	Having a treatment planning team with a number of doctors and other health care professionals who are experts in different disciplines.
Service provision	Wait times	Improved times between the date of request for a consultation to the date of the primary care consultation, the date of the request for a test and the date of examination, the referral date from the first specialist to the date of the subsequent specialist/ surgical consultation, the date of the decision to treat and the date of surgery, the date of booking or placement on the hospital waiting list and the date of surgery, the request for diagnostic testing and when the request is accepted by the radiologist, when the request for diagnostic testing has been accepted by the radiology department and the date of the diagnostic testing
Social	Companionship, participation in social roles, support	Family relationships, community acceptance, involvement in relationships and social roles, and coping with changing relationships with friends/family members

APPENDIX B

Systematic literature review search strategy

PICO research question:

What are the health care and supportive needs of adolescent and young adult cancer patients and survivors aged 15 to 30?

Lower Age limit: 15
Upper age limit: 30

Exclusion
Age: younger then 15 years of age and/or older then 30 years of age
Language: none
Types of studies: abstracts, reviews, editorials, dissertations

Journals to search:

CINAHL, Cochrane Central, EMBASE, Medline, PsycInfo and PubMed

Narrowed down search terms:

Adolescent, adolescence, young adult, cancer, sexuality, sexual function, support needs, support, psychosocial, distress, unmet needs, health behavior, intervention programs, social support, survivorship, survivors, brain tumor, surgery, supportive care, qualitative research, social problems, psychosocial support systems, process assessment (health care), patient-care team, oncology, health care, needs assessment, supportive care, support services

Detailed Search terms:

Clinical	
Age	Adolescence, adolescent, young adult, teen-age, teenage, youth, adult
Issues	Cancer, oncology, hematology, blood disorders, blood disease, tumors, solid tumors, leukemia, lymphoma, brain tumors, glioma
Needs	
	Needs, needs assessment, evaluation of needs, health, supportive care, care, psychological, adjustment, physical, activity, coping, health behavior, social, information, health facility, health center, client centered care, family centered care, patient centered care
Client/family centered care	Relationships, relationships with staff, client care, client centered care, family care, family centered care, family services, physicians, nurses, support team, dietician, social worker, councilor, counseling, hospital staff, staff, services, services provided, service provision, service delivery, decision making, personalized care, coordination of care, accessibility, wait times, scheduling
Physical	Participation, physical function, physical ability, participation in physical activity, mobility, physical symptoms, energy level, strength, stamina, nausea, pain, discomfort, appetite, vision, hearing, weight, appearance, sensitivity, temperature, sexual function, sleep, sleep disturbance, fertility, fitness, exercise, weight loss, appearance, changes
Psychological	Anxiety, worry, fear, sadness, depression, self consciousness, self-consciousness, self confidence, self-confidence, anger, happiness, impact of diagnosis, reaction to diagnosis, reaction to physical changes, cognitive function, spirituality, feeling normal, motivation, control, joy, drive, strength, planning for the future, getting back to normal, life impact, life changes, self esteem, self concept, self-perception
Coping	Ability, strategies, methods, degree, level, diagnosis, treatment, survivorship, family coping, family, relatives, friends, peers, schoolmates, classmates, co-workers
Health behavior	Diet, poor eating, nutrition, eating habits, exercise, physical activity, sports, activity, working-out, risk behavior, smoking, drugs, alcohol, sexual activity, sex, sexuality
Social	Participation, family, relatives, friends, peers, schoolmates, classmates, peers with cancer, roommates, partner, activities, isolation, missing out, telling others about diagnosis, telling others about treatment, reaction to cancer, quality of support, financial support, housekeeping, feeding, grooming, shopping, transportation, meeting new people, intimate relationships, sexual partner, sexual relationships, boyfriend, girlfriend, significant other

Needs	
Information	Delivery of information, use of information, diagnosis, treatment, survivorship, transitioning, sexual health, side affects, information from peers with cancer, nutrition, form of information, recipient of information, understanding information, information seeking, asking questions
Health facility	Facility, state of facility, hospital facility, hospital, cleanliness, clean, oncology ward, ward, common room, TV room, lounge room, treatment room, waiting room, waiting area, bathroom, washroom, hospital room, examining room, rules, amenities, activities, services, food, roommates, peers with cancer, cancer patients
Miscellaneous	
	Needs, other needs, solutions, advice, suggestions, strategies

APPENDIX C

CASP evaluation tool

Critical Appraisal Skills Programme (CASP)

making sense of evidence

10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is *not a definitive guide* and extensive further reading is recommended.

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

- **Rigour: has a thorough and appropriate approach been applied to**
- **key research methods in the study?**
- **Credibility: are the findings well presented and meaningful?**
- **Relevance: how useful are the findings to you and your organisation?**

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

Screening Questions

1. Was there a clear statement of the aims of the research? ☐ Yes ☐ No

Consider:

– what the goal of the research was

– why it is important

– its relevance

---

2. Is a qualitative methodology appropriate? ☐ Yes ☐ No

Consider:

– if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

---

Is it worth continuing?

Detailed questions

Appropriate research design

3. Was the research design appropriate to address the aims of the research?

Write comments here

Consider:

– if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

Sampling

4. Was the recruitment strategy appropriate to the aims of the research?

Write comments here

Consider:

– if the researcher has explained how the participants were selected

– if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study

– if there are any discussions around recruitment (e.g. why some people chose not to take part)

Data collection

5. Were the data collected in a way that addressed the research issue?

Write comments here

Consider:

- *if the setting for data collection was justified*
- *if it is clear how data were collected (e.g. focus group, semi-structured interview etc)*
- *if the researcher has justified the methods chosen*
- *if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)*
- *if methods were modified during the study. If so, has the researcher explained how and why?*
- *if the form of data is clear (e.g. tape recordings, video material, notes etc)*
- *if the researcher has discussed saturation of data*

Reflexivity (research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and participants been adequately considered?

Write comments here

Consider whether it is clear:

- *if the researcher critically examined their own role, potential bias and influence during:*
  - *formulation of research questions*
  - *data collection, including sample recruitment and choice of location*
- *how the researcher responded to events during the study and whether they considered the implications of any changes in the research design*

Ethical Issues

7. Have ethical issues been taken into consideration?

Write comments here

Consider:

- *if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *if approval has been sought from the ethics committee*

Data Analysis

8. Was the data analysis sufficiently rigorous? Write comments here

Consider:

- *if there is an in-depth description of the analysis process*
- *if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?*
- *whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*
- *if sufficient data are presented to support the findings*
- *to what extent contradictory data are taken into account*
- *whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*

Findings

9. Is there a clear statement of findings? Write comments here

Consider:

- *if the findings are explicit*
- *if there is adequate discussion of the evidence both for and against the researcher's arguments*
- *if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)*
- *if the findings are discussed in relation to the original research questions*

Value of the research

10. How valuable is the research? Write comments here

Consider:

- *if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
- *if they identify new areas where research is necessary*
- *if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

APPENDIX D

STROBE evaluation tool

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Continued on next page

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

APPENDIX E

Systematic literature review characteristics of included articles

Ref.	Country	Design	Setting	Outcome Measure	Study Sample	Age enrolled (years)	Age diagnosed (years)	Number of F:M	Type of cancer	Ethnicity
62	UK	Qualitative focus group	Regional cancer centers in Wales	n/a	7	n/a	18-24	3:4	n/a	n/a
63	Australia	Qualitative focus group	Victoria Australia	n/a	6	20.5 (avg.)	14-21	4:2	Hodgkins; Non-Hodgkins; Melanoma; Brain; Ewing's sarcoma; Soft tissue sarcoma	n/a

Ref.	**Country**	**Design**	**Setting**	**Outcome Measure**	**Study Sample**	**Age enrolled (years)**	**Age diagnosed (years)**	**Number of F:M**	**Type of cancer**	**Ethnicity**
64	Australia	Qualitative focus groups	Melbourne Australia	n/a	8	22-30	22-29	5:3	Synovial sarcoma; Rhabdomyosarcoma; Squamous cell carcinoma tongue; Testicular;Bowel; Acute myeloid leukemia; Breast; Non-Hodgkin's	n/a

Ref.	Country	Design	Setting	Outcome Measure	Study Sample	Age enrolled (years)	Age diagnosed (years)	Number of F:M	Type of cancer	Ethnicity
65	USA	Qualitative interviews	Tumor registry at local hospital	n/a	20	18-39	18-39	15:5	Thyroid; Breast; Melanoma; Sarcoma; Rectal; Nasopharyngeal; Leukemia; Hodgkin's lymphoma; Endometrial; Brain	White (18); White Hispanic (1); More then one race Hispanic (1)

Ref.	**Country**	**Design**	**Setting**	**Outcome Measure**	**Study Sample**	**Age enrolled (years)**	**Age diagnosed (years)**	**Number of F:M**	**Type of cancer**	**Ethnicity**
66	UK	Qualitative focus groups and interviews	Cancer unit in Yorkshire	n/a	14	13-20	n/a	4:10	Hodgkins; Osteosar-coma; Acute lymphoblastic leukemia; Rhabdomyosarcoma; Ewing's Sarcoma; Primative neuroectodermal tumor; Soft tissue sarcoma	White (12); Asian (2)

Ref.	**Country**	**Design**	**Setting**	**Outcome Measure**	**Study Sample**	**Age enrolled (years)**	**Age diagnosed (years)**	**Number of F:M**	**Type of cancer**	**Ethnicity**
67	USA	Qualitative	Treatment centers in Texas Tennessee, Missouri and New York	n/a	89	13-19	Teenage years	18:29 (only available for 47 patients)	Leukemia; Non-Hodgkin's; Hodgkin's; Ewing's sarcoma; Osteogenic sarcoma; Brain; Rhabdomyosarcoma	n/a

Ref.	Country	Design	Setting	Outcome Measure	Study Sample	Age enrolled (years)	Age diagnosed (years)	Number of F:M	Type of cancer	Ethnicity
68	USA	Quantitative cross-sectional survey	No setting electronic survey	Rank order needs	1,088	18-39	15-35	823:257	Breast; Hodgkin’s; Non-Hodgkin's; Leukemia; Testicular; Bone and other soft tissue sarcoma; Adenosar-coma; Brain tumor	White (920); African American (31); Asian (44); Hispanic (41); Native American (4)
69	USA	Quantitative cross-sectional survey	No setting electronic survey	n/a	217	18-40	15-35	186:28	Hodgkin’s; Non-Hodgkin’s; Leukemia; Breast;	White (178); African American (8); Asian (10); Hispanic (9); Native American (1)

Ref.	**Country**	**Design**	**Setting**	**Outcome Measure**	**Study Sample**	**Age enrolled (years)**	**Age diagnosed (years)**	**Number of F:M**	**Type of cancer**	**Ethnicity**
70	USA	Quantitative cross-sectional survey	No setting electronic survey	n/a	879	18-35	15-35	635:230	Hodgkin's; Non-Hodgkin's; Leukemia; Breast; Germ cell tumor; Soft tissue sarcoma or carcinoma; Brain; Thyroid	White (741); African American (22); Asian (33); Hispanic (32); Native American (3)

Ref.	**Country**	**Design**	**Setting**	**Outcome Measure**	**Study Sample**	**Age enrolled (years)**	**Age diagnosed (years)**	**Number of F:M**	**Type of cancer**	**Ethnicity**
71	USA	Quantitative longitudinal survey	North American cancer centers	Information Prefer-ences of Adoles-cents (IPA)	ARM I n=39; ARM II n=74	ARM I 11-21; ARM II 11-19	n/a	ARM I 19:20; ARM II 30:42	n/a	ARM I: African American. (3); Asian (3); Hispanic (9); White (24); Other (4); Missing (2) ARM II: African Am. (3); Asian (4); Hispanic (10); White (46);Other (7);Missing (2)
72	Austra-lia	Quantitative cross-sectional survey	Population based	Cancer Needs questionnaire for Young People (CNQ-YP)	63	18-24	n/a	40:23	n/a	n/a

Ref.	**Country**	**Design**	**Setting**	**Outcome Measure**	**Study Sample**	**Age enrolled (years)**	**Age diagnosed (years)**	**Number of F:M**	**Type of cancer**	**Ethnicity**
73	USA	Mixed Methods Delphi panel	Community based clinics private practices or academic medical centers	n/a	37	18-44	15-39	n/a	Brain; Breast; Endometrial; Germ cell testicular or ovarian; Sarcoma; Hodgkin; Leukemia; Melanoma	n/a

APPENDIX F

Systematic literature review needs categories

Category	**Sub-category**	**Need**	**Citation numbers**
Facility	Amenities	AYA ward	63, 66, 72
	Entertainment	Entertainment for AYAs (e.g., TV, movies, gaming system, board games, cards, magazines, special visitors, crafts)	72
		Entertainment room (i.e. computer room, lounge, movie room)	72
	Food/drink	Better quality	63, 72
Information-sharing and communication	Cancer treatment and diagnosis	Discuss side effects	62, 69, 70, 71, 72
		Explain what they are doing and changes to procedures/plans	73
		Diagnosis	69, 70
		Sexual function	63, 65, 64, 69, 70, 71, 73
		Other - reassurance that physical and emotional responses to cancer are ‘‘normal’’	73
		Personalized information	73
	Mode of information	Electronic	62, 65, 69, 70
		Verbal	65
		Written	65, 67
	Information delivery	Explain things in a way I can understand	64
		Talk to me honestly	66, 67

Category	**Sub-category**	**Need**	**Citation numbers**
Information-sharing and communication cont.	Other	Available services for young people	62, 69, 70, 72
		Getting back to exercising	69, 70
		Diet and nutrition	65, 69, 70
		Feelings caused by the experience	72
		Cancer discrimination in school and college, jobs and the military	71
		Practical matters	62, 65, 71
	Seeking information	Seeking information from outside sources	65
	Talking about cancer	Patient being able to give back to cancer community/raise awareness about cancer	73
		Patient being able to talk about cancer	62, 71, 73
Physical and daily living	Health maintenance	Programs to remain active and/or eat healthy	65
		Relaxation activities	65
	Practical	Financial support	73
		Transportation assistance	69, 70
Psychological /emotional	Autonomy	Gain back independence	62, 67, 63, 73
	Feeling normal	To feel normal	62, 73
	Feeling self conscious	To deal with physical changes	62, 71
	Support	Available support services	62, 63, 64, 65, 67, 69, 70, 71, 72, 73

Category	**Sub-category**	**Need**	**Citation numbers**
Service provision	Availability/accessibility	Access to specialized staff	63
		Access to treatment	64
	Client (AYA) centered care	Friendly staff	62, 63, 72
		Knowledgeable and qualified staff	73
		Staff that the patient can trust/relate	63, 73
	Client safety	Management of treatment-related symptoms	73
	Coordination	Better transitioning	73
		Staff cohesiveness	63
	Multidisciplinary team	Multidisciplinary team	65, 69, 70, 73
	Other	Choice of treatment days	63, 73
		Opportunity to be involved in clinic trials	73
		High quality treatment	66
	Wait times	Improve wait times	63, 66
	Support independence	Encourage patient education	66
		To be involved in discussion and decision making	63, 73
		Time alone with doctors to discuss sensitive matters	67
Social	Companionship	Friends	72, 73
	Participation in social roles	School	63, 66, 71
		Work	63, 72
	Support	Proximity to family and/or friends	66
		Support from family and/or friends	62, 67, 73
		Support from peer with cancer	65, 67, 73

APPENDIX G

Systematic literature review variables related to patient reported needs

Determinant	**Category**	**Sub-category**	**Need**	**Citation numbers**
Age	Facility	Amenities	AYA ward	68
	Information-sharing and communication	Cancer treatment and diagnosis	Explain what they are doing and any changes to procedures/plans	68
			Diagnosis	68, 70
			Sexual function	68, 69, 70
			Personalized information	68
		Mode of information	Electronic	69, 70
		Other	Available services for young people	70
	Physical and daily living	Practical	Financial support	68
			Transportation assistance	70
	Psychological/ emotional	Support	Available support services	68, 69, 70
	Service provision	Availability/ accessibility	Access to specialized staff	68
		Client safety	Management of treatment-related symptoms	68
		Coordination	Better transitioning	68
			Other	68
		Multidisciplinary team	Multidisciplinary team	68, 69, 70
		Other	Choice of treatment days	68
		Support independence	To be involved in discussion and decision making	68
	Social	Companionship	Deal with not being able to hang out/do the same things as my friends	68
		Support	Support from family and/or friends	68
			Support from peer with cancer	68
			Support group	68

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Age at diagnosis	Facility	Amenities	AYA ward	68
	Information-sharing and communication	Cancer treatment and diagnosis	Explain what they are doing and any changes to procedures/plans	68
			Diagnosis	63, 68, 70
			Sexual function	68, 69, 70
			Personalized information	68
		Mode of information	Electronic	69, 70
		Other	Available services for young people	70
	Physical and daily living	Practical	Financial support	68
			Transportation assistance	70
	Psychological/ emotional	Support	Available support services	68, 69, 70
	Service provision	Availability/ accessibility	Access to specialized staff	68
		Client safety	Management of treatment-related symptoms	68
		Coordination	Better transitioning	68
			Other	68
		Multidisciplinary team	Multidisciplinary team	68, 69, 70
		Other	Choice of treatment days	68
		Support independence	To be involved in discussion and decision making	68
	Social	Companionship	Deal with not being able to hang out/do the same things as my friends	68
		Support	Support from family and/or friends	68
			Support from peer with cancer	68
			Support group	68

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Education level	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	70
			Sexual function	70
		Mode of information	Electronic	70
		Other	Available services for young people	70
			Getting back to exercising	70
			Diet and nutrition	70
	Physical and daily living	Practical	Transportation assistance	70
	Psychological/ emotional	Support	Available support services	70
	Service provision	Multidisciplinary team	Multidisciplinary team	70
Ethnicity	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	70
			Sexual function	70
		Mode of information	Electronic	70
		Other	Available services for young people	70
			Getting back to exercising	70
			Diet and nutrition	70
	Physical and daily living	Practical	Transportation assistance	70
	Psychological/ emotional	Support	Available support services	70
	Service provision	Multidisciplinary team	Multidisciplinary team	70

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Gender	Information-sharing and communication	Cancer treatment and diagnosis	Discuss side effects	71
			Diagnosis	70, 71
			Sexual function	70, 71
		Mode of information	Electronic	62, 70
		Other	Available services for young people	70
			Getting back to exercising	70
			Diet and nutrition	70
			Cancer discrimination in school and college, jobs and the military	71
			Practical matters	71
		Talking about cancer	Being able to talk about cancer	71
	Physical and daily living	Practical	Transportation assistance	70
	Psychological/ emotional	Self conscious	Deal with physical changes	71
		Support	Available support services	70, 71
	Service provision	Multidisciplinary team	Multidisciplinary team	70
	Social	Participation in social roles	Getting back to school/keeping up with school	71

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Marital status	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	70
			Sexual function	70
		Mode of information	Electronic	70
		Other	Available services for young people	70
			Getting back to exercising	70
			Diet and nutrition	70
	Physical and daily living	Practical	Transportation assistance	70
	Psychological/ emotional	Support	Available support services	70
	Service provision	Multidisciplinary team	Multidisciplinary team	70
Occupational status	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	70
			Sexual function	70
		Mode of information	Electronic	70
		Other	Available services for young people	70
			Getting back to exercising	70
			Diet and nutrition	70
	Physical and daily living	Practical	Transportation assistance	70
	Psychological/ emotional	Support	Available support services	70
	Service provision	Multidisciplinary team	Multidisciplinary team	70

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Recurrence	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	70
			Sexual function	69
		Mode of information	Electronic	70
		Other	Available services for young people	69, 70
			Getting back to exercising	70
			Diet and nutrition	70
	Physical and daily living	Practical	Transportation assistance	69, 70
	Psychological/ emotional	Support	Available support services	69, 70
	Service provision	Multidisciplinary team	Multidisciplinary team	69, 70
Stage of treatment	Information-sharing and communication	Cancer treatment and diagnosis	Explain what they are doing and any changes to procedures/plans	73
			Sexual function	73
			Other	73
			Personalized information	73
		Mode of information	Electronic	70
		Talking about cancer	Being able to raise awareness about cancer	73
			Being able to talk about cancer	73

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Stage of treatment cont.	Physical and daily living	Practical	Financial support	73
	Psychological/ emotional	Autonomy	Gain independence back	73
		Feeling normal	To feel normal	73
		Support	Available support services	73
	Service provision	Client (AYA) centered care	Knowledgeable and qualified staff	73
			Staff that I can trust/can relate/understand me	73
		Client safety	Management of treatment-related symptoms	73
		Coordination	Better transitioning	73
		Multidisciplinary team	Multidisciplinary team	73
		Other	Choice of treatment days	73
			Clinic trials	73
		Support independence	To be involved in discussion and decision making	73
	Social	Companionship	Deal with not being able to hang out/do the same things as my friends	73
		Support	Support from family and/or friends	73
			Support from peer with cancer	73
Time since diagnosis	Facility	Amenities	AYA ward	68
	Information-sharing and communication	Cancer treatment and diagnosis	Discuss side effects	71
			Explain what they are doing and any changes to procedures/plans	68
			Diagnosis	68, 71

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Time since diagnosis cont.	Information-sharing and communication	Cancer treatment and diagnosis	Sexual function	68, 71
			Personalized information	68
		Other	Cancer discrimination in school and college, jobs and the military	71
			Practical matters	71
		Talking about cancer	Being able to talk about cancer	71
	Physical and daily living	Practical	Financial support	68
	Psychological/ emotional	Self conscious	Deal with physical changes	71
		Support	Available support services	68, 71
	Service provision	Availability/ accessibility	Access to specialized staff	68
		Client safety	Management of treatment-related symptoms	68
		Coordination	Better transitioning	68
			Access to multiple medical opinions	68
		Multidisciplinary team	Multidisciplinary team	68
		Other	Choice of treatment days	68
		Support independence	To be involved in discussion and decision making	68
	Social	Companionship	Deal with not being able to hang out/do the same things as my friends	68
		Participation in social roles	Getting back to school/keeping up with school	71
		Support	Support from family and/or friends	68
			Support from peer with cancer	68
			Support group	68

Determinant	**Category**	**Sub-category**	**Sub-sub category**	**Citation numbers**
Time since treatment	Facility	Entertainment	Entertainment room	72
		Food/drink	Better quality	72
	Information-sharing and communication	Cancer treatment and diagnosis	Discuss side effects	72
		Other	Available services for young people	72
			Feelings caused by the experience	72
	Psychological/ emotional	Support	Available support services	72
	Service provision	Client (AYA) centered care	Approachable staff	72
	Social	Companionship	Deal with not being able to hang out/do the same things as my friends	72
		Participation in social roles	Getting back to work	72
Treating institution	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	63
	Service provision	Wait times	Improve wait times	66
Type of cancer	Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	70
			Sexual function	69, 70
		Mode of information	Electronic	69, 70
		Other	Available services for young people	70
	Physical and daily living	Practical	Transportation assistance	70
	Psychological/ emotional	Support	Available support services	69, 70
	Service provision	Multidisciplinary team	Multidisciplinary team	69, 70

APPENDIX H

Qualitative study assent and consent forms

Assessing the Needs of Adolescents and Young Adults (AYA) with Cancer in the Hamilton Region: A Qualitative Study

Subject Information and Consent Form

Local Principal Investigator(s) and Principal Investigator:

Graeme Fraser, Assistant Professor, Juravinski Cancer Centre, 3rd Floor, 699 Concession Street, Hamilton, Ontario, L8V5C2, Tel: 905-387-9711 Ext 67680; graeme.fraser@jcc.hhsc.ca

Anne Klassen, Associate Professor, Department of Pediatrics, McMaster Children's Hospital, Hamilton, Ontario, L8S 4J9, Tel: 905 521-2100 Ext 73775; aklass@mcmaster.ca

Co-Investigator(s), Department/Hospital/Institution:

Denise Bryant-Lukosius, Assistant Professor, Juravinski Cancer Centre, 3rd Floor, 699 Concession Street, Hamilton, Ontario, L8V 5C2, 525-9140 Ext 22408; bryantl@mcmaster.ca

Ronald Barr, Professor, Department of Pediatrics, McMaster Children's Hospital, HSC 3N27B Hamilton, Ontario, L8S4J9, Tel: 905 521-2100 Ext 75624; rbarr@mcmaster.ca

Sponsor: Juravinski Cancer Centre Foundation

Introduction

Your adolescent has been invited to take part in this research study because he/she has or had in the past some form of childhood cancer. This letter is to help you decide if you should let your child take part in our study.

Why is this study being done?

In order to improve the way doctors, nurses and other staff provide care to adolescents and young adults (AYA) with cancer; we need to ask a group of AYA what their view is on the subject. We believe that AYA are a unique group of cancer patients and that their needs are not being adequately met by the way healthcare services are provided. So we want to interview a total of 16 AYA patients in order to find out what their healthcare and other needs are. We will use this information to develop a questionnaire that we will send to a large sample of AYA. The information we collect from the large sample of AYA will be used to develop and improve care in the future.

Who can participate in this study?

Your adolescent is eligible to participate in this study if he/she is aged 15-25 years and is being treated for any type of cancer, or has completed treatment for cancer, at McMaster Children's Hospital or the Hamilton Health Sciences Center.

What is involved in participating in this study?
If your adolescent agrees to be in this study, he/she will be asked to take part in an interview with a research assistant. During the interview, he/she will be asked to talk about his/her experiences as an AYA. He/she will be asked questions about his/her cancer and treatment. Then he/she will have a chance to describe his/her needs (e.g., healthcare needs, information needs) as a cancer patient and/or as a cancer survivor. The interview will take about 60-90 minutes. The interview can take place at a time and location that is convenient to your adolescent. The interview will be tape-recorded. After the interview, the research assistant may call to ask a few questions of clarification.

What are the risks of the study?
We believe there are minimal risks involved in taking part in this study. However, sometimes when people talk about their experiences they may find it helpful to talk to someone afterwards for support. If your adolescent feels this way, your interviewer will be able to help you find someone to talk to. He/she could also call Dr. Graeme Fraser, the study investigator, on 905 387-9711 Ext 67680.

Are there benefits to taking part in the study?
There is no direct benefit to taking part in this study. However, the information your adolescent provides will be used to improve healthcare services provide to AYA in the Hamilton Region in the future.

What happens if I decide to withdraw my consent to participate?
Your adolescent’s participation in this study is entirely voluntary. He/she may withdraw from this study at any time. If he/she decide to enter the study but then wants to withdraw, there will be no penalty or loss of benefits to which he/she is otherwise entitled, and his/her future medical care will not be affected.

What will the study cost me?
Your adolescent will not incur any expenses as a result of participation with this study. To thank him/her for the time and the effort that it took to participate in the study we will provide a $50 gift card.

What happens to the questionnaire data that you provide?
If your adolescent participates, his/her privacy will be respected. Information about him/her will not be given out without his/her permission unless required by law or regulation. Information collected will be used for research purposes only. All personal information such as name or phone number will be kept separate from the interview data and will be replaced with a number. A list linking the number with his/her name will be kept in a secure place, separate from the interview data. If the results of the study are published, no names will be used. Only the researchers in charge will have access to his/her personal information.

Who do you call if you have questions or problems?
For more information concerning the research, you may call Dr. Anne Klassen on 905-521-2100 Ext 73775, or Dr. Graeme Fraser on 905 387-9711 Ext 67680. If you have any questions regarding your adolescent’s rights as a research participant you may contact the Office of the Chair of the

Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-521-2100 Ext 42013.

Where can I get more information about childhood cancer?

I may call The Canadian Cancer Society: 1-888-939-3333

I may visit the Canadian Cancer Society Web site: http://www.cancer.ca

I may visit the National Cancer Institute website: http://cancernet.nci.nih.gov.

I have read the above information carefully. I have had the chance to ask questions. All of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Parent	Date	Name printed
Participant	Date	Name printed
Researcher	Date	Name printed

Assessing the Needs of Adolescents and Young Adults (AYA) with Cancer in the Hamilton Region: A Qualitative Study

Subject Information and Consent Form

Local Principal Investigator(s) and Principal Investigator:

Graeme Fraser, Assistant Professor, Juravinski Cancer Centre, 3rd Floor, 699 Concession Street, Hamilton, Ontario, L8V5C2, Tel: 905-387-9711 Ext 67680; graeme.fraser@jcc.hhsc.ca

Anne Klassen, Associate Professor, Department of Pediatrics, McMaster Children's Hospital, Hamilton, Ontario, L8S 4J9, Tel: 905 521-2100 Ext 73775; aklass@mcmaster.ca

Co-Investigator(s), Department/Hospital/Institution:

Denise Bryant-Lukosius, Assistant Professor, Juravinski Cancer Centre, 3rd Floor, 699 Concession Street, Hamilton, Ontario, L8V 5C2, 525-9140 Ext 22408; bryantl@mcmaster.ca

Ronald Barr, Professor, Department of Pediatrics, McMaster Children's Hospital, HSC 3N27B Hamilton, Ontario, L8S4J9, Tel: 905 521-2100 Ext 75624; rbarr@mcmaster.ca

Sponsor: Juravinski Cancer Centre Foundation

Introduction
You have been invited to take part in this research study because you are an adolescent or young adult (AYA) who has or had in the past some form of cancer. This letter is to help you decide if you would like to take part in our study.

Why is this study being done?
In order to improve the way doctors, nurses and other staff provide care to the AYA group, we need to ask a group of AYA what their view is on the subject. We believe that you are a unique group of cancer patients and that your needs are not being adequately met by the way healthcare services are provided. So we want to interview a total of 16 AYA patients in order to find out what your healthcare and other needs are. We will use this information to develop a questionnaire that we will send to a large sample of AYA. The information we collect from the large sample of AYA will be used to develop and improve care in the future.

Who can participate in this study?
You are eligible to participate in this study if you are aged 15-25 years and are being treated for any type of cancer, or have completed treatment for cancer, at McMaster Children's Hospital or the Hamilton Health Sciences Center.

What is involved in participating in this study?
If you agree to be in this study, you will be asked to take part in an interview with a research assistant. During the interview, you will be asked to talk about your experiences as an AYA. You will be asked

questions about your cancer and treatment. Then you will have a chance to describe your needs (e.g., healthcare needs, information needs) as a cancer patient and/or as a cancer survivor. The interview will take about 60-90 minutes of your time. The interview can take place at a time and location that is convenient to you. The interview will be tape recorded. After the interview, the research assistant may call you to ask a few questions of clarification.

What are the risks of the study?
We believe there are minimal risks involved in taking part in this study. However, sometimes when people talk about their experiences they may find it helpful to talk to someone afterwards for support. If you feel this way, your interviewer will be able to help you find someone to talk to. You could also call Dr. Graeme Fraser, the study investigator, on 905 387-9711 Ext 67680.

Are there benefits to taking part in the study?
There is no direct benefit to taking part in this study. However, the information you provide will be used to improve healthcare services provide to AYA in the Hamilton Region in the future.

What happens if I decide to withdraw my consent to participate?
Your participation in this study is entirely voluntary. You may withdraw from this study at any time. If you decide to enter the study but then want to withdraw, there will be no penalty or loss of benefits to which you are otherwise entitled, and your future medical care will not be affected.

What will the study cost me?
You will not incur any expenses as a result of participation with this study. To thank you for the time and the effort that it took to participate in the study you will be given a $50 gift card.

What happens to the questionnaire data that you provide?
If you participate, your privacy will be respected. Information about you will not be given out without your permission unless required by law or regulation. Information collected will be used for research purposes only. All personal information such as your name or phone number will be kept separate from your interview data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from the interview data. If the results of the study are published, no names will be used. Only the researchers in charge will have access to your personal information.

Who do you call if you have questions or problems?
For more information concerning the research, you may call Dr. Anne Klassen on 905-521-2100 Ext 73775, or Dr. Graeme Fraser on 905 387-9711 Ext 67680. If you have any questions regarding your rights as a research participant you may contact the Office of the Chair of the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board at 905-521-2100 Ext 42013.

Where can I get more information about childhood cancer?
I may call The Canadian Cancer Society: 1-888-939-3333

I may visit the Canadian Cancer Society Web site: http://www.cancer.ca

I may visit the National Cancer Institute website:
http://cancernet.nci.nih.gov.

I have read the above information carefully. I have had the chance to ask questions. All of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Participant	Date	Name printed
Researcher	Date	Name printed

APPENDIX I

Qualitative study interview guide

Assessing the Needs of Adolescents and Young Adults (AYA) with Cancer in the Hamilton Region: A Qualitative Study

INTERVIEW GUIDE

(Note: Confirm Consent Form was Reviewed & Understood on Tape).

Preamble: This study is about understanding the needs of Adolescents and Young Adults with Cancer. I would like you to tell me stories that will help me to understand what your experience has been of the healthcare system and what kinds of things have been helpful to you and what kinds of things you might have wanted or needed but did not receive.

1. Can you tell me about the details of your cancer?

    - Age at diagnosis
    - Details about type of cancer
    - Stage/risk/relapse
    - Any other health issues (may or may not be related to cancer dx) that require you to frequently visit another department in the hospital

2. What types of cancer treatments have you had?

    - Chemotherapy
    - Radiation
    - Surgery
    - Transplant

3. Coping skills?
    - How have you coped with your diagnosis?
    - How did the physicians and supporting staff at the hospital help you cope with the news of your cancer diagnosis?
    - How did your family help you cope with the news of your cancer diagnosis?
    - How has your family themselves coped with the diagnosis?
    - If you are finished treatment how do you cope with the fear of relapse?
    - How have you coped with returning to 'normal' life after cancer treatment?
    - How do you think about the future/make plans?

4. Tell me about how your diagnosis helped you develop as an individual?
    - Has it made you stronger/weaker/changed you in any way?
    - Are these changes accepted by family/friends?

5. Do you feel isolated because of your diagnosis?
    - Do you frequently have to stay home from school/work/social events?
    - Are you treated differently by others (i.e. parents, teachers, students etc.)
    - Do you feel you can talk openly with other about your cancer experience?

7. What has your experience been with receiving healthcare services for your cancer?

    - What was good about that care you received?
    - What was bad about the care you received?

8. Could the health care you received have been improved?

    - What could your team of professional caregivers have done better?
    - What could your family and informal caregivers have done better?
    - What could you have done better?
    - How could the health care facility have been improved?
    - What advice do you have for health care providers?
    - What advice do you have for other patients?

9. I would like to ask you to talk about the various needs you have as a cancer patient or survivor. I'll ask you to talk about your needs for a number of different areas. I would be interested to learn for each area whether you have needs in this area and whether or not your needs have been addressed.

    - Informational Needs

        - o Who/what where your main sources of information about your cancer? (medical professionals, parents, Internet, other patients)
        - o If you had questions about your cancer care or follow-up care was it easy to get clear answers?
        - o Age appropriateness of information? Readily understandable?
        - o Physical accessibility of information
        - o Use of Internet sites and other modes of communicating information
        - o Assessing the quality of information received (especially regarding Internet sites)
        - o Unmet information needs?
        - o How can the accessibility of information be improved for your age group?

    - Psychological/Emotional Needs Positive and Negative

  - What were/are your emotional/psychological needs relating to your caner diagnosis? (fear, anxiety, worry, self-worth, body image)
  - Told that death is a potential outcome? Needs around this issue?
  - Where you able to access counselling and support for these needs?
  - Age appropriateness of counselling/support
  - Effectiveness of counselling
  - Counselling and support to develop self-efficacy and ability to assume responsibility for their own health care and decision-making
  - How could the counselling and support provision be changed to better meet your needs?
  - Any other psychological needs?

- Physical needs

  - Cancer or treatment related
  - To deal with cancer symptoms (pain, nausea, vomiting, fatigue) *frequency of symptoms
  - Diet and nutritional needs
  - Exercise information
  - Needs related to cancer late effects
  - Co-morbid conditions and other ongoing health concerns
  - Energy and fatigue
  - Any other physical needs
  - How could your physical needs have been better meet during your experience with cancer/in the future?

- Risk behaviour needs

  - Sexual health, drugs, alcohol
  - Use of drugs/alcohol/smoking
  - Comfort in intimate relationships/dating
  - Fertility needs (planning for the children in the future)
  - Counselling needs
  - Safe sex practices
  - Any other risk behaviour needs
  - How could your risk behaviour needs have been better meet during your experience with cancer/in the future?

- Practical needs

  - Educational needs
  - Financial needs - insurance needs, family financial needs
  - Employment needs
  - Child care needs
  - Housekeeping needs
  - Legal needs
  - Transportation needs
  - Any other practical needs
  - How could your practical needs have been better meet during your experience with caner/in the future?

- Social needs
    - Support from family
    - How did you family handle your diagnosis (parents, siblings, extended family)?
    - Support from friends
    - Interaction with *"normal"* peers of the same or different sex
    - Opportunities to meet other young adult cancer patients or survivors with similar diseases and similar ages
    - Support groups led by trained mental health professionals such as social workers or psychologists.
    - School and university
    - Occupation or vocation
    - Any other social needs
    - What could be done to better meet your social needs both during and after cancer treatment?

- Spiritual needs
    - Religious/spiritual counselling
    - Any other spiritual needs
    - What could be done to better meet your spiritual/religious needs during and after your cancer treatment?

- Healthcare needs
    - Physical facilities
    - Staff with expertise in AYA
    - Complementary/alternative health care needs
    - Scheduling needs
    - Hospice or end-of-life services
    - Any other healthcare needs
    - What is your advice for health care providers to better meet your health care needs?

10. What sort of health risk behaviours are you involved in? Was this during treatment or survivorship? Did anyone talk to you about this? What advice would you have liked to have?
    - Smoking
    - Drugs
    - Alcohol
    - Safe sex practices
11. Do you have any concerns about your health in the future?
    - Strategies to promote health (given these concerns what, if anything, are you doing to promote your health?)
        - Diet
        - Exercise
        - Risk behaviours (alcohol, drugs, smoking)
        - Other health habits

12. If you could design the perfect treatment center for AYA patients what would it look like for cancer patients that are undergoing treatment? What would it look like for survivor care? Please be as creative as possible as we are interested in your ideas.

13. Out of everything we have talked about today, what are your top three needs and how could they be better met?
  - Solutions

14. Is there anything else about needs related to cancer treatment or survivorship that you can think of that we have not already discussed?

Thank you for your time!

Appendix J

AYA initial coding domains and descriptions

DIAGNOSIS/TREATMENT

SUB-DOMAIN	DESCRIPTION
▪ Logistics	Comments about any medical information related to their cancer including diagnosis, age at diagnosis, diagnosis type, treatment, alternative therapies, process of being diagnosed, aftercare routine etc.

CLIENT/FAMILY CENTERED CARE

SUB-DOMAIN	DESCRIPTION
▪ Relationships with staff o Physicians o Nurses o Support team o Dietician o Social worker/ counselor o Overall o Other	Comments about the patient's positive/negative relationships with various staff members and how their needs were/were not met.
▪ Services provided	Comments about the services the hospital provided to the patient and/or tangible resource needs (e.g., taste tablets, resource kits for side effects etc.) and/or the positive/negative experiences of these services.
▪ Counseling needs	Comments about the patients use of and/or need for counseling services.
▪ Delivery of information o Diagnosis o Treatment o Survivorship o Sensitive information o Other o Overall	Comments about how the patient was provided with information. *Not about what information was received but how it was delivered.
▪ Decision making o Treatment o Survivorship	Comments about who decides the treatments for the patients.

CLIENT/FAMILY CENTERED CARE CONT.

SUB-DOMAIN	DESCRIPTION
▪ Personalized care	Comments about when the patient's care was centered on their personal needs. Whether or not the patient felt that they were being respected as an individual and their preferences adhered to by their health care providers, including all major and minor procedures.
▪ Family services	Comments about the care/programs provided to assist patient's families or what support/programs were needed.
▪ Coordination of care	Comments about time when the patients had to go to different centers or departments and whether or not that cares was coordinated.
▪ Accessibility	Comments about the patient's accessibility to health services.
▪ Wait times	Comments about wait times to appointments/treatments.
▪ Diagnostic results	Comments about the patient's satisfaction with receiving test results.

PHYSICAL NEEDS

SUB-DOMAIN	DESCRIPTION
PHYSICAL FUNCTION	
▪ Participation in practical activities ○ Treatment ○ Survivorship	Comments about the patient's ability to complete everyday tasks (e.g., housekeeping, hygiene maintenance, climbing stairs etc).
▪ Mobility	Comments about the patient's mobility in relation to cancer symptoms, effects or treatments.
PHYSICAL SYMPTOMS	
▪ Energy level ○ Treatment ○ Survivorship	Comments about patient's energy level/fatigue.
▪ Strength/weakness	Comments about patient's strength/weakness or feeling strong or weak.
▪ Nausea	Comments about the patient being unwell.
▪ Pain/discomfort ○ Treatment ○ Survivorship	Comments about any pain the patient experiences.
▪ Appetite	Comments about any changes in appetite and the causes of this (e.g., changes in tastes) in relation to cancer treatments.
▪ Vision	Comments about vision changes in relation to cancer treatments or symptoms.

PHYSICAL NEEDS CONT.

SUB-DOMAIN	DESCRIPTION
▪ Hearing	Comments about hearing changes in relation to cancer treatments or symptoms.
▪ Weight	Comments about weight changes in relation to cancer treatments or symptoms.
▪ Appearance changes o Treatment o Survivorship	Comments about physical appearance changes as a result of cancer treatment and into survivorship.
▪ Sensitivity	Comments about the patient being sensitive to light, sound smells etc.
▪ Temperature changes	Comments about a patient constantly feeling hot/cold or experiencing body temperature changes.
▪ Overall o Diagnosis o Treatment o Survivorship	Comments about the patients overall physical wellbeing.
▪ Other o Treatment o Survivorship	Comments about any other physical symptoms.
SEXUAL FUNCTION	
▪ Sexual function o Treatment o Survivorship	Comments about the patients' sexual function relating to cancer treatment.
▪ Fertility o Treatment o Survivorship	Comments the patient has about their fertility needs.
SLEEP FUNCTION	
▪ Sleep disturbance o Treatment o Survivorship	Comments about sleep changes in relation to cancer treatments, symptoms or psychological distress.

PSYCHOLOGICAL HEALTH NEEDS

SUB-DOMAIN	DESCRIPTION
EMOTIONAL DISTRESS	
▪ Anxiety/worry/fear o Diagnosis o Treatment o Survivorship	Comments about any anxiety/worry/fear/uncertainty uncertainty and or feelings of being overwhelmed that the patient experienced during various stages of their cancer.
▪ Sadness/depression	Comments about the patient feeling depressed, sad, hopeless or apathetic as a result of cancer or treatments.
▪ Self-conscious	Comments about patients feeling self-conscious in relation to cancer.
▪ Anger	Comments about feelings of anger.
▪ Early life impact of diagnosis o Positive o Negative	Comments about how a diagnosis of cancer affected the patient's life in the first days/weeks.
▪ Reaction to diagnosis o Positive o Negative	Comments about the patients reaction to their diagnosis.
▪ Other	Comments about any other instances where the patient felt emotionally distressed.
▪ Reaction to physical changes o Positive o Negative	Comments about the patient's reaction to physical changes resulting from cancer and/or ways they dealt with these changes (e.g., concealing etc.).
COGNITIVE FUNCTION	
▪ Cognitive function	Comments about the patients' cognitive ability.

PSYCHOLOGICAL HEALTH NEEDS CONT.

SUB-DOMAIN	DESCRIPTION
POSITIVE PSYCHOLOGICAL FUNCTION	
▪ Spirituality	Comments about spirituality/religious needs.
▪ Feeling normal	Comments about whether or not that patient felt normal, what that means and the importance of this OR instances where the patient wanted to just feel normal.
▪ Motivation	Comments about when the patient felt motivated to fulfill their desire.
▪ Control	Comments about instances where the patient felt they were in control/not in control over treatments/their body/life etc.
▪ Joy/strength	Comments about a patient being confident, having an internal strength, happy, excited, proud, relieved, thankful, though etc. in relation to cancer treatment.
▪ Planning for the future	Comments about whether or not the patient is making future plans/what those plans are.
▪ Getting back to normal	Comments about the patients' life going back to normal in the survivorship phase.
▪ Life impact/changes ○ Positive ○ Negative	Comments about the patient feeling like life perspectives/personality/views were changed by their cancer diagnosis/treatment.

COPING STRATEGY

SUB-DOMAIN	DESCRIPTION
▪ Dealing with diagnosis	Comments about how the patient coped with news of their diagnosis and any need relating to this.
▪ Coping during treatment ○ Activities ○ Attitude ○ Other	Comments about how the patient coped during treatment and any need relating to this.
▪ Coping in survivorship ○ Activities ○ Attitude ○ Other	Comments about how the patient coped in survivorship and any need relating to this.
▪ Family coping style	Comments about how the parents coped with the patient having cancer and any needs relating to this.
▪ Family coping	Comments about the families coping ability and any needs relating to this.

HEALTH BEHAVIOUR NEEDS

SUB-DOMAIN	DESCRIPTION
▪ Diet o Treatment o Survivorship	Comments about the patient's dietary practices and any advice they would have like with regards to this.
▪ Exercise o Treatment o Survivorship	Comments about the patient's exercise practices and any advice they would have like with regards to this.
▪ Risk behavior o Treatment o Survivorship	Comments about the patient's risk behaviors (e.g., smoking, drugs, alcohol, extreme activities) and any advice they would have like with regards to this.
▪ Others o Treatment o Survivorship	Comments about needs relating to other health behaviors as they relate to cancer diagnosis/treatments and any advice they would have like with regards to this.

SOCIAL FUCNTION

SUB-DOMAIN	DESCRIPTION
SATISFACTION WITH PARTICIPATION ABILITY	
▪ Family	Comments about the patient's ability to participate in their role as a family member (e.g., sibling, child, parent etc).
▪ Work	Comments about the patient's ability to participate in their role as an employee/employer.
▪ School	Comments about the patient's ability to participate in their role as a student.
▪ Friends	Comments about the patient's ability to participate in their role as a friend.
▪ Peers with cancer.	Comments about the patient's ability to participate in their role as a peer/friend with cancer to other's with cancer.
▪ Partner relationships	Comments about the patient's ability to participate in their role as a partner in an intimate relationship.
▪ Activities	Comments about the patients' ability to participate in desired activities.
▪ Special activities	Comments about 'special' social interactions such as meeting famous people or getting to attend special events and the importance of this.
SOCIAL COMPANIONSHIP	
▪ Missing out/companionship	Comments about feelings of not being able to do things kids their age are doing.

SOCIAL FUCNTION CONT.

SUB-DOMAIN	DESCRIPTION
SOCIAL SUPPORT	
▪ Telling others about diagnosis/treatment ○ Family ○ Friends ○ Peers with cancer ○ School ○ Co-workers ○ Partner ○ Other ○ Overall	Comments about who the patient chooses to inform of their diagnosis and the process of care throughout their treatment.
▪ Reactions to cancer ○ Family ○ Friends ○ Peers with cancer ○ School ○ Co-workers ○ Partner ○ Other	Comments about how the patient's social network reacted to the news of their diagnosis and/or effects of cancer.
▪ Quality of support ○ Family ○ Friends ○ Peers with cancer ○ Health care providers ○ School ○ Co-workers ○ Partner ○ Other	Comments about support that the patient received from various people that helped them cope with having cancer.
▪ Other	Comments about any other needs relating to social support.
INSTRUMENTAL/PRACTICAL SUPPORT	
▪ Financial ○ Insurance	Comments about financial support needs and whom did/did not provide it.
▪ Housekeeping	Comments about housekeeping support needs and whom did/did not provide it.
▪ Feeding	Comments about feeding support needs and who did/did not provide it.
▪ Grooming	Comments about grooming support needs and who did/did not provide it
▪ Shopping	Comments about shopping needs and who did/did not provide it.
▪ Transportation	Comments about transportation support needs and whom did/did not provide it.
▪ Other	Comments about other practical needs and whom did/did not provide them.

SOCIAL FUCNTION CONT.

SUB-DOMAIN	DESCRIPTION
RELATIONSHIPS	
▪ Meeting new people	Comments about how meeting new people has been affected by having cancer (e.g., withdrawal from meeting new peers, or want to meet new peers).
▪ Intimate or sexual relationships o Diagnosis o Treatment o Survivorship o Overall	Comments about current or future intimate relationships (e.g., fear of being in a relationship, desire for relationship, positive or negative experiences).

INFORMATION NEEDS

SUB-DOMAIN	DESCRIPTION
▪ Use of information	Comments about whether or not the patient used the information provided.
▪ Diagnosis	Comments about information needs relating to diagnosis.
▪ Treatment	Comments about information needs relating to treatment.
▪ Survivorship	Comments about information relating to survivorship.
▪ Transitioning	Comments about information provided to patients when transitioning from diagnosis to treatment phase OR from treatment to survivorship phase OR from pediatric to adult care.
▪ Sexual health	Comments about information need relating to sexual function/health.
▪ Side affects o Cancer o Treatment o Late effects	Comments about information needs pertaining to treatment side affects the patient experienced and how they managed them.
▪ Info from peers with cancer	Comments about any information received from peers with cancer and the usefulness of the information.
▪ Nutrition information	Comments about information needs relating to nutrition/diet.
▪ Form of information	Comments about the form of information were provided to the patient (e.g., pamphlet, hand out, books etc).
▪ Recipient of information	Comments about who received the information (patient vs. parents) and how did the patient feel about this.
▪ Understanding information	Comments about the patient's ability to understand information presented to them and whether or not it was targeted to their specific age.

INFORMATION NEEDS CONT.

SUB-DOMAIN	DESCRIPTION
▪ Information seeking	Comments about if/where information was sought and from what sources. Including the use of the internet.
▪ Asking Questions	Did the patient feel their concerns where addressed/where they able to ask questions.
▪ Other	Any other information needs

OTHER NEEDS

SUB-DOMAIN	DESCRIPTION
▪ State of Facility	Comments about the physical state of the health facility (cleanliness, construction, organization etc).
▪ Common room	Comments relating to a common room on the wards or the need for one.
▪ Treatment area in clinic	Comments about the treatment areas in clinics.
▪ Waiting room	Comments relating to the waiting room.
▪ Bathroom facilities	Comments relating to a common room or the need for one.
▪ Hospital room	Comments relating to the hospital room
▪ Examining room	Comments relating to the examining room
▪ Rules	Comments about the rules of the hospital (visiting hours etc).
▪ Amenities	Comments about the amenities offered by the hospital or lack there of (internet, TV).
▪ Food services	Comments about the food services of the hospital.
▪ Facility Needs	Comments about any other needs regarding the hospital facility.
▪ Activities	Comments about the activities run at the hospital for patient's QOL.
▪ Roommates	Comments about whom the patient shared a room with during inpatient stays.
▪ Other	Comments about any other facility/amenity needs

OTHER NEEDS

SUB-DOMAIN	DESCRIPTION
▪ Other	Any other related comments
▪ Solutions/Advice	Comments about tangible solutions to cancer related problems or advice to others going through cancer
▪ Quotes	Any especially poignant quote.

APPENDIX K

Qualitative study demographic questionnaires

Questionnaire to be completed by participants who are 15 to 18 years old:

<u>About You:</u>

1) Are you ○ Male ○ Female

2) What is your current age?

____

3) What is your **ethnic background** (e.g., South Asian, Chinese)?

____

4) What grade/level of education are you in? ____________________________

5) How many days in the last month have you been absent from school due to cancer?

____

6) Are you currently working? ○ Yes ○ No

7) Please choose one category that best describes the hours usually worked at **your** job*?*

○ Working full-time for pay (30 hours a week or more)
○ Working part-time for pay (less than 30 hours a week)

8) What is **your** main job? (If you have more than one job, please describe the job with more hours worked per week)

____

9) How many days in the last month have you been absent from work due to cancer?

____

<u>About your family</u>

1) What is your current living situation? (alone, with parents, with roommate etc)

____

2) Which of the following categories best describes your **<u>parents' or caregivers' marital status</u>**?

Married	Widowed	Separated	Divorced	Single never married
○	○	○	○	○

3) What is the **highest level of education** your mother and father have completed? (Choose only one answer for each parent)

Mother	**Father**
○ Did not finish High School	○ Did not finish High School
○ Finished High School	○ Finished High School
○ Finished College or University University	○ Finished College or

4) Is your **mother** currently working? working?	Is your **father** currently
○ Yes ○ No	○ Yes ○ No
5) What job does your **mother** do? ______________________________	What job does your **father** do? ______________________________

6) How many siblings do you have?

____

About Your Cancer:

1) What kind of cancer do/did you have?

____

2) What was your age when you were diagnosed with cancer?

____

3) If applicable, how old were you when your treatment ended?

____

4) What cancer treatments have you received? (Check **all** that apply)

	Yes	No
a) Chemotherapy	○	○
b) Radiation	○	○
c) Surgery that involved loss of a limb	○	○
d) Other surgery to remove cancer	○	○
e) Bone marrow/stem cell transplant	○	○
f) Other____________________		

	Yes	No
5) Has your cancer ever relapsed?	○	○

6) Other than cancer, do you have **any other health problems** that you worry about (e.g., ADHD, diabetes)? If yes, please describe these on the line below.

____

____

Questionnaire to be completed by participants who are 19 to 25 years old:

About You:

1) Are you ○ Male ○ Female

2) What is your current age?

3) What is your **ethnic background** (e.g., South Asian, Chinese)?

4) Which of the following categories best describes your current relationship status?

○ Single, never married
○ Dating/In a relationship
○ Married
○ Living common-law
○ Widowed
○ Separated
○ Divorced

5) What is the highest level of education **you** have completed?

Some high school	○
High school diploma	○
Some trade, technical or vocational school, or Business college	○
Diploma or certificate from trade, technical or vocational, or business college	○
Some community college, CEGEP, or nursing school	○
Diploma or certificate from community college, CEGEP, or nursing school	○
Some university	○
Bachelor or undergraduate degree, or teacher’s college	○
Master’s degree	○
Medical degree, dentistry, veterinary medicine or optometry	○
Earned doctorate	○

6) What do you consider to be **your current** main activity?

- ○ Caring for family
- ○ Working for pay or profit
- ○ Both caring for family and working for pay or profit
- ○ Going to school
- ○ Recovering from illness or on disability
- ○ Looking for work
- ○ Other, please explain

8) If working for pay, please choose one category that best describes the hours usually worked?

- ○ Working full-time for pay (30 hours a week or more)
- ○ Working part-time for pay (less than 30 hours a week)

9) If working, what is **your** main job? (If you have more than one job, please describe the job with more hours worked per week).

10) Can you estimate in which of the following groups your annual income falls?

- ○ Less than $20,000
- ○ $ 20,000 - $29,999
- ○ $ 30,000 - $39,999
- ○ $ 40,000 - $49,999
- ○ $ 50,000 - $59,999
- ○ $ 60,000 - $69,999
- ○ $ 70,000 - $79,999
- ○ $ 80,000 - $89,999
- ○ $ 90,000 - $99,999
- ○ $ 100,000 or more

About your family

1) What is your current living situation? (alone, with parents, with roommate etc.)

If you are currently living at home please answer questions 2-5. If you are not currently living at home, please skip to question 6.

2) Which of the following categories best describes your **parents' or caregivers' marital status**?

Married	Widowed	Separated	Divorced	Single/ never married
○	○	○	○	○

3) What is the **highest level of education** your mother and father have completed? (Choose only one answer for each parent)

Mother	**Father**
○ Did not finish High School	○ Did not finish High School
○ Finished High School	○ Finished High School
○ Finished College or University University	○ Finished College or

4) What job does your **mother** do?	What job does your **father** do?
______________________________	______________________________
5) Is your **mother** currently working?	Is your **father** currently working?
Yes ○ No ○	Yes ○ No ○

6) How many siblings do you have? ______________________________

About Your Cancer:

1) What kind of cancer do/did you have?
____

2) What was your age when you were diagnosed with cancer?
____

3) If applicable, how old were you when your treatment ended?
____

4) What cancer treatments have you received? (Check **all** that apply)

	Yes	No
a) Chemotherapy	○	○
b) Radiation	○	○
c) Surgery that involved loss of a limb	○	○
d) Other surgery to remove cancer	○	○
e) Bone marrow/stem cell transplant	○	○
f) Other______________________________		

	Yes	No
5) Has your cancer ever relapsed?	○	○

6) Other than cancer, do you have **any other health problems** that you worry about? (e.g., ADHD, diabetes)? If yes, please describe these on the line below.
____

APPENDIX L

Quantifying needs categories from the qualitative study

Category	**Sub-category**	**Sub-sub-category**	**Variables of needs**	**Number of times reported**	**Number of participants**
Collaboration	Hospital-other services	Collaboration (e.g., between school and hospital/other services, pharmacies	Current age, age at treatment completion, age at diagnosis, stage of treatment	10	4
Facility	Amenities	Bathroom (e.g., close in proximity, private)	Current age, age at treatment completion, age at diagnosis, gender	11	5
Facility	Amenities	Outdoor area	Gender, stage of treatment	8	5
Facility	Amenities	Patient kitchen	Current age, age at treatment completion, age at diagnosis,	11	7
Facility	Amenities	Hospital room (e.g., private)	Current age, age at treatment completion, age at diagnosis, stage of treatment	12	8
Facility	Amenities	AYA ward (e.g., roommates same age, gender, type of cancer)	Current age, age at treatment completion, age at diagnosis, gender	33	15
Facility	Design/décor	e.g., balcony/windows, darker curtains, option to dim lighting, pleasant décor	Stage of treatment	18	8

Category	**Sub-category**	**Sub-sub-category**	**Variables of needs**	**Number of times reported**	**Number of participants**
Facility	Entertainment	Entertainment for AYA (e.g., AYA outings, Internet, TV, movies, gaming system, board games, cards, magazines, special visitors, crafts)	Stage of treatment	77	15
Facility	Entertainment	Entertainment room (e.g., computer room, lounge, movie room)	-	18	8
Facility	Food/drink	Accessible food e.g., cafeteria on the ward, vending machine, free snacks and drinks, flexible meal times, larger portion sizes, room service	Stage of treatment	13	8
Facility	Food/drink	Better quality	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	6	6
Facility	Food/drink	Variety of food options	-	12	9
Facility	Other	e.g., air conditioner, control number of visitors, furniture, parking, phone	Stage of treatment	22	14
Information-sharing and communication	Asking questions	e.g., answer my questions, cancer, treatment, opportunity to ask questions, alcohol/drugs/smoking,	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	19	11

Category	Sub-category	Sub-sub-category	Variables of needs	Number of times reported	Number of participants
Information-sharing and communication	Cancer treatment and diagnosis	e.g., side effects, treatment process, diagnosis, sexual function	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	35	15
Information-sharing and communication	Cancer treatment and diagnosis	Other e.g., public awareness on specific type of cancer, personalized information	-	3	1
Information-sharing and communication	Mode of information	Peers with cancer	-	15	9
Information-sharing and communication	Mode of information	Online information	Gender, stage of treatment	2	2
Information-sharing and communication	Mode of information	Verbal information	Gender, stage of treatment	3	2
Information-sharing and communication	Mode of information	Written information	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	12	10
Information-sharing and communication	Information delivery	Discuss difficult news in a caring way	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	6	4
Information-sharing and communication	Information delivery	Explain things in a way I can understand	Stage of treatment	10	7
Information-sharing and communication	Information delivery	Provide detailed/consistent information	Gender	5	4

Category	**Sub-category**	**Sub-sub-category**	**Variables of needs**	**Number of times reported**	**Number of participants**
Information-sharing and communication	Information delivery	Talk to me honestly	Stage of treatment	4	3
Information-sharing and communication	Other	e.g., available services for young people getting back to exercising, preventative measures, types of food to eat, option for financial coverage, available support services, spiritual beliefs, coping strategies,	Gender, stage of treatment	16	11
Information-sharing and communication	Seeking information	Seeking information from outside sources (e.g., Internet, organizations)	Current age, age at treatment completion, age at diagnosis, stage of treatment	6	5
Information-sharing and communication	Talking about cancer	Other (e.g., raise awareness about cancer through public speaking, control who knows about)	-	2	1
Information-sharing and communication	Talking about cancer	Talk about cancer with family and friends	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	7	5
Physical and daily living	Health maintenance	e.g., meditation, stay active, eat healthy	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	5	4

Category	**Sub-category**	**Sub-sub-category**	**Variables of needs**	**Number of times reported**	**Number of participants**
Physical and daily living	Practical	Financial support (e.g., to cover uninsured medications, sperm banking, parking, gas)	Current age, age at treatment completion, age at diagnosis, stage of treatment	30	13
Physical and daily living	Practical	Help with house chores	-	10	5
Physical and daily living	Practical	Other (e.g., legal advice, home care)	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	2	2
Physical and daily living	Practical	Support for grooming (e.g., washing/styling hair, shower stool)	Gender, stage of treatment	6	4
Physical and daily living	Practical	Transportation assistance	Current age, age at treatment completion, age at diagnosis, stage of treatment	9	7
Physical and daily living	Symptoms	Managing symptoms (e.g., mobility issues, energy, pain, nausea)	Gender	10	8
Psychological/ emotional	Autonomy	Gain independence back	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	4	2
Psychological/ emotional	Feeling normal	To feel normal	Stage of treatment	11	8

Category	**Sub-category**	**Sub-sub-category**	**Variables of needs**	**Number of times reported**	**Number of participants**
Psychological/ emotional	Self conscious	Deal with how I look during cancer treatment	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	7	6
Psychological/ emotional	Support	Spiritual support	Gender, stage of treatment	10	6
Psychological/ emotional	Support	Other (e.g., age appropriate, stay focused on goals, deal with fears, physical changes, impact of cancer, life after cancer, telling family or friends about cancer, deal with uncertainty for the future, support for family members)	Stage of treatment	49	14
Service provision	Availability/ accessibility	Access to health care professionals (e.g., doctors, social workers, diagnostic tests, treatment)	Stage of treatment	11	6
Service provision	Client (AYA) centered care	Friendly/supportive staff	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	19	6
Service provision	Client (AYA) centered care	Knowledgeable and qualified staff	Gender	8	5

Category	Sub-category	Sub-sub-category	Variables of needs	Number of times reported	Number of participants
Service provision	Client (AYA) centered care	Other (e.g., doctors who are prepared to talk about sexual health, phone call or in-person appointment bookings, students to build a rapport with patients)	Stage of treatment	8	5
Service provision	Client (AYA) centered care	Staff that I can trust/can relate/understand me	Current age, age at treatment completion, age at diagnosis, stage of treatment	14	8
Service provision	Client (AYA) centered care	To pay more attention/take their time with me	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	12	8
Service provision	Client (AYA) centered care	Treat me like a teen/young adult	Stage of treatment	6	5
Service provision	Client safety	e.g., supervise new students, caution when treating me	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	6	3
Service provision	Coordination	Communication (e.g., between doctors, services)	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	6	5
Service provision	Coordination	Deal with one health care provider	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	4	3

Category	Sub-category	Sub-sub-category	Variables of needs	Number of times reported	Number of participants
Service provision	Coordination	Other (e.g., scheduling multiple appointments within one day, better transitioning)	Current age, age at treatment completion, age at diagnosis, stage of treatment	2	2
Service provision	Multidisciplinary team	e.g., rehabilitation physiotherapy personal trainer, multiple doctors	Stage of treatment	6	6
Service provision	Other	e.g., preventative measures, child life specialist, high quality treatment, choice of treatment days	Stage of treatment, gender	7	4
Service provision	Support independence	Encourage patient education/health maintenance	Current age, age at treatment completion, age at diagnosis, stage of treatment	10	4
Service provision	Support independence	To be involved in discussion and decision making	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	16	10
Service provision	Support independence	Time alone with doctors to discuss sensitive matters	Stage of treatment	4	2
Service provision	Wait times	Improved wait times	Current age, age at treatment completion, age at diagnosis	18	9
Social	Companionship	Not being able to hang out/do the same things as my friends (e.g., going out)	Current age, age at treatment completion, age at diagnosis, gender	14	10

Category	**Sub-category**	**Sub-sub-category**	**Variables of needs**	**Number of times reported**	**Number of participants**
Social	Participation in social roles	e.g., school, work, important events/activities	Current age, age at treatment completion, age at diagnosis, gender, stage of treatment	70	17
Social	Support	e.g., family, friends, peers with cancer, school, work, support groups	Stage of treatment	137	19

APPENDIX M

Needs categories and quotes from participants from the qualitative study

Category	Sub-category	Sub-sub-category	Adolescent quotes	Young adult quotes
Collaboration	-	-	*"It was kind of annoying cause like we would talk to the school and then the school would tell us that we had to go to the doctors and the doctors would tell us stuff that we had to go to the school so we were like from here to here to here…just direct so those two could talk instead of us having to tell them information"*	*"In OSAP system they think I'm done school and they gave me that six months after I'm supposed to be done school and they sent me a notice where they're like now you have to start paying back your loan and I kind of got a heart attack. I was like what? Like I'm not even done school.* *Like I thought they would know that I dropped out and that I still have more courses like you know 5 courses outstanding but I guess they don't"*
Facility	Amenities	Outdoor area	*"It would be nice if there was like a no smoking area and then you can just go and sit outside. That would be nice"*	*"An outdoor area, it would be nice to go out too. I guess even in the winter though, there are some nice days in the winter. If you have a little covered area or something so you could go outside"*
Facility	Amenities	Patient kitchen	*"That would have been awesome, I'd put a whole kitchen in there and like cook"*	*"Having yeah, having your own kitchen area, something where you could make your own food, bring your own food. You don't have to worry about like nurses having to do that"*

Category	Sub-category	Sub-sub-category	Adolescent quotes	Young adult quotes
Facility	Amenities	Private hospital room	*"Cause I liked the private room, I felt really safe and like I had my own space"*	*" I think if everyone could get a private room. I mean really it'd be the ideal situation if everyone could be on their own, have their own room"*
Facility	Design/ Décor	Balcony/ windows	*"Yeah, and be able to go get some fresh air, or at least like windows that open cause the windows in the room, you can't open them so you can't get any fresh air"*	*"A balcony would be nice because you breath air…when your staying in a closed up space for a month you want to explode"*
Facility	Design/ Décor	Pleasant décor	*"It's got light and it's got color and I mean the floor is a hopscotch, that's awesome"*	*"Just making it more welcoming and not like the minute you walk in, you're like, yeah it's a hospital, you're going to know it's a hospital. So, I don't know, making it seem more inviting"*
Facility	Entertainment	Entertainment for AYAs	*"Maybe have more like teenage games like the board games that they have in there are all like Candy Land and stuff and they don't even have a deck of cards because people would just lose them or rip them or eat them whatever"*	*"I would have loved to, you know, just check my email whenever I wanted to, or I don't know, go on websites and stuff but I didn't have that opportunity. I think that helps like the healing and the recovery process"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Facility	Entertainment	Entertainment room	*"Have a place where you could go when you were on the ward for more like a common space like maybe like um I don't know just like a lounging area, the Ronald McDonald house was really good for that like the room that they have in the ward. It was really nice"*	*"Having like for young people like having a room with computers or something I think could be really cool because when you're in the hospital you kind of like you know maybe you want to go on Facebook and see how your friends are doing or whatever"*
Facility	Entertainment	AYA outings	*"Yeah, I'd go. They had a teen night once a week where they did like this meeting thing and I would go there and I really enjoyed that"*	*"Like maybe have afternoon activities or whatever. I would have loved that when I was in the hospital. But also for people who are not in the hospital because there are a whole lot of us that are not in the hospital, that are still sick and don't have those opportunities because our social life is different"*
Facility	Food/drink	Accessible food	*"It would be cool to like have something you don't have to pay for. They have the café in the basement but it's expensive and I feel bad asking to get food from there all the time. I think it would be better if they had something on the ward people could go and get food without having to worry about having to pay extra for it"*	*"I think that's about it, your kind of like perfect place. Or maybe even to have like a café that had good food that is accessible. Like this café here, it's not too far I guess, but something that's a bit more local"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Facility	Food/drink	Food option	*"They really need to give better options for the food"*	*"They bring the breakfast tray and I just turn it away because it's the same thing every day and I don't want it. Either Cheerios or Special K, those are your options, so I got sick of those really fast"*
Facility	Food/drink	Quality	*"I hated the food there. I despise food there. It's disgusting. They just warm it up and it's like, UGH! Like I throw up every time I think about it"*	*"The smell of lunch, especially the smell of the dinner is horrible. Even though I turn away the tray, I got two other people in the room that eat the dinner, so I still have to smell it. And it's just like torture for an hour having to sit there. It all smells the same no matter what day it is or what it is and I don't understand why it smells so bad"*
Facility	Amenities	Bathroom	*"Well there was two rooms that had like washroom built in and I had those a lot. But when I didn't, you'd have to like walk out and go into the washroom, which is, I mean, it's not really what you want to do"*	*"It's disgusting. I don't know. I have an issue with just like shared washrooms and stuff, like it's just in a hospital. I just find it really gross"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Facility	Amenities	AYA ward	*"I was with a boy twice, a little boy, an infant once and their was a ten year old once and I'm like I'm a fifteen year old girl, that's not okay. I finally ended up with a teenage girl beside me for my last room but it was like it was really uncomfortable those couple of times where it was like I either had an infant wailing all night, or I had a like what is this having a ten year old boy as my roommate "*	*"It would have been good if, I was surrounded by people who were my age, who, you know, were in the same cycle of their life, where they were just being, you know, in the process of taking courses, or you know, working part-time jobs and stuff, to have that to relate to. Or, you know, just dating someone, not being married and having kids or grandkids, and you know being retired and stuff"*
Information-sharing and communication	Asking questions	Alcohol consumption, drug use and other risky behaviors	*"I kind of asked about it in a way. Like I'll call and say-I'll actually just straight up ask them, like, okay what about alcohol? And they are like we don't recommend it, but you can if you want to"*	*"I had no appetite after the bone marrow and slowly wouldn't every day coming out losing weight, losing weight and just no appetite and finally I asked them I said what do you guys think about marijuana?"*
Information-sharing and communication	Asking questions	Answer my questions	*"If they say they are going to look into it, they should actually look into it and actually tell you the answer"*	*"So any questions I have usually she answers most of them. Anything that she had to answer or she doesn't really know the answer to she'll be like oh you know I'll ask the doctor"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Information-sharing and communication	Asking questions	Opportunity to ask questions	*"They didn’t even ask if I had any questions to ask, that’s the thing"*	*"I saw a social worker two times I think it was. But I didn't really talk to her because the first time I saw her was just the very first time. So I’m still kind of uncomfortable trying to get used to it and I guess like why I didn't open up like how I am right now is because my parents were there. So it’s just like ah I didn't really feel comfortable. And then the second time my Mom was there too so I was just like I didn't really"*
Information-sharing and communication	Cancer treatment and diagnosis	Diagnosis	*"I wanted to know like percent and numbers, and she goes some people will like numbers and other people don’t, but like, cause, I could tell you like, 99% but like you could be that 1%. But I liked hearing it, cause it’s like it’s-the odds are good right? But, I’ve talked to somebody who has had it before and he goes, “it’s 100% curable”, and everything"*	*"They always give like actual little package, which comes in a little bag and everything. It’s really cute but it’s just kind of in general. It just talks about chemotherapy in general and like just cancer in general. So I think if there’s something more geared towards actual type of cancer you have"*

Category	**Sub-category**	**Sub-sub-Category**	**Adolescent quotes**	**Young adult quotes**
Information-sharing and communication	Cancer treatment and diagnosis	Explain treatment process	*"I ended up losing my hair but uh I was hoping I wouldn't lose it and I lost it like two weeks later and yeah but they didn't tell us everything that was going on at the time, like what was to be expected"*	*"It was easier just you know for me to kind of know what I am doing next and knowing, you know, if that doesn't work, what I am doing and just kind of concentrating on that"*
Information-sharing and communication	Cancer treatment and diagnosis	Sexual function	*n/a*	*"They never really told me that my libido was going to be null. You know like, um, yeah so I think, you know just if like telling people prior so they-they can uh…what's the word I am looking for…like be warned about it"*
Information-sharing and communication	Cancer treatment and diagnosis	Side effects	*"Like treatment, maybe if they told us the side effects beforehand rather than me finding out as it was going along"*	*"I don't know but I feel like they could have liked helped me a little bit like in that sense. Like not so much in the short-term like what's going to happen when you have chemo but like yeah like what's going to happen a year or two years down the road after this chemo"*
Information-sharing and communication	Mode of information	Information from peers with cancer	*"Some of it made me realize just how lucky I was cause I know my case is really not too severe so that was really nice to talk to people and understand different things"*	*"It's nicer to get feedback from someone who's got it then a pamphlet or someone who knows anything about it or has seen it. Someone with experience is much better"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Information-sharing and communication	Mode of information	Online information	*"We weren’t given any web site to go to or any, no one to call for support, nothing, like absolutely nothing"*	*"Okay I found some websites helpful. Probably would have liked if they gave me some websites to search"*
Information-sharing and communication	Mode of information	Verbal information	*"Well they gave me like a booklet to like read through it. But do you think I’m going to read through that? No, I don’t think so don’t have time. Don’t have the morale to go through it and see what’s good. Well if like a doctor sat down with me"*	*"I think I got a few forms and things again with the forms but like it’s hard to internalize that stuff I think. If you have a form it’s easier to toss it aside than if you’re actually talking face to face with someone um yeah"*
Information-sharing and communication	Mode of information	Written information	*"I don’t know like a welcome package as awful as that kind of sounds but just something to give to new patients, an emergency care package, and some information about some other stuff, not to scare you but just if this happens then there are some things you can do so your life isn’t miserable"*	*"I think more than websites I think if like they actually had like some kind of pamphlet or book for my type"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Information-sharing and communication	Information delivery	Discuss difficult news in a caring way	*"Well like the hair was a touchy subject for me, right. They were like you are going to lose it all like a definite 100% right? So I'm like, okay like that's a bummer right. And um, yeah. And that was just really hard to hear. Like I don't think they should have been that harsh about it"*	*"He kept on telling me it could be cancer of this, or cancer of that and this is treatable and this is untreatable and pretty much he scared the crap out of me. Um he was not very pleasing I guess from the way he talked and I wasn't really happy with him and didn't really want to see him before or after my original diagnosis"*
Information-sharing and communication	Information delivery	Explain things in a way I can understand	*"She wasn't that great let's just say that. She just was very vague with her appointments and then when she'd tell you something it would be, she'd kind of leave you thinking what am I supposed to take from that? It doesn't make any sense"*	*"He was like oh this is how it is whatever. So that stuff I really liked. But when I went to [hospital] like they're really really nice people but I feel like they're when they give the information and stuff, I always, I was kind of like still confused"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Information-sharing and communication	Information delivery	Provide detailed/ consistent information	*"Right after my surgery because I'd had a tube down in my throat for a long time, I couldn't talk, like at all and then one person came in and told me that I should try exercising it as much as possible but then someone else, shortly after I had left like told me that I should be resting it so that it had a chance to recover so it was like hold on, two specialists told me the exact opposite thing"*	*"They weren't clear. I think it could have been better if they were a little more detailed with the stuff they tell me"*
Information-sharing and communication	Information delivery	Talk to me honestly	*"That was hard cause it was like they didn't come out and directly say it, it was just like they had to be asked kind of if people are asking is it cancer?"*	*"We talk freely, like I enjoy my conversation and he gives me everything in reality…which is what you want"*
Information-sharing and communication	Seeking information	Seeking information from outside sources	*"After I was taken off the drug I was feeling aches and pains. I searched on the Internet and found that it was withdrawal because they took me off abruptly"*	*"Oh yeah, yeah. I'm one of those people that knowledge is power. Like I love, and I love learning in general so yeah. I did a lot of research on my own which you know that's okay"*
Information-sharing and communication	Support independence	Encourage patient education	*"He like really takes his time with you and questions like what do you want to know?"*	*"Just emphasizing the part about educating people who have cancer in my age group on what they can do because, yeah, you might have cancer but it's always good to be preventative"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Information-sharing and communication	Support independence	Talk to me and not just my parents	*"I remember the day that [doctor] walked in and he's like can I talk to your parents, and when they were about to walk out, I'm like I think it's about time you talk to me too. And that's when he asked my parents, is that ok? And they're like, it's him, do it, talk to him. So then we had the meeting so"*	*"When you're in your like 20s or whatever you're kind of coming out of your parent's shell in a sense. And I think it's important for people to communicate with you. If he would have spoke to my parents I would have felt like I was a child and you know my parents are making the decisions you know what I mean?"*
Information-sharing and communication	Talking about cancer	Being able to talk about cancer	*"My boyfriend now I've been with him for almost two years, and um, I was upfront with him. So I was upfront with him when I first met him, and he was like, oh cool, you're okay now? And I was like, yeah (laughs), and then that was it"*	*"I was going to say, I think uh, too like you have to be really open with your partner and talk to them about it. Um, I think that was like the most helpful for me, like you know, like I worried about you know, oh geez, like she's dying to have sex and I can't, like she is getting frustrated with me? Whoa…you can get the answers you just have to talk about it"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Physical and daily living	Health maintenance	Stay active/ eat healthy	*"Oh I'm active every day. I go on the treadmill every day for at least 45 minutes. I walk the dog every day around the lawn, which we have a huge lawn and she loves to run. And then just I know it sounds really funny but I like to dance to the music in my room"*	*"Uh one of the guys I knew in the hospital, he lied in his bed the entire day and never got out of his bed, and I-I think that's really bad. Like I think it's really important exercise, so for me it was never a problem. But I know for like uh, for some people I think they should push them to become more"*
Physical and daily living	Practical	Financial support	*"I live in a small town, so my school, they did like a fundraiser for me. So they did that. And then like my brother plays hockey so like the arena does like a fundraiser, so like I had money and I used that money for school"*	*"So, if there is some sort of program put into place for young adolescents who, you know, do get cancer, to help back them up because a lot of them are in school, especially now these days you have an undergrad degree, that's means nothing, yeah"*
Physical and daily living	Practical	Help with grooming	*"I had a shower stool that I sat cause I didn't want my mom to bathe me. No, no that's embarrassing so I tried the shower seat so like I sat there and the water would just go down and we had it like a low pressure so it wouldn't like hurt me and then have the door unlocked in case something happened"*	*"In the beginning like my Mom had to give me showers and stuff like that was really awkward. I was just like okay this is awkward. But they asked me if I want like somebody to come in especially for that. So I thought instead of somebody random that I don't even know"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Physical and daily living	Practical	Help with house chores	*"I still showered everyday—it felt-felt nice. But, cleaning my room and cleaning just didn't go well"*	*"Normally I would help out with cleaning and everything, but I can't really do that now, so they kind of do that. My nana is home now from out east so if she stays over with us, she'll do some dishes or she'll do stuff around the house"*
Physical and daily living	Practical	Transportation assistance	*n/a*	*"Cancer Society, they had a great program where you call someone up, you tell them when your appointment is and they drove you and they brought you back home, and that was, huge, huge help. I was really happy and thankful to have that service, because it was free of charge and they did a really good job of always showing up on time and the people were always nice and polite"*
Physical and daily living	Symptoms	Manage symptoms	*"I find, I don't know, it kind of helped me. Cause all the pain and struggles I was going through, and I was getting high, is just like yeah. And I didn't think about nothing that had anything to do with it and took my pain away and thought about good things"*	*"The only time I really took it was at night when I was trying to sleep, when lying down it hurt more so it was to help me fall asleep and then be able to sleep through the night. If I didn't take painkillers every time I rolled over, I'd wake up from pain"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Psychological /emotional	Autonomy	Gain independence back	*n/a*	*"When I first got out of the hospital I was so happy…you have a bit of your independence back, so I was just like floored with happiness, even though I was still in pain"*
Psychological /emotional	Feeling normal	To feel normal	*"I was irritated because I don't want pity…I want to be treated normally"*	*"I didn't tell a lot of people because I found even with my family and friends, the minute you tell them that you had cancer surgery or whatever, they treat you differently, and I didn't want that. And I also found that when I did tell a lot of people, they'd be like, oh you're so young. And they would like, I'm so sorry to hear that, and I'm like well, don't feel sorry for me. I'm still alive and, you know, doing everything. But, I didn't like, there is stigma attached to it still"*
Psychological /emotional	Self conscious	Deal with how I look during cancer treatment	*"Yeah I was self conscious. I always want to look good but then you can't really look good when you're like a chipmunk"*	*"I would always wear my wig when family members came over. And I would start like I guess in the beginning I kind of wore my wig and after a while I just stayed with the dreg."*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Psychological /emotional	Spiritual support	Spiritual support	*"I don't know I guess it kind of helped me get through it just praying and all that stuff so…It was important to me"*	*"It wasn't about religion at all. It was more about trying to be okay with what I'd done here and being okay with that it was enough. Because when you feel like well when they tell you you're going to die and you're 27 or whatever you feel like you haven't left your mark in a sense. Like you haven't done anything significant. And so I was having trouble feeling like how can I leave?"*
Psychological /emotional	Support	Support services	*"I think it just would have been important like for them to come talk about how I was feeling about things and how I was coping with things and just like, or even to just ask if there is anything that they could do"*	*"I have a girlfriend now and she's been my girlfriend pretty much since I was sick and it was um, it's a little uncomfortable like when to say it, um if not like really early but I do remember like in my head were like "Is now the right time?" like when do I make this heavy like you know and I never thought that that would be a problem it's a little difficult"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Service provision	Availability/ accessibility	Access to staff/ services	*"I haven't seen my surgeon for awhile, cause she's really hard to get appointments with, I kind of want to see her more to see how my leg is doing and the progress"*	*"I would have preferred it if they ask me like you know yeah do you want it (treatment) somewhere close to home or anything?"*
Service provision	Client (AYA) centered care	Doctors who are prepared to talk about sexual health	*"Yeah, the only other doctor that I had kicked my parents out to ask me those questions and I thought that was amazing that she did that"*	*"It was never brought up. You know like you're going through chemotherapy, they tell you about the nausea you will be dealing with and like the hair loss you'll be dealing with and like you know skin rashes and stuff like that, but they never mentioned any changes towards your-like physical sexuality and like um, mentally"*
Service provision	Client (AYA) centered care	Friendly staff	*"Um, the nurses in the ward were very good. Like they were very caring and always like happy to see me and happy to do whatever I asked them to so they were very good like what I wanted"*	*"Oh yeah she was very comforting. She was really, really nice. And then later she actually was the surgeon that did my surgery like a year later or whatever so yeah she was a very nice lady"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Service provision	Client (AYA) centered care	Knowledgeable and qualified staff	*"Last year hasn't been that good with the hospital, and a couple of weeks ago they messed up, like ever since their the receptionist left, all these other people started to do her job and they messed everything up like appointments and everything"*	*"After my experience with seeing all these specialists and professionals, I found that some of them weren't like on top of everything. I had some great people who helped me out and who were passionate and who really knew what they were doing, but then you also encounter people who they're just going through the motions, like you're just another person coming in"*
Service provision	Client (AYA) centered care	Staff that I can trust/ relate/ understand me	*"It's kind of hard for a nurse because they really don't know what the patient is going through. I know the one girl there did know, so I connected really well with her because she did know how we would feel, she did know what was happening, but some of the other nurses don't know"*	*"See this is one of the reasons why I kind of stuck with [doctor], he kind of understands me a bit better and he talks openly about things which I kind of like…doctors should be very open with their patients"*
Service provision	Client (AYA) centered care	To pay more attention/ take their time with me	*"I always see people going ahead of us, then we're always the last ones there and it just feels like we're being pushed aside for the last year"*	*"Some nurses are good, they talk to you and they take their time and some of them just come in and if they're in a mood you know, sure it's hard to leave all your issues at home but"*

Category	Sub-category	Sub-sub-category	Adolescent quotes	Young adult quotes
Service provision	Client safety	-	*"They kept battling to give me the wrong size needle I was like "no the needle that I have used every week, because the other size doesn't work for me" and that it just felt like they wanted to do it their way when I knew that it didn't work"*	*"Well I would much rather cause I am getting it from someone who grows it now, I am smoking it but it would be a lot nicer if they gave me something that I knew was clean and everything right?"*
Service provision	Coordination	-	*"I felt like I wasn't being as looked after as I needed to be, cause then one doctor's saying something and the other doctor didn't even know about it, I felt like they were like losing information, like it wasn't secure"*	*"My family doctor is updated with everything. He has a copy of all my results and everything. They send him a copy for everything. Yeah so that stuff is okay because I don't have to fill him in on anything he knows"*
Service provision	Multidisciplinary team	-	*"It's nice having a team, like more people around. It's nice having that"*	*"Physiotherapy, I think if they offered more physiotherapy for um people who were finishing up treatment and getting better, would be a big plus"*
Service provision	Support independence	Encourage patient education	*"He like really takes his time with you and questions like what do you want to know?"*	*"Just emphasizing the part about educating people who have cancer in my age group, really educating people on what they can do because, yeah, you might have cancer but it's always good to be preventative"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Service provision	Support independence	Talk to me and not just my parents	*"I remember the day that [doctor] walked in and he's like can I talk to your parents, and when they were about to walk out, I'm like I think it's about time you talk to me too. And that's when he asked my parents, is that ok? And they're like, it's him, do it, talk to him"*	*"When you're in your like 20s or whatever you're kind of coming out of your parent's shell in a sense. And I think it's important for people to communicate with you. If he would have spoke to my parents I would have felt like I was a child and you know my parents are making the decisions you know what I mean?"*
Service provision	Support independence	Time alone with doctors to discuss sensitive matters	*"They didn't really have like any time alone with me and my doctor to talk about certain things. Like the only thing we did talk about was like sex of course. But that was the only thing. Like they don't think through a teenage life, what we could be going through so I didn't really talk about that with my doctor. Or they didn't bring it up, cause of course I wouldn't want to bring it up in front of them. So they didn't really have program type of thing"*	*"I think if I was alone yeah I would have rather. If I had somebody to talk to like 1:1 I would have probably used the opportunity yeah"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Service provision	Support independence	To make the final decisions	*n/a*	*"I felt like he did a great job of speaking to me and you know letting me communicate with my parents in private and then me bring the responses back that I was the one giving like telling him what I wanted to do and you know like yeah I don't know. I felt like he did a great job making me feel equal and not a child"*
Service provision	Wait times	Improve wait times	*"Well I mean they plan, how far ahead do they schedule the MRI, like three or four or six months ahead, you'd think that they could arrange to have someone there who could do that especially when they know that someone from 3F is coming down. It's like really?"*	*"Schedule something better maybe…like come in this time and we'll start right away…or tell you on the phone we're not going to start today, it's ok if you come in later, just something where you're not wasting your whole day here for no reason"*
Social	Companionship	Deal with not being able to hang out/ do the same things as my friends	*"I means it sucks because I miss out on things that are happening at school and then they all have to like tell me and stuff, and I'm like oh, I've just been, you know, sitting here at home doing nothing"*	*"Like that's what's bothering me or like I can't go to any parties like you know you know I found myself uh buying random people birthday presents that I barely knew because I was like "Outside world!"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Social	Participation in social roles	Activities/ events	*"But it was like "well I'm still going to be in band. There's no way you are taking me out of band." And the doctors kept going "just watch your limit" or whatever and I was like "I don't want to have to have a limit"*	*"I was just getting out and about, I'd go hang out with a friend, if you get up and actually have a shower and move around and do stuff you feel, your mind is off it right so you don't feel it as much"*
Social	Participation in social roles	School	*"Yeah so that it interrupted as little school as possible so my weekends were shot but at least I didn't miss as much school. I mean I missed periods one, two, three and four but I could still get back for period five if I wanted to and choir and that stuff and not have to miss the next day"*	*"My entire, it was like my 5 last courses. So now if I have to go back now it's like I have to go back, do all those courses probably from the start. And it's like 5. But like I did one degree. So it's my second degree that I have to go back and finish"*
Social	Participation in social roles	Work	*"She's like you don't have to go back to school until next year, and I'm like yeah but I don't want to sit at home all day. So, that's why I'm mostly trying to get a job too"*	*"Yeah I think that would be a really huge one. Like helping people after their illness find work or figure out what they want to do for work or whatever. Because it's definitely yeah it's changing right like some people lose limbs and then they can't you know go back to roofing or whatever"*

Category	Sub-category	Sub-sub-category	Adolescent quotes	Young adult quotes
Social	Support	Proximity to friends	*"When you live forty-five minutes away from the hospital so all your friends are way out there and it's like I just want to talk to someone normal"*	*"I was moving to their new house and all my old friends were kind of like on the other side of [city] and uh my new friends were in [city] so it was like me and my family chilling out watching Oprah"*
Social	Support	Peers with cancer	*"So there are people here that we see them and they go "oh you're looking great! How many more weeks left?" But so it's better when we do talk to each other cause it's like we can encourage each other"*	*"It's good when you have people outside of your family and your friends who are going through the same thing, who are like, yeah, you can do this! Like, we're doing it too! And you hear their experiences, and that kind of feeds, you know, your drive and, you don't feel so different"*
Social	Support	School	*"I had a home school teacher and she came in like three times a week and helped me well tried to keep me up with all the school work but uh I still have to get lots of credits, I only have apparently ten or eleven credits and I need thirty"*	*"I think the school is more of a piss off than everything else cause they're not really understanding even when I went with a full like doctor's note and it says you know cancer and they like okay maybe the note wasn't that like"*

Category	**Sub-category**	**Sub-sub-category**	**Adolescent quotes**	**Young adult quotes**
Social	Support	Support from family and/or friends	*"My brother came home from [city] for Christmas so he was there and we had a massive neighborhood party cause we were trying to thank people that had helped us and supported us during the treatment and we had a lot of people at our house"*	*"There's the one friend I was like best friends with since grade 1 and she's the one that was probably the most disappointing. Yeah I thought she would be the one that was there for me and I have really not talked to her"*
Social	Support	Support group	*n/a*	*"I looked into going to like group counseling just to go, just to do something just to talk and stuff. But I found it was all older people. Or just breast cancer not just women but like men and women, just younger people. I think that would have been awesome. Like if I could have met like a younger person who was going through it all like I said maybe that would have been cool like you know"*
Social	Support	Work	*"Yeah, they were very good. My boss basically just held my position for me and just said whenever you are good to come back, you can come back. They were very supportive"*	*"I talked to one lady that I used to work with. One staff member that I was close with there and she kind of relays to everyone else. She calls me every so often, we talk and then she kind of lets everyone know how I'm doing"*

APPENDIX N

Comparison of findings from the qualitative study and systematic literature review to the CNQ-YP and the documentary

Category	**Sub-category**	**Sub-sub-category**	**Systematic literature review**	**CNQ-YP**	**Documentary**
Collaboration	Hospital-school	Collaboration (e.g., between school and hospital/other services, pharmacies	No	No	No
Facility	Amenities	Bathroom (e.g., close in proximity, private)	No	No	No
Facility	Amenities	Outdoor area	No	No	No
Facility	Amenities	Patient kitchen	No	No	No
Facility	Amenities	Hospital room (e.g., private)	No	No	No
Facility	Amenities	AYA ward (e.g, roommates same age, gender, type of cancer)	Yes	No	No
Facility	Design/décor	(e.g., balcony/windows, darker curtains, option to dim lighting, pleasant décor)	No	No	No
Facility	Entertainment	Entertainment for AYA (e.g., AYA outings, Internet, TV, movies, gaming system, board games, cards, magazines, special visitors, crafts)	Yes	Yes	No
Facility	Entertainment	Entertainment room (e.g, computer room, lounge, movie room)	Yes	Yes	No
Facility	Food/drink	Accessible food (e.g., cafeteria on the ward, vending machine, free snacks and drinks, flexible meal times, larger portion sizes, room service)	No	No	No

Category	**Sub-category**	**Sub-sub-category**	**Systematic literature review**	**CNQ-YP**	**Documentary**
Facility	Food/drink	Better quality	Yes	Yes	No
Facility	Food/drink	Variety of food options	No	No	No
Facility	Other	(e.g., air conditioner, control number of visitors, furniture, parking, phone)	No	No	No
Information-sharing and communication	Asking questions	(e.g., answer my questions, cancer, treatment, opportunity to ask questions, alcohol/drugs/smoking)	No	No	No
Information-sharing and communication	Cancer treatment and diagnosis	(e.g., side effects, treatment process, diagnosis, sexual function)	Yes	Yes	Yes
Information-sharing and communication	Cancer treatment and diagnosis	Other (e.g., public awareness on specific type of cancer, personalized information)	Yes	Yes	No
Information-sharing and communication	Mode of information	Information from peers with cancer	Yes	No	No
Information-sharing and communication	Mode of information	Online information	Yes	Yes	No
Information-sharing and communication	Mode of information	Verbal information	Yes	Yes	No
Information-sharing and communication	Mode of information	Written information	Yes	Yes	No
Information-sharing and communication	Information delivery	Discuss difficult news in a caring way	No	No	No

Category	**Sub-category**	**Sub-sub-category**	**Systematic literature review**	**CNQ-YP**	**Documentary**
Information-sharing and communication	Information delivery	Explain things in a way I can understand	Yes	Yes	No
Information-sharing and communication	Information delivery	Provide detailed/consistent information	No	No	No
Information-sharing and communication	Information delivery	Talk to me honestly	Yes	Yes	No
Information-sharing and communication	Other	(e.g., available services for young people getting back to exercising, preventative measures, types of food to eat, option for financial coverage, available support services, spiritual beliefs, coping strategies)	Yes	Yes	No
Information-sharing and communication	Seeking information	Seeking information from outside sources (e.g., Internet, organizations)	Yes	Yes	No
Information-sharing and communication	Talking about cancer	Other (e.g., raise awareness about cancer through public speaking, control who knows about)	Yes	Yes	No
Information-sharing and communication	Talking about cancer	Talk about cancer with family and friends	Yes	Yes	No

Category	Sub-category	Sub-sub-category	Systematic literature review	CNQ-YP	Documentary
Physical and daily living	Health maintenance	(e.g., meditation, stay active, eat healthy)	Yes	No	No
Physical and daily living	Practical	Financial support (e.g., to cover uninsured medications, sperm banking, parking, gas)	Yes	Yes	No
Physical and daily living	Practical	Help with house chores	No	Yes	No
Physical and daily living	Practical	Other (e.g., legal advice, home care)	No	No	No
Physical and daily living	Practical	Support for grooming (e.g., washing/styling hair, shower stool)	No	Yes	No
Physical and daily living	Practical	Transportation assistance	Yes	Yes	No
Physical and daily living	Symptoms	Managing symptoms (e.g., mobility issues, energy, pain, nausea)	No	No	No
Psychological /emotional	Autonomy	Gain independence back	Yes	Yes	Yes
Psychological /emotional	Feeling normal	To feel normal	Yes	No	No
Psychological /emotional	Self conscious	Deal with how I look during cancer treatment	Yes	Yes	No
Psychological /emotional	Support	Spiritual support	No	Yes	Yes
Psychological /emotional	Support	Other (e.g., age appropriate, stay focused on goals, deal with fears, physical changes, impact of cancer, life after cancer, telling family or friends about cancer, deal with uncertainty for the future, family support)	Yes	Yes	Yes

Category	Sub-category	Sub-sub-category	Systematic literature review	CNQ-YP	Documentary
Service provision	Availability/ accessibility	Access to health care professionals (e.g., doctors, social workers, diagnostic tests, treatment)	Yes	No	No
Service provision	Client (AYA) centered care	Friendly/supportive staff	Yes	Yes	No
Service provision	Client (AYA) centered care	Knowledgeable and qualified staff	Yes	No	No
Service provision	Client (AYA) centered care	Other (e.g., doctors who are prepared to talk about sexual health, phone call or in-person appointment bookings, students to build a rapport with patients)	No	No	No
Service provision	Client (AYA) centered care	Staff that I can trust/can relate/understand me	Yes	No	Yes
Service provision	Client (AYA) centered care	To pay more attention/take their time with me	No	No	No
Service provision	Client (AYA) centered care	Treat me like a teen/young adult	Yes	Yes	No
Service provision	Client safety	(e.g., supervise new students, caution when treating me)	Yes	No	No
Service provision	Coordination	Communication (e.g., between doctors, services)	Yes	No	No
Service provision	Coordination	Deal with one health care provider	No	No	No

Category	**Sub-category**	**Sub-sub-category**	**Systematic literature review**	**CNQ-YP**	**Documentary**
Service Provision	Coordination	Other (e.g., scheduling multiple appointments within one day, better transitioning (on- and off-treatment)	Yes	Yes	Yes
Service Provision	Multidisciplinary team	(e.g., rehabilitation physiotherapy personal trainer, multiple doctors)	Yes	Yes	No
Service Provision	Support independence	Encourage patient education/health maintenance	Yes	Yes	No
Service Provision	Support independence	To be involved in discussion and decision making	Yes	Yes	No
Service Provision	Support independence	Time alone with doctors to discuss sensitive matters	Yes	Yes	No
Service Provision	Other	(e.g., services for preventative measures, child life specialist, high quality treatment, choice of treatment days)	Yes	Yes	No
Service Provision	Wait times	Improved wait times	Yes	Yes	No
Social	Companionship	Not being able to hang out/do the same things as my friends (e.g., going out, drinking)	Yes	Yes	Yes
Social	Participation in social roles	(e.g., school, work, important events/activities)	Yes	Yes	No
Social	Support	(e.g., family, friends, peers with cancer, school, work, support groups)	Yes	Yes	Yes