PSYCHOSOCIAL ISSUES AND UNMET SUPPORTIVE CARE NEEDS OF YOUNG ADULTS WITH CANCER

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ISBN: 978-94-6458-834-7
EBOOK ISBN: 978-94-6458-847-7
Cover design: Ridderprint | www.ridderprint.nl
Lay-out: Publiss | www.publiss.nl
Print: Ridderprint | www.ridderprint.nl

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Psychosociale uitdagingen en onvervulde zorgbehoeften van jong volwassenen met kanker

Thesis

to obtain the degree of Doctor from the
Erasmus University Rotterdam
by command of the
rector magnificus

Prof. dr. A.L. Bredenoord

and in accordance with the decision of the Doctorate Board.
The public defence shall be held on

10 February 2023 at hrs 13.00
by

Emma Kay Lidington
born in Ascot, United Kingdom

ERASMUS UNIVERSITY ROTTERDAM

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CHAPTER 1

General Introduction

ADOLESCENT AND YOUNG ADULT ONCOLOGY

In the last few decades, adolescents and young adults (AYAs) have been recognised as a distinct subgroup of patients within oncology requiring special attention.[1] The age range for AYAs is increasingly accepted as 15-39 years, although the range used varies substantially between countries and according to purpose.[2,3] National teenage and young adult (TYA) programs in Australia and the United Kingdom (UK) include patients 13-24 years old, while epidemiological data in the United States and Canada include ages 15-39.[3] The AYA Progress Review Group has argued for the inclusion of patients up to age 39 to account for psychosocial similarities with younger ages and to provide them with a 'home' for research and care.[1] This lack of 'home' is evident in research and service provision which largely focuses on patients up to age 24, leaving the older group of young adults (YAs) under-researched and under-served. The UK provides a good example of how research and services tend to concentrate on the TYAs despite recognition of unique needs among 25-39 years olds as well.

From the first symptom to the end of therapy and beyond, AYAs face physical, psychological, and social challenges that are significantly different from those of adults and children.[4] Researchers have used theories incorporating the stages of development to explain the unique psychosocial impact of a cancer diagnosis on AYAs.[5]

Erikson's identity theory suggests there are eight stages of psychosocial development which move from infancy to maturity.[6] In each stage, an individual must overcome crises specific to that life stage to gain a sense of mastery and move on to the next stage. School age children must become proficient academically to achieve a sense of industry, adolescents must develop social relationships to achieve a sense of identity, young adults must establish romantic relationships to achieve a sense of intimacy, middle-aged adults must become competent in work and parenthood to achieve a sense of generativity and older adults must be able to reflect on their life with happiness to gain a sense of fulfilment. If individuals fail to overcome the conflict posed in their life stage, they may fail to develop a strong sense of self.

As cancer and its treatment may inhibit an individual's ability to participate in usual activities, one may be prevented from achieving a sense of competency in a given life stage. While critics argue these models oversimplify human development and fail to recognise the influence of social contexts and values, they do provide a helpful schema to conceptualise how a cancer diagnosis may impact an individual differently in each life stage.[7] With the transitional nature of adolescence and young adulthood and the particular importance of peer relationships, AYAs may experience greater interruption from a cancer diagnosis than children or older adults.

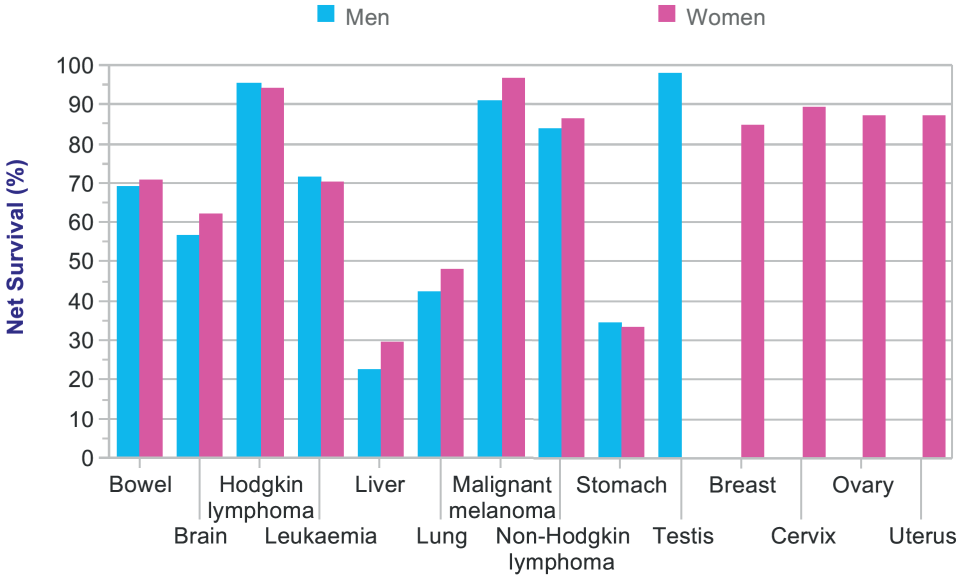
Recently, scientists have begun to argue against focusing on the ‘distinctness’ of the AYA group as a whole as this fails to recognise the heterogeneity of experience within this age range.[8] Barr *et al*. have argued the range could be split into three cohorts based on physiological and psychosocial differences, namely early young adulthood (15-18), young adulthood (19-24) and late young adulthood (25-39).[9] Taking the UK as an example, many traditional ‘milestones’ of adulthood occur on average between the ages of 25 and 39 such as moving in with a partner, having a child and purchasing a home.[10] This contrasts the younger ages when the majority of individuals complete education and move out of the parental home for the first time.[10] Research and care thus far have often grouped the cohorts together or focused largely on TYAs, obscuring potential differences in psychosocial impacts due to the varying priorities in each life stage. More research is needed to understand the specific experiences and needs of those in ‘late young adulthood’ to develop age-tailored services where required.

Cancer incidence and survival in AYAs

On average, about 2,000 TYA ages 15-24 and 12,000 YAs ages 25-39 are diagnosed with cancer each year in the UK.[11] This number among AYAs is increasing annually for most cancers, particularly obesity-related malignancies such as colorectal and pancreatic cancers.[12,13] The distribution of cancers that arise in AYAs are unique compared to paediatric and adult patients. These include certain haematological cancers (such as acute lymphatic leukaemia) and certain brain tumours (such as medulloblastoma) which are generally observed in children, solid tumours such as breast and colorectal cancers seen in adults and cancer types which are unique to AYAs such as thyroid cancer and testicular cancer.[3] However, even among AYAs, the profile of cancers is heterogeneous across five-year age intervals.[14] Cancers frequently observed among children decrease with age while those common in adults increase with age. This means TYAs tend to experience leukaemias and other cancers with long inpatient stays, while YAs experience more solid tumours, such as breast cancer, which require predominantly more outpatient treatment.

Across the 15-39 year age range, five-year survival varies by cancer type but passes 80% for the most common cancers except bowel and brain tumours (Figure 1).[15] This equates to around 300 TYAs and 1,600 YAs per year dying from cancer in the UK.[16] While survival has been improving annually, compared to paediatric patients and adults over 40 years old, AYAs have not benefitted from the same rate of improvement in survival for some tumours.[17,18] This has largely been attributed to low participation in clinical trials, limited access to age-tailored care, the need for support in symptom and side-effect management and the need for facilitated transitions to off-treatment care.[1,4,19] Efforts in the UK succeeded in improving participation in clinical trials for TYAs.[20] However, this did not include YAs and a notable drop in the proportion of patients taking part in trials can be seen between the 15-24 and 25-39 year age groups.

Figure 1. 5-year net survival for selected cancers for people in England diagnosed between age 15 and 39, 2009-2013 (source cruk.org/cancerstats).



Biomedical issues

Evidence suggests that tumour biology of cancer in AYAs may differ from that of children and older adults. AYAs tend to have more high grade, advanced stage and metastatic disease than children have at presentation.[21–25] However, these studies do not distinguish between AYA age groups which may mask differences in diagnostic characteristics between cohorts. Reasons for the difference in disease severity are incompletely defined. However, higher prevalence of subtypes with poor prognoses have been identified among leukaemia, breast and colorectal cancers in AYA patients compared to paediatric and adult groups, respectively.[26,27] A lengthy time to diagnosis among AYAs may also contribute to worse disease at diagnosis.[28] However, these studies again grouped all AYA age cohorts together obscuring any potential differences. Evidence on TYAs up to age 24 found diagnostic timeliness was worse for this group compared to children and adults.[29] Research focussing on the diagnostic trajectory of YAs is very limited.

Despite the relatively high survival, physical and psychological late effects from treatment are common. About two-thirds of AYA survivors will experience at least one late effect and a fourth will experience a severe or life-threatening late-effect including secondary neoplasms, cerebrovascular events or mortality due to cardiac disease.[30–33] Excess risk of cerebrovascular and cardiac events decrease with increasing age at diagnosis among AYAs, highlighting the need to investigate differences by age among this group.[32,33] Other common late effects that impact quality of life include fatigue, infertility, sexual dysfunction, cognitive deficits and osteoporosis.[34] Given the number of life years left after treatment as an AYA, age-tailored supportive care should be a priority to address these late-effects. Late effects may impact older and younger AYAs differently given potentially different priorities and responsibilities they may impede. Indeed, some studies have shown perceived fatigue is higher in YAs compared to TYAs.[35] However, the lack of research among YAs limits our understanding of the impact of symptoms and side-effects.

Psychological issues

Beyond biomedical issues, AYAs with cancer are specifically more likely to experience distress, anxiety, depression and fear of cancer recurrence or progression than adults.[36–38] However, much of the available evidence groups together the whole AYA age range which may obscure differences between cohorts. Studies that did compare AYA age groups found poorer mental health, greater psychological need and poorer health-related quality of life with increasing age, particularly in off-treatment survivors.[39–41] The potential differences highlighted in the small number of studies comparing these groups warrant further research into this specific population.

Social issues

Physical and emotional isolation is a key issue for AYAs during cancer treatment. Patients may have lengthy hospital stays depending on cancer type, limiting social interactions, or may be unable to attend social events due to side-effects of treatment such as immunosuppression and fatigue.[42] Evidence from TYAs up to age 24 suggests that due to the burden of hospital appointments and side-effects of treatment, AYAs with cancer are often required to take leave from education or work, further limiting social interactions.[43] Additionally, as cancer and severe illness is rare among this age group, AYAs have reported that cancer can cause emotional distance between themselves and healthy peers.[42,43] Friends may not understand what patients are going through or fear the cancer diagnosis.[44]

While evidence shows cancer and its treatment can impact social relationships with friends across the AYA age range, very little research has focused on other types of relationships. Romantic relationships may be particularly important for YAs who are interested in starting a family. Some evidence from the United States suggests fewer AYAs are married compared to age-matched controls.[45] Depending on the type of cancer and treatment received, sexual function may be impacted by a range of side-effects including diminished arousal, pain with sexual activity and vaginal dryness.[46] Some survivors may also find disclosing the diagnosis to potential partners uncomfortable or difficult.[47] However, there is little understanding of the impact on existing partner relationships and relationships with young children which may be more salient to YAs compared to TYAs.

Practical issues

Challenges in managing work, finances and childcare may be more relevant to YAs compared to TYAs who are generally supported by parents, or older adults who may be more financially stable and potentially retired. YAs ages 25-39 are likely to be working or in higher education and may have children or other dependents. Attending appointments and managing side-effects such as fatigue or pain can make continuing school or work difficult.[48] Additionally, physical impairments such as cognitive deficits may impact a patients' ability to return to work part or full time.[49,50] Most of the psychosocial research for YAs has focused on returning to work, but little research exists on the experience of having young children during cancer treatment. In one study, patients reported childcare posed a barrier to attending follow-up appointments, suggesting challenges with childcare should be explored in more depth to better understand the supportive care needs of YAs.[51] Qualitative work is necessary to gain a full understanding given the lack of age-specific validation instruments identifying supportive care needs for this group.

Taking a leave of absence for treatment or reducing working hours can lead to financial strains due to loss of income.[52] YAs report higher financial toxicity and further reduced income compared to TYAs.[53] A substantially higher proportion of AYAs highlighted finances and work/school as specific areas of distress compared to adults.[36] Furthermore, reduced income may contribute to concerns related to living situations which are higher among working age YAs compared to younger TYAs and older adults.[54] Government support and grants are available through charities such as Macmillan but the barriers and facilitators to accessing relevant support are unknown.

Available care and support

In the UK, the Teenage Cancer Trust provides specialist cancer support including inpatient units for TYAs with cancer ages 13-24.[55] This includes age-tailored supportive care services such as educational tutoring, psychological support and peer support. In cancer, supportive care refers to 'the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement.'[56] The development of age-tailored services for patients ages 15 to 24 reflects the focus of research on this younger cohort in the UK. Among a number of reviews of supportive care needs, no UK studies included YAs.[57,58] Despite the potential challenges described above, national-level support for YAs currently does not exist. Increasing the age range of AYA services to 39 is untenable given the psychosocial differences between the youngest and oldest ages and the fact this would require a six-fold expansion in resources to accommodate the increased incidence of cancer in YAs compared to TYAs.[2] Additionally, many cancer types common in YAs are treated in outpatient settings meaning dedicated inpatient units may be unnecessary.[3] A comprehensive investigation into the key supportive needs of YAs is crucial to developing support tailored for this group.

Gaps in understanding

Looking back at Erikson's stages of psychosocial development, one can imagine how cancer and its treatment may have a different impact on TYAs versus YAs resulting in differing need for supportive care services. Acknowledging individual trajectories may differ depending on geographic, socioeconomic and cultural context, younger TYAs would likely prioritise maintaining peer relationships, completing education and establishing independence from parents. In contrast, YAs may be more likely to prioritise pursuing romantic relationships, gaining employment and starting a family. In combination with the different distribution of cancers in the two cohorts, younger patients likely need inpatient services that provide educational support and facilitate relationships with other patients and healthy peers. These have been incorporated into inpatient services developed specifically for AYAs as described above. Older YAs may be more likely to need outpatient services focusing on psychological support for intimate relationships, fertility, childcare and return to work. However, research focusing on the needs of YAs is limited and dedicated services currently do not exist.

Aims of this thesis

Given the potential gap in support and the relative lack of evidence on the experiences of YAs ages 25 to 39 with cancer, this work aims to gain a better understanding of the specific psychosocial experiences and supportive care needs of this group.

We conducted a mixed methods study which included YA patients with any cancer type from 6 hospitals across Southeast England. Four of these were in London, one in Southampton and one in Ipswich. Sixty-five YAs took part in qualitative interviews and focus groups exploring psychosocial and healthcare experiences. Three hundred and forty-seven YAs took part in a cross-sectional survey investigating diagnostic intervals, supportive care needs, health-related quality of life and psychological outcomes.

Chapter Two

We explored key psychosocial issues faced by YAs through qualitative interviews and focus groups. Qualitative methodology allowed us to explore areas of interest that may not be covered by traditional questionnaires as many have not been designed with input from YAs. Qualitative data was analysed using thematic analysis. In this chapter, we focused on the emotional impact of cancer and its treatment, the social impact on relationships with friends, partners and children and practical challenges commonly faced.

Chapter Three

To understand supportive care needs in depth, we examined the healthcare experiences of YAs again using the qualitative data. We aimed to better understand the needs of YA patients in the healthcare setting and their expectations of the healthcare team. Again, qualitative methodology allowed us to explore the topic in-depth and avoid missing information excluded from questionnaires developed primarily with older adults or children. Data was analysed using thematic analysis, which involved four YAs with cancer experience to improve the robustness of the findings.

Chapter Four

To understand the average time from first symptom to cancer diagnosis for YAs, we measured the diagnostic trajectory of patients using self-report in the cross-sectional survey. We assessed both the time from first symptom to first consultation and the time from first consultation to diagnosis to understand where potential barriers to timely diagnosis may lie. We also stratified the findings by cancer type to understand if time to diagnosis varies by type of malignancy.

Chapter Five

To identify key areas of need among YAs, we measured supportive care needs using a validated questionnaire in the cross-sectional survey. We assessed supportive care need in five domains including psychological, health system and information, physical and daily living, patient care and support and sexuality needs. To identify underlying patterns of need and explore clinical and psychological factors associated with specific unmet need patterns, we used latent class analysis.

Chapter Six

The YA cancer population is heterogeneous and healthcare support needs to be addressed adequately and efficiently. To identify patients with unmet supportive care needs and help address the gap in care, we planned to develop a method to screen for patients with need using a common quality of life questionnaire. Analysing data from the cross-sectional survey, we identified cut-off scores on the questionnaire that indicate the need for support. This will allow for identification of supportive care needs among YAs in routine cancer care.

Chapter Seven

As the COVID-19 pandemic occurred during the course of this work, we examined the impact of self-isolation on AYAs with cancer given the importance of peers and socialisation to this cohort. We conducted a secondary analysis of questionnaire data collected from sarcoma patients at two London hospitals. Given the small sample size, we were unable to conduct subgroup analysis looking specifically at YAs compared to TYAs. However, we were able to look at well-being and emotional functioning among AYAs compared to older adult sarcoma patients.

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CHAPTER 2

'This is not part of my life plan': A qualitative study on the psychosocial experiences and practical challenges in young adults with cancer age 25 to 39 years at diagnosis.

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European Journal of Cancer Care. 2021; 30:e13458. doi: 10.1111/ecc.13458

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ABSTRACT

Objective

Adolescents and young adults with cancer face unique psychosocial and practical issues. However, patients across this group encounter different life experiences, cancer diagnoses and treatment settings given the tailored services for patients ages 15 to 24. Here we qualitatively explore the psychosocial experiences and practical challenges of young adults (YAs) with cancer diagnosed between ages 25 and 39 in the United Kingdom.

Methods

We invited YAs diagnosed with cancer in the five years prior to enrolment at participating sites to take part in semi-structured interviews or focus groups. Transcripts were analysed using inductive thematic analysis. Two YA patients reviewed the results to ensure robustness.

Results

Sixty-five YAs with varied diagnoses participated. Participants struggled to balance work, childcare and financial solvency with treatment. The halt in family and work life as well as changes in image and ability threatened participants' identity and perceived 'normality' as a YA, however, these also stimulated positive changes. YAs experienced social isolation from friends and family, including children. Many struggled to cope with uncertainty around treatment outcomes and disease recurrence.

Conclusions

The disruption of family and work life can lead to age-specific issues in YAs diagnosed with cancer. Age-tailored psychological and practical services must be considered.

INTRODUCTION

Due to the transitional period in life, adolescents and young adults (AYAs) with cancer face specific psychosocial issues compared to paediatric and older adult cancer patients, including loss of independence, frustration with changes in appearance, school or work interruption and fertility impairment.[1–3] Incident cancer types and tumour biology in AYAs, commonly defined by the oncology community as ages 15 to 39, also differ from older and paediatric patients, whilst improvements in survival have been slower.[4,5]

Past psychosocial research in AYA oncology used traditional task-based developmental theories to describe how cancer impacts the lives of AYAs, such as Erikson's framework, the Stages of Psychosocial Development.[6,7] These theories infer that psychosocial development is a linear progression and that the interference of cancer on completing prescribed tasks leads to developmental failure.

Recently, however, researchers have encouraged moving away from the notion that all young people share the same stepwise 'life goals' advancing from educational and vocational attainment to establishing romantic relationships and having children.[8,9] They reject the assumption that AYAs are a distinct homogenous group and suggest that research should recognise the context in which AYAs exist such as increasing financial precarity, changing timelines and priorities and expanding cultural diversity. This is particularly relevant when considering the potential differences in cancer types and life circumstances between the lower and upper ends of the AYA age spectrum.[10,11] In addition, in the United Kingdom (UK), there are substantial differences in the healthcare context across AYAs, with teenagers and young adults (TYAs) ages 15 to 24 receiving care in age-specialised services but young adults (YAs) ages 25-39 receiving cancer care in adult settings.

Past research and healthcare interventions in the UK, have focused largely on the TYA group, without distinguishing between TYAs and YAs. The lack of focus specifically on YAs may obscure important differences in experience and priorities. Here we aim to explore the specific experiences of YAs diagnosed with cancer in a UK context and describe the age-specific psychosocial impact and practical challenges of cancer and its treatment.

METHODS

Study design

This was a phenomenological qualitative research study aiming to describe the experiences of YAs diagnosed with cancer in the UK within the last five years. Phenomenological methodologies have been increasingly used in health research to explore the lived experience of illness and recovery.[12] Given the diversity of YAs in the UK, this approach was chosen for its ability to capture the richness and complexity of the direct and subjective experience of time, space, self and relations with others.

Participants

Potential participants were identified in clinic lists or locally held patient databases by the clinical team. In person or by phone, a clinical team member invited patients diagnosed with any cancer type aged 25-39 in the 5 years prior to enrolment. We recruited a convenience sample, aiming to sample a range of tumour types, from participating sites including the Royal Marsden NHS Foundation Trust, Imperial College Healthcare NHS Trust, University Hospital Southampton NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust, and Bart's Health NHS Trust.

The Royal Marsden and Institute of Cancer Research Joint Committee on Clinical Research reviewed and sponsored the study (CCR4648). The Research Ethics Committee and Health Research Authority in the UK approved the study nationally (17/LO/0219). Informed consent was obtained from all individual participants included in the study. The study complies with the standards of the Declaration of Helsinki.

Setting

Focus groups were conducted in hospital meeting rooms or local charity centres. A nurse or oncologist was present to address clinical questions. One-to-one interviews were conducted in-person either in hospital or by telephone.

Data collection

Data collection took place between November 2017 and July 2018. Each participant provided written informed consent and chose to take part in a focus group or interview. Travel was reimbursed for participants who participated in person. Participants self-reported sociodemographic and clinical information prior to participation.

Semi-structured individual interviews and focus groups were conducted as complementary data collection methods to enhance the richness of the data collected.[13] Integrating both methods of collection allowed the interviewers to obtain a description of personal experience in individual interviews and explore agreeing and contrasting opinions and beliefs in focus groups. The facilitator (EL), a non-clinical public health researcher formally trained in qualitative research, followed a semi-structured interview schedule (Table 1). The interview schedule, drafted specifically for this study by the authors, was intentionally broad to elicit the issues most salient to the participant and avoid inference about developmental tasks or timelines. The two YA patients and two healthcare providers with a research focus on young people with cancer reviewed the interview schedule for relevance and comprehensiveness and provided written feedback by email. Based on the comments, we amended the question exploring areas of need to elicit issues perceived to be specifically related to age. Discussions were audio-recorded and transcribed verbatim. Field notes were kept to provide context.

Table 1. Semi-structure interview schedule.

Questions
1. Could you tell me about your experiences in the time since your cancer diagnosis? 2. Have you faced any challenges or problems? 3. Have you had any particular needs or issues in the following areas as a YA cancer patient? • Psychological or emotional • Risk behaviour • Practical • Social • Spiritual

Data analysis

Transcripts were analysed using the six phases of inductive thematic analysis described by Braun and Clarke which include: (1) familiarisation with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing potential themes, (5) defining and naming themes and (6) writing the report.[14] Two researchers (EL and CV) openly coded the data independently and reconciled the initial codes in NVivo (Version 12, QSR International). Field notes were consulted during initial coding to provide context to the transcripts and aid interpretation. The researchers used the codes to identify potential themes and subthemes. These were refined in an iterative process in discussion with the larger study team including two YA patients (ET and KS). The YA patients provided an expert opinion on interpretation of the data and robustness of the results. The analysis process was fluid rather than linear as we continued to refine the themes while producing the manuscript. We specifically sought to identify commonalities across participants and provide a detailed account of important themes unique to YAs.

RESULTS

Of the 152 patients invited, 65 (42.8%) patients participated, 50 (76.9%) in individual interviews and 15 (23.1%) in five focus groups. Three patients declined due to illness, two felt too distressed, seven were too busy, 45 declined without reason, six did not meet eligibility criteria after review and 24 did not participate after consent. Interviews averaged 43 minutes (range: 20–88 minutes) while focus groups averaged 117 minutes (range: 92–150 minutes).

YAs were 33.6 years old on average at the time of participation (Table 2). The majority of participants were female (N=39; 60.0%), white (N=50; 74.6%), married (N=35; 53.8%), university educated (N=45; 69.2%) and did not have children (N=38; 59.4%). YAs varied in living arrangements and employment status but the majority experienced some level of financial difficulty (N=33; 54.1%).

A range of tumour types were included, most commonly sarcomas (N=13; 20.0%), breast cancer (N=12; 18.5%) and central nervous system (CNS) tumours (N=12; 18.5%) (Table 3). YAs were an average of 31.7 years old at diagnosis and a mean of 1.9 years from diagnosis. The majority were in follow-up (N=37; 56.9%), treated with curative intent (N=40; 66.7%) and had received chemotherapy (N=46; 71.9%) or surgery (N=38; 59.4%).

We identified four main themes. The themes and subthemes along with codes and exemplary excerpts are presented in Table 4. Numbers in parentheses denote the in-text reference for the excerpt in the table.

Table 2. Patient-reported demographic information.

Participant characteristics (N=65)	**Mean (Range)**
Age at participation	33.6 (25-42) years
	Number (%)
Gender	
Female	39 (60.0)
Male	26 (40.0)
Ethnicity	
White	50 (74.6)
Asian / Asian British	11 (16.4)
Black / African / Caribbean / Black British	2 (3.0)
Mixed / Multiple ethnic groups	2 (3.0)
Relationship status	
Married	35 (53.8)
In a relationship	16 (24.6)
Single	13 (20.0)
Divorced	1 (1.5)
Children under 18 (n=64)	
No	38 (59.4)
Yes	26 (40.6)
Current living situation	
Live with spouse / partner	24 (36.9)
Live with spouse / partner and children	20 (30.8)
Live with parents	6 (9.2)
Live with housemate(s)	6 (9.2)
Live alone	6 (9.2)
Live with spouse / partner and parents	2 (3.1)
Live with children	1 (1.5)
Highest level of education	
University or degree	45 (69.2)
College or diploma	11 (16.9)
Secondary School	7 (10.8)
Vocational qualification	2 (3.1)
Current employment status (n=64)	
Full-time employed	30 (46.9)
On sick-leave	15 (23.4)
Part-time employed	7 (10.9)
Self-employed	5 (7.8)
Unemployed	3 (4.7)
Homemaker and/or caretaker for children	2 (3.1)
Other	2 (3.1)
Experienced financial difficulties (n=61)	
Not at all	28 (45.9)
A little	20 (32.8)
Quite a bit	9 (14.8)
Very much	4 (6.6)
Decrease in income	27 (81.8)
Travel costs	8 (24.2)
Childcare	2 (6.1)

Table 3. Patient-reported clinical information.

Participant characteristics (N=65)	**Mean (Range)**
Age at diagnosis	31.7 (25-39) years
Years since diagnosis	1.9 (0-5) years
	Number (%)
Diagnosis	
Sarcoma	13 (20.0)
Breast cancer	12 (18.5)
Central nervous system tumour	12 (18.5)
Gastrointestinal cancer	7 (10.8)
Urological cancer	6 (9.2)
Gynaecological cancer	5 (7.7)
Haematological cancer	5 (7.7)
Lung cancer	3(4.6)
Melanoma	2 (3.1)
Current treatment status	
In follow-up	37 (56.9)
On treatment	28 (43.1)
Treatments received (n=64)	
Chemotherapy	46 (71.9)
Surgery	38 (59.4)
Radiotherapy	28 (43.8)
Clinical trial	13 (20.3)
Hormone therapy	7 (10.9)
Immunotherapy	7 (10.9)
No treatment	5 (7.8)
Targeted therapy	5 (7.8)
Bone marrow or stem cell transplant	1 (1.6)
Brachytherapy	1 (1.6)
Treatment intent (n=60)	
Curative	40 (66.7)
Unknown	12 (20.0)
Palliative	8 (13.3)
Disease recurrence (n=61)	
No	41 (67.2)
Yes	10 (16.4)
Not applicable	10 (16.4)
Number of comorbidities (n=61)	
None	45 (73.8)
1	12 (19.7)
2	1 (1.6)
3	3 (4.9)

Theme 1: Competing responsibilities

Subtheme 1: Balancing treatment and work or childcare

YAs encountered difficulty balancing responsibilities while undergoing treatment or in recovery due to hospital appointments and immobilising side-effects. Some participants could not or did not want to stop working for extended periods of time. Patients felt the challenge of navigating treatments and appointments among work commitments were not always appreciated by the healthcare team (1.1.1). Particularly for single parents, the unpredictability of wait times and hospital admissions made childcare challenging. Some patients felt there was little support around caring for children while on treatment (1.1.2).

Subtheme 2: Financial insecurity

A number of participants experienced financial difficulties after receiving a cancer diagnosis. This was often due to a loss of income with extended sick leave but also to concurrent events such as moving house or reduced income during maternity leave (1.2.1). YAs often relied on parents for childcare and in some cases received financial support or moved back in, which was perceived as a relief. Some YAs worryingly described financial difficulty as a major factor in returning to work before full recovery, leading to mental health challenges (1.2.2).

Theme 2: Retaining normality and identity as a YA

Subtheme 1: Avoid cancer identity

YAs wanted to ‘get on with it’ and avoid cancer becoming the focus of daily life. For YAs this often meant continuing to work or spending time with friends and family, often avoiding cancer-related activities as much as possible (2.1.1). Changes in physical appearance such as hair loss or weight gain were often distressing as they belied their illness and attracted attention, particularly as YAs compared themselves to healthy peers (2.1.2). Hair had particular cultural importance for some YAs from minority backgrounds who faced a lack of inclusive wig services, where the hair offered was more appropriate for Caucasian women. Changes in physical ability, including sexual function, lowered confidence and made YAs feel ‘less capable’.

Subtheme 2: Work life a component of YA identity

Working life was a central component to YA’s sense of normality in terms of goals and daily routine (2.2.1). Returning to work was an important part of returning to ‘normal.’

However, many YAs found returning to work difficult or daunting due changes in cognition, energy levels, physical ability and time passed (2.2.2). Many YAs viewed their ability at work as a part of their identity and self-worth. Some participants were frustrated if they were unable to return to the same level of performance or the same role as before the cancer diagnosis (2.2.3). A number of YAs described a great amount of pride in their careers and experienced immense feelings of loss if unable to return.

Subtheme 3: Positive change in outlook and priorities

Despite the adversities described, many YAs felt the unexpected cancer diagnosis was a catalyst for personal growth in various ways, including gaining fearlessness or confidence and learning to accept a lack of control (2.3.1). Some participants felt they learned to prioritise family and personal experiences over work, appreciating time spent with loved ones (2.3.2). Experiencing cancer also helped improve relationships with partners, parents and friends when confronted with emotional distress and potential early mortality (2.3.3).

Theme 3: Facing isolation

Subtheme 1: Distancing from friends

Although some relationships improved, YAs found that other friendships were weakened by the cancer diagnosis. YAs found that friends without personal experience of cancer or severe illness did not understand what they were going through, making it difficult to relate and leading to discomfort (3.1.1). YAs worried about forming new relationships as they were unsure how or whether to disclose their diagnosis, particularly with potential romantic partners (3.1.2). Participants experienced a range of cancer-related worries including fear of disease progression or recurrence. Despite these concerns, many YAs downplayed their emotions or declined to disclose full details about the diagnosis in order to protect loved ones, sometimes contributing to perceived emotional distance (3.1.3).

Subtheme 2: Feeling younger than other cancer patients

Not only did YAs find it difficult to relate to peers, but they often found it difficult to relate with other oncology patients due to the common age difference (3.2.1). YAs felt their psychosocial concerns, healthcare needs and social interests were very different from those of older patients. Being visibly younger also made participants feel uncomfortable and out of place in the hospital as it attracted unwanted attention from patients and hospital staff (3.2.2).

Subtheme 3: Missing out

Many patients felt isolated from friends and family due to side-effects like fatigue, fear of infection or extended hospital admissions. For YAs with young children this was particularly distressing as they felt they missed out on important developmental changes (3.3.1). Hospital settings, designed for older adults, made it difficult to bring children to visit. YAs usually felt extremely busy before the cancer diagnosis, making the isolation due to treatment and side-effects more difficult to cope with. Participants felt that they missed out on social activities with friends and family as well as the social aspects of work (3.3.2). Only a few YAs discussed missing religious gatherings as a source of frustration, but this was particularly important for some.

Theme 4: Coping with Uncertainty

Subtheme 1: Uncertain life circumstances

Challenges faced by YAs were compounded by the transitional nature of YA life and future uncertainty. All participants were extremely shocked by their diagnosis as cancer is rare and unexpected among YAs who are usually otherwise healthy (4.1.1). At the time of diagnosis, many participants described moving house, changing jobs, building new relationships or having children. The uncertainty in life circumstances made managing treatments and appointments more difficult (4.1.2). While not all YAs were interested in having children or growing their family, the need for timely treatment required YAs to make decisions about fertility treatment they felt unprepared for. The diagnosis and treatment were particularly disruptive as it forced YAs to face possible mortality at a time full of plans for the future.

Subtheme 2: Uncertain clinical outcomes

Uncertainty about short-term treatment outcomes and long-term life expectancy weighed heavily on the minds of many participants, particularly for patients with rare or advanced cancers. YAs had to defer plans for relationships, moving home and furthering careers. Several patients felt the uncertainty made them feel like life was ‘on hold’ (4.2.1). Other patients described coping with the uncertainty by ‘living one day at a time’ or actively deciding not to focus on prognosis and staying positive about future life expectancy (4.2.2). After treatment, anxiety around cancer recurrence was heightened by reduced monitoring and less frequent contact with the healthcare team (4.2.3).

Table 4. Coding hierarchy.

Theme	Subtheme	Code	In-text reference	Example excerpts
1. Competing responsibilities	1.1 Balancing treatment and work or childcare	*Work and treatment or recovery*	1.1.1	*I was, like, so stressed trying to finish loads of work off… It was almost like, well don't burden yourself with thinking about all those other things; let's just get through the treatment… I can't not burden myself with these things. I have to; they're there. – female breast cancer patient on treatment*
		Childcare and treatment or recovery	1.1.2	*The logistics between having two young children that aren't at school. Husband having to go back at work. Fatigue and just generally trying to find childcare for them when I'm in the hospital, in and out of hospital. – female haematological cancer patient on treatment*
	1.2 Financial insecurity	*Financial strain*	1.2.1	*It did affect financially. So the house that we lived in, we had to rent out. And we had to move in with our parents; my wife and kids. So yes, so financially it was meaning that we couldn't pay our mortgage. – male CNS tumour patient on treatment*
		Returning to work prematurely	1.2.2	*I certainly couldn't afford to take time off when I was going through treatment. I knew I had to work through treatment financially. – female breast cancer patient in follow-up* *I tried to get right back to work in October. Partly that was because I think I was going to be going down to half pay… I think the realisation of what I had gone through plus the fact that I was really struggling at work. I kind of then went off with severe depression. – female CNS tumour patient in follow-up*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Example excerpts
2. Retaining normality and identity	2.1 Avoid cancer identity	*'Get on with it'*	2.1.1	*It was maybe also a bit of a coping mechanism ... when I went up to the hospital I was a patient the duration of the appointment. And then once the appointment was over, that was it... kind of a way, I guess, of telling myself that the illness wasn't the most important thing in my life. – male sarcoma patient on treatment*
		Self-conscious	2.1.2	*They gave me a zimmer frame. I actually looked at it and said, no, I'm not using that... I'm 37 years old. I'm not 78 years old. I didn't want to do it. I'm very proud and private and I didn't want to be seen as old and frail.... I want to be me and I haven't been able to be me since being diagnosed and I will never be me again. – male urological cancer patient on treatment*
	2.2 Work life a component of YA identity	*Retaining a sense of normality*	2.2.1	*I'm really pleased to be back, and, like you say, because obviously I'm young and my career was my focus in life before my diagnosis, having that stripped away, yes, it was a huge, huge deal. – female breast cancer patient in follow-up*
		Difficulty returning to work	2.2.2	*I just don't know if I can put myself back into a situation where people feel they knew me, like I was second in charge of my department, like doing all this stuff, like aiming for head of department, and now I am just not there. – female gynaecological cancer patient on treatment*
		Changes in ability	2.2.3	*I am so embarrassed, I am still young, I want to be strong and I want to be the top performer again. – male CNS tumour patient in follow-up*
	2.3 Positive change in outlook and priorities	*Personal growth*	2.3.1	*It really allowed me to understand better who I am. I have made some pretty important decisions, and if there is anything good that has come out of this disease it's that really, I think I have matured enormously. – male urological cancer patient in follow-up*
		Prioritising family and well-being	2.3.2	*I do miss [teaching] incredibly. I miss the kids, I miss the colleagues I worked with, but ultimately, now, I'm just like it's not important for me anymore. My family is important, my friends are important, my health is important, my life is important. – female CNS tumour patient on treatment*
		Improving relationships	2.3.3	*I think also, because like I say my relationship was relatively young, we were relatively early in our relationship. My partner has been incredibly supportive; it has made us stronger I think. – female breast cancer patient in follow-up*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Example excerpts
3. Facing isolation	3.1 Distancing from friends	*Friends can't relate or don't understand*	3.1.1	*Relationships I had deteriorated, kind of disappeared... So it's difficult. It was very isolating in some ways. And yes, you do feel ashamed for kind of the situation that you're in. Well, I certainly have anyway. In the end, you find out who your friends are and the world becomes much, much smaller. – female gastrointestinal cancer patient on treatment*
		Difficulty forming new relationships	3.1.2	*I feel like I'm always dropping a bombshell, that this happened. Like, like, even with, like, things like, I don't know, dating someone new and things like that, I don't quite know. I haven't sort of really, like, broached that sort of bit yet and I don't know how I will. – female breast cancer patient in follow-up*
		Wanting to protect loved ones	3.1.3	*I was trying to protect people, to some extent, because I remember certain people being really affected and emotional or freaked out and even distancing themselves because they didn't know what to say or how to be around me. – female gastrointestinal cancer patient in follow-up* *I think sometimes you don't realize as well, how much you are holding in... the hardest part is seeing how it affects other people. For me, it was seeing the way my father reacted when I told him... he just totally broke down and flopped his arms on the table in front of me. – male gastrointestinal cancer patient on treatment*
	3.2 Feeling younger than other cancer patients	*Can't relate to older patients*	3.2.1	*The people who were in there with cancer had generally retired, so there was very little in common when it came to my wife taking time off work, working hours, what type of job you did, those type of things weren't on their agenda. – male haematological cancer patient in follow-up*
		Feeling out of place in hospital	3.2.2	*I don't enjoy sitting in the waiting room mainly because I do feel everyone there is so much older than me... I walk through and people are, What's that person doing there? What's she doing there? She's too young to be here. – female melanoma patient in follow-up*
	3.3 Missing out	*Miss children due to treatments*	3.3.1	*There wasn't really a good place to take him while we were [in hospital], so that was quite difficult and we stopped bringing him up... It was quite hard. Especially, I'd see such a change in him when I'd go in and then come home afterwards. It was quite tough. – male sarcoma patient in follow-up*
		Miss social life	3.3.2	*There are certain activities I can't take part in any more, like big nights out drinking... I can't do big physical activities, like going for runs... there's a longing in me sometimes, I wish I could train for this and take part. So there are things I do miss out on now. – male CNS tumour patient in follow-up*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Example excerpts
4. Coping with uncertainty	4.1 Uncertain life circumstances	*Unexpected illness*	4.1.1	*I was well, I was running, just fit and healthy. There was no symptoms of the lung cancer and obviously I'm not really in the demographic… it's a lot more shocking I think for a young adult. – female lung cancer patient on treatment*
		Transitional period	4.1.2	*I was 31 and I was not expecting it. I'd resigned from my job as well. It was loads going on. I had to go back and tell my employer that it's come up and that I couldn't start the new job, and then it was all a bit of a blur… we were actually going to start IVF. It was a tough, tough time. – female breast cancer patient in follow-up*
	4.2 Uncertain clinical outcomes	*Life on hold*	4.2.1	*It's not knowing what to do next. If I can find a job… Anything feels permanent I can't put my foot into it, because I don't know when I'll have to take my foot out of it… I feel like I'm floating through my life. – female sarcoma patient in follow-up* *It's the fear of always waiting for the next blood test, always waiting to see are the markers going to go down. It's the fear of the unknown. Fear of… not knowing if you're going to be alive any more or not in the near future. It's very hard, it's extremely hard. – male urological cancer patient in follow-up*
		Coping with uncertainty	4.2.2	*When I sit down and have two minutes to myself and I think of what's happened and what's going to happen for the future. Yes it can be a bit worrying if it ever comes back and how am I going to tackle that and what is going to happen. As I said, all I can do is take one day at a time. It happens. – male CNS tumour patient on treatment*
		Fear of recurrence	4.2.3	*I think that, when you first finish treatment as a cancer patient, I think you literally live with a fear all of the time that something is going to return. So, every headache you get, every time your arm hurts, everything… You feel that's it, it's coming back. – female breast patient in follow-up*

CNS Central nervous system

DISCUSSION

The psychosocial experiences and practical issues identified here are centred on the active day-to-day routine of YAs with early careers and young families and the sudden disruption of their activity following a cancer diagnosis. This interruption may threaten YAs' sense of identity as a young person, in contrast to older adults who may find cancer less disruptive to personal identity in the context of ageing and declining health.[15]

Family, important to people of any age, plays a unique role for YAs. While social isolation is experienced acutely across the AYA age range, YAs have the added complexity of missing out on the lives and development of young children.[16] At present, YAs do not benefit from tailored measures to reduce social isolation in wards and clinics that exist in TYA treatment centres.[17] While psychosocial support for TYAs focuses on access to peers, services for YAs need to also provide family support. Although not specifically asked about, YAs did not describe feeling frustrated about becoming dependent on parents again or perceive relying on parents for childcare or housing as a regression in development as previous theories infer. Notably these feelings are often observed in TYAs.[18,19] In contrast, YAs actively protected parents and friends from the emotional burden of the condition.[20]

Work plays an important role for YAs as a financial necessity but also in providing a sense of normality, a source of social interaction and, for some, a contributor to identity and self-worth. Interventions to support attaining educational and vocational goals have been developed for TYAs to facilitate reintegration after treatment.[6] YAs need similar support to return to work and 'normal life,' navigating the myriad of legal, social, material and health-related issues they face.[21] This is particularly important given the difficulty YAs in this study described in returning to work. Previous research has shown YAs experience higher perceived physical and cognitive deficits compared to older adults that may limit their ability to return to work.[22,23] Financial toxicity, reported extensively in North America, is also experienced by YAs in the UK due to loss of income and travel costs.[24,25] This needs to be addressed to ensure YAs return to work at an appropriate time.

Coping with uncertainty was a strong theme amongst YAs. While uncertainty and fear of recurrence may occur among cancer patients of any age, it may be particularly pronounced in young patients.[26] Additional social uncertainty for YAs due to the transitional period in life, as highlighted by the patients here, may contribute to the concerns. Higher illness uncertainty is linked to lower social support and lower quality of life, making the YA experiences of social isolation a cause for concern.[27] Despite worries about short-term treatment outcomes and recurrence, many YAs shared stories of personal growth and strengthening in relationships. This suggests the current discourse around young people experiencing either post-traumatic growth or post-traumatic stress may simplify the human condition as patients can experience both simultaneously.

Participants in this study shared experiences of job and financial insecurity, also reflected in the responses to the background questionnaire. These findings support the new frameworks suggested by Levin and Hammond that take the changing economic context for young people with cancer into account.[8,9] Our findings also support the idea that life goals and priorities vary between individuals, as a number of YAs did not plan to have children and were happy to live with family members. However, the contribution of work to identity and the focus on family life and children fits with previous theories taking developmental life course perspectives.[28] The lack of culturally appropriate supportive care services reflects the scarcity of research and support tailored to meet the needs of the diverse UK population. The specific issues faced by growing minority groups of YAs should be explored in-depth in future research.

Clinical implications

YA experiences suggest that there may be a need for more awareness of YA-specific issues by healthcare providers and improved age-specific practical, emotional and social support during cancer treatment and recovery. The National Institute for Health and Care Excellence guidelines for providing cancer care to children and young people provide excellent recommendations for age-specific multi-disciplinary care.[29] Patients and providers should review these guidelines to determine whether they should extend to YAs and if current adult supportive care services should be supplemented with YA-specific support.[30]

Scalable interventions should be explored, particularly those that can be delivered remotely.[31,32] A paper-based discussion aid called ‘Snapshot’ providing prompts for psychosocial issues and a mobile phone app supporting symptom tracking have shown to facilitate conversations around personal or sensitive topics in AYAs.[33,34] Individual psychological support focusing on AYA-related issues including social, family and romantic relationships and a similar intervention using cognitive behavioural therapy have shown to improve quality of life.[35,36] Consulting with a fertility specialist and undertaking fertility preservation has the biggest impact on reducing decisional regret and improving quality of life, however, web-based decision aids in conjunction with specialist consultation have also shown to reduce decisional conflict.[37–39] Multidisciplinary interventions including physical, psychological information and/or vocational facets can improve return-to-work rates and quality of life in people of working age with cancer.[40]

Study limitations

While this study included a large number of YAs, the conclusions are limited by its geographic focus in Southeast England, with a majority of patients treated in London. The study did benefit from representation of ethnicities that roughly match the population distribution in Southeast England.[41] Future work should focus specifically on the needs of growing minority groups in order to provide culturally appropriate care. The large number of patients from London may also have influenced the results with the emphasis on careers. However, this perspective is important for treating YAs from a metropolitan area.

A high number of patients in this study had rare cancer types and advanced disease that may also have impacted the main themes identified such as the focus on uncertainty. However, this is also an important group of patients that is often excluded from studies. This study had a broad, exploratory focus allowing participants more autonomy in directing the interviews and focus groups but reducing the possibility for in-depth analysis of the topics identified. Asking patient in follow-up to reflect on their experience since diagnosis also limited our ability to attribute certain issues to treatment status. The large sample enabled the identification of patterns across a variety of tumour types, even though the amount of data also limited in-depth analyses. Future work will conduct sub-group analysis to further explore the diversity in experiences.

CONCLUSIONS

With an unexpected cancer diagnosis, YAs face a number of specific psychosocial experiences and practical challenges with the sudden halt of family and work lives. Current healthcare services designed to treat much older adults may not fully address these issues and provide adequate support to YA patients. Further research should identify age-specific requirements in supportive care services.

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CHAPTER 3

Beyond teenage and young adult cancer care: Care experiences of patients aged 25 to 39 years old in the United Kingdom National Health Service.

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Clinical Oncology.. 2021; 33:494-506. doi: 10.1016/j.clon.2021.02.010

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ABSTRACT

Purpose

Adolescents and young adults with cancer ages 15-39 face unique medical, practical and psychosocial issues. In the United Kingdom, principal treatment centres and programmes have been designed to care for teenage and young adult (TYA) patients aged 13-24 in an age-appropriate manner. However, for young adults (YAs) with cancer aged 25-39, little access to age-specific support is available. We aim to examine this possible gap by qualitatively exploring YA care experiences, involving patients as research partners in the analysis to ensure robust results.

Methods

We conducted a phenomenological qualitative study with YAs diagnosed with any cancer type between ages 25 and 39 in the last five years. Participants took part in interviews or focus groups and data was analysed using inductive thematic analysis. Results were shaped in an iterative process with the initial coders and four YA patients who did not participate in the study to improve the rigor of the results.

Results

Sixty-five YAs with a range of tumour types participated. We identified seven themes and 13 subthemes. YAs found navigating the healthcare system difficult and commonly experienced prolonged diagnostic pathways. Participants felt under-informed about current clinical details and the long-term implications of side-effects on daily life. YAs found online resources overwhelming but also a source of information and treatment support. Some patients regretted not discussing fertility before cancer treatment or felt uninformed or rush when making fertility preservation decisions. A lack of age-tailored content or age-specific groups deterred YAs from accessing psychological support and rehabilitation services.

Conclusions

YAs with cancer may miss some benefits provided to TYAs in age-tailored cancer services. Improving services for YAs in adult settings should focus on provision of age-specific information and access to existing relevant support.

INTRODUCTION

Adolescents and young adults (AYAs) with cancer ages 15 to 39 years have been described as a distinct group in oncology. AYAs face heightened psychosocial and practical issues compared to paediatric and older adult patients that include the drive to achieve 'normality,' the importance of family and friends, and difficulty balancing school, treatment and family matters.[1–4] Furthermore, tumour biology and incident cancer types differ in AYAs compared to other ages, further highlighting the need for tailored care.[5,6]

While this message of distinction has brought international attention and action, critics have suggested it fails to appreciate the heterogeneity of AYAs and differences in experience depending on context.[7,8] The 15 to 39 year age range encompasses a spectrum of life stages, meaning the experiences of patients can vary extensively.[9,10] Younger AYAs tend to develop cancers common in paediatric patients, such as leukaemia, requiring in-patient admissions, while older AYAs tend to develop adult cancers, such as breast cancer or melanoma, which are usually treated in outpatient settings.[11,12]

Treatment setting is particularly relevant in the United Kingdom where tailored cancer units and services have been established for teenagers and young adults (TYAs) ages 13 to 24.[13] TYAs are routinely referred to these services which have multi-disciplinary input providing age-tailored medical and psychosocial support.[14,15] However, young adults (YAs) ages 25 to 39 are treated in general adult settings with minimal provision of age-specific support through hospital services.

Studies that consider the complete AYA age range as a single group may obscure important differences driven by access to relevant services. The 2017 National Cancer Patient Experience Survey reflects these differences in care experience where YA participants between ages 25 and 34 scored the lowest of all ages groups on over half of the items, including questions about involvement in treatment decisions and overall ratings of care.[16]

While it is recognised that unique medical, practical and psychosocial issues arise in cancer patients across the AYA age range, previous research and age-specific services have focused primarily on TYAs. To understand whether tailored support is also needed for YAs treated in an adult setting, we aimed to qualitatively explore the healthcare experiences of YAs with cancer treated in UK hospitals.

MATERIAL AND METHODS

Study design

We aimed to explore the care experiences of YAs in a phenomenological qualitative study and involve patients in the analysis to accurately describe the data and improve the robustness of the results.

Participants

Eligible patients were diagnosed with any cancer type between age 25 and 39 in the previous 5 years at one of the participating sites, including the Royal Marsden NHS Foundation Trust, Imperial College Healthcare NHS Trust, University Hospital Southampton NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust and Barts Health NHS Trust. Potential participants were identified in clinic lists or local databases and approached in clinic or by telephone by the clinical team. We recruited a convenience sample with a view to including patients with a range of tumour types across hospital sites.

Research team

The study coordinator, formally trained in qualitative methodology, facilitated the interviews and focus groups. The research team included clinicians, nurses, patients, psychologists and health scientists, providing multi-disciplinary perspectives. Additional funding was secured to involve four YA patients who did not participate in the study in data analysis. A YA cancer charity advertised the opportunity by email.

Data collection

Each participant provided informed consent before choosing to take part in an individual interview or focus group. Patients reported sociodemographic and clinical information in a structured questionnaire before taking part. The researcher conducted the interviews and focus groups following a semi-structured schedule reviewed by patient representatives and health care providers to ensure relevance and comprehensiveness (Table 1). Focus groups were held in hospital meeting rooms or local charities. A clinician was present to answer arising clinical questions. Interviews were conducted in-person at the hospital or by telephone. Focus groups and interviews were audio-recorded and field notes were kept by the facilitator or an observer.

Table 1. Semi-structured interview and focus group schedule.

Questions
1. Could you tell me about yours experiences leading up to and in the time since your cancer diagnosis? 2. What has your experience been like receiving healthcare and supportive care services for your cancer? 3. Have you faced any challenges or problems? 4. What are your expectations for age-specific cancer care for young adults? 5. Have you had any particular needs or issues in the following areas as a YA cancer patient? · Psychological or emotional · Physical · Risk behaviour · Practical · Social · Spiritual · Healthcare

Data analysis

Data analysis followed the six phases of inductive thematic analysis described by Braun and Clarke.[17] These phases include (1) getting to know the data, (2) initial coding, (3) generating potential themes and subthemes, (4) reviewing potential themes and subthemes, (5) defining and naming themes and (6) report writing.

Audio-recordings were transcribed verbatim and stored and analysed in NVIVO.[18] Two researchers initially open-coded the data and reconciled the codes using field notes to justify decisions. The two researchers used the initial codes to generate potential subthemes and themes. The potential themes and subthemes were then reviewed by the study team in an iterative process.

Rigoru

Potential themes and subthemes with five exemplary quotes from each subtheme were shared with YA patients along with training materials on qualitative methodology. The quote interpretation, theme and subtheme structure and the salience, definition and wording of each theme and subtheme were discussed in-depth across three half-day sessions held in hospital meeting rooms or remotely by video conference. Suggested changes were evaluated against the full dataset by the researcher. In this iterative process, changes made by the researcher according to patient suggestions were reviewed and agreed at the next session. The patients and study team also reviewed and commented on each manuscript version. Reporting of patient involvement follows GRIPP2 guidelines.[19]

RESULTS

Clinical team members approached 152 patients. Sixty-five (42.8%) patients participated, 50 (76.9%) in interviews and 15 (23.1%) in five focus groups. Three individuals declined because they felt too ill, two felt too distressed, seven were too busy, 45 gave no reason, six did not meet eligibility criteria after careful review and 24 did not participate after consent. Interviews lasted on average 42 minutes (range 20-88 minutes) while focus groups lasted 117 minutes on average (range 92-150 minutes).

Participants on average were 33.6 years at participation and 1.9 years from diagnosis (Table 2). The majority of YAs were female (N=39; 60.0%), white (N=50; 74.6%), married (N=35; 53.8%), university educated (N=45; 69.2%) and did not have children (N=38; 59.4%).

Participants had a range of tumour types; most commonly sarcomas (N=13; 20.0%), breast cancer (N=12; 18.5%) and central nervous system tumours (N=12; 18.5%) (Table 3). The majority of patients had completed treatment (N=37; 56.9%).

Initial analysis identified five themes (delay in diagnosis, navigating the healthcare system, health information, variability in fertility preservation discussion and sign-posting to relevant resources) with 14 subthemes. YA patient analysis elevated 'internet double-edged sword' and 'psychological and emotional support' to themes and reshaped subthemes resulting in seven themes and 13 subthemes. YAs also advocated renaming 'delay in diagnosis' to 'prolonged diagnosis' to better reflect the diagnostic experience. Patients felt the size of 'navigating the healthcare system' appropriately highlighted the salience of the theme.

In-text parentheses refer to the exemplary quotes in Table 4 which presents the coding hierarchy with the final themes, subthemes, codes and quotes. The healthcare experience themes broadly translate to two categories of needs: health system needs and information needs.

Table 2. Self-reported patient demographic information.

Participant characteristics (N=65)	**Mean (Range)**
Age at participation	33.6 (25-42) years
	Number (%)
Gender	
Female	39 (60.0)
Male	26 (40.0)
Ethnicity	
White	50 (74.6)
Asian / Asian British	11 (16.4)
Black / African / Caribbean / Black British	2 (3.0)
Mixed / Multiple ethnic groups	2 (3.0)
Relationship status	
Married	35 (53.8)
In a relationship	16 (24.6)
Single	13 (20.0)
Divorced	1 (1.5)
Children under 18 (n=64)	
No	38 (59.4)
Yes	26 (40.6)
Current living situation	
Live with spouse / partner	24 (36.9)
Live with spouse / partner and children	20 (30.8)
Live with parents	6 (9.2)
Live with housemate(s)	6 (9.2)
Live alone	6 (9.2)
Live with spouse / partner and parents	2 (3.1)
Live with children	1 (1.5)
Highest level of education	
University or degree	45 (69.2)
College or diploma	11 (16.9)
Secondary School	7 (10.8)
Vocational qualification	2 (3.1)
Current employment status (n=64)	
Full-time employed	30 (46.9)
On sick-leave	15 (23.4)
Part-time employed	7 (10.9)
Self-employed	5 (7.8)
Unemployed	3 (4.7)
Homemaker and/or caretaker for children	2 (3.1)
Other	2 (3.1)
Experienced financial difficulties (n=61)	
Not at all	28 (45.9)
A little	20 (32.8)
Quite a bit	9 (14.8)
Very much	4 (6.6)
If so, why? (n=37; non-exclusive)	
Decrease in income	27 (73.0)
Travel costs	8 (21.6)
Childcare	2 (5.4)

Table 3. Self-reported patient clinical information.

Participant characteristics (N=65)	**Mean (Range)**
Age at diagnosis	31.7 (25-39) years
Years since diagnosis	1.9 (0-5) years
	Number (%)
Diagnosis	
Sarcomas	13 (20.0)
Breast cancer	12 (18.5)
Central nervous system tumours	12 (18.5)
Gastrointestinal cancer	7 (10.8)
Urological cancers	6 (9.2)
Gynaecological cancers	5 (7.7)
Haematological cancers	5 (7.7)
Lung cancer	3 (4.6)
Melanoma	2 (3.1)
Current treatment status	
In follow-up	37 (56.9)
On treatment	28 (43.1)
Treatments received (n=64; non-exclusive)	
Chemotherapy	46 (71.9)
Surgery	38 (59.4)
Radiotherapy	28 (43.8)
Clinical trial	13 (20.3)
Hormone therapy	7 (10.9)
Immunotherapy	7 (10.9)
No treatment	5 (7.8)
Targeted therapy	5 (7.8)
Bone marrow or stem cell transplant	1 (1.6)
Brachytherapy	1 (1.6)
Treatment intent	
Curative	42 (64.6)
Unknown	13 (20.0)
Palliative	10 (15.4)
Disease recurrence (n=61)	
No	41 (67.2)
Yes	10 (16.4)
Not applicable	10 (16.4)
Number of comorbidities (n=61)	
None	45 (73.8)
1	12 (19.7)
2	1 (1.6)
3	3 (4.9)

Theme 1: Prolonged diagnosis

Subtheme 1a: Patient interval

Participants recognised personal factors that delayed contact with a clinician about symptoms, including a lack of awareness about cancer symptoms and life circumstances that hindered addressing issues. Many YAs noticed symptoms but assumed they were related to other causes such as work stress or pregnancy (1a-1). Participants described feeling too busy to visit a general practitioner due to work, childcare and travel plans and often assumed the symptoms were unlikely to be serious (1a-2).

Subtheme 1b: Care interval

Participants highlighted a number of disease and system-related factors that contributed to a prolonged time from first consultation to diagnosis. Patients felt the relative rarity of cancer in the YA age range was partly responsible for the hesitance of healthcare providers to investigate symptoms (1b-1). The symptoms patients experienced were also sometimes non-specific or different from classical cancer presentations (1b-2). As a result, a number of patients were misdiagnosed, lengthening the time to diagnosis. In some cases, this led to severe symptoms and receiving the diagnosis in an emergency setting. Some patients felt the reasons for further investigations or potential diagnoses were not communicated clearly which made the period to diagnosis feel further extended.

Theme 2: Navigating the healthcare system

Subtheme 2a: First interaction with the healthcare system

Participants often felt overwhelmed by the system and the assumption by healthcare professionals that the process was routine (2a-1). After receiving the cancer diagnosis, many YAs were surprised by how quickly decisions were made and treatment began. For many participants, this was their first experience with a serious illness and they felt they needed more communication about how the healthcare process worked, including basic information about who to contact for particular issues and how (2a-2). This naivety, in combination with a self-awareness for looking visibly younger than other patients, added to feelings of discomfort in hospital.

Subtheme 2b: Need to be self-advocate

Participants felt a lack of provider continuity and the need to chase appointment confirmations and results shifted the responsibility of treatment management onto the patient (2b-1). YAs believed that seeing different providers meant the clinician lacked an understanding of their medical and personal situation. Many told stories of missing appointments due to receiving letters after the date, miscommunication between treating teams and delays to treatment due to clerical errors. Delays in hospital were particularly frustrating as they clashed with work and childcare. YAs often also felt burdened by needing to research relevant resources such as financial advice, access to charities or complementary services (2b-2).

Subtheme 2c: Appreciation of care

Patients were largely happy with the care they received and praised individual efforts of the treating doctors, nurses and staff (2c-1). YAs were particularly appreciative of the support that seemed to go beyond the staff role, coordinating care and answering questions (2c-2). YAs rejected the need for age-specific care compared to older adults other than the opportunity to meet other YAs in hospital. In particular, a few participants with in-patient stays experienced severe emotional distress with being exposed to other patients with advanced disease or very elderly patients for extended periods. Seeing other patients with advanced disease or dementia confronted the YAs with their own mortality or added to feelings of discomfort.

Theme 3: Health information

Subtheme 3a: Level of clinical detail

As with any age of patient, participants varied in the amount of information they needed regarding clinical details, prognosis, possible side-effects, etc. However, around a quarter of participants in this study felt they lacked full and accurate information about their own disease and treatment or the reasons for certain tests and investigations, particularly in the time soon after diagnosis (3a-1). Participants that wanted further details felt this would give them a greater sense of control and comfort, allowing them to actively engage in decision-making (3a-2). In particular, patients wanted to have access to their electronic medical records to see their own blood results, scans and treatments to have access to accurate, personal clinical details (3a-3).

Subtheme 3b: Impact of side-effects

Beyond clinical details, many YAs wanted a deeper understanding of how potential side-effects and treatment recovery could physically and practically impact their lives (3b-1). As busy YAs, participants felt information was lacking to indicate recovery timelines to manage caring for children and returning to work. Many YAs felt the list of side-effects was given but it was still difficult to distinguish between what is a worrying side-effect and what is normal (3b-2). In addition, patients wanted much more information about how the cancer and treatment may impact them physically and cognitively in the long term (3b-3). YAs prioritised recovery of function and wanted information about how to mitigate long-term effects by potentially making adjustments to treatment and changing their behaviour along the treatment pathway.

Theme 4: Internet double-edged sword

Subtheme 4a: Overwhelming

As young people, the internet was a common source of information about the cancer diagnosis, clinical details and treatment options. However, a majority of patients were overwhelmed by large amounts of information not specific to their disease characteristics or treatment. This was particularly the case for YAs with rare cancer types. Encountering information about prognosis often caused distress. Patients also found it difficult to identify trustworthy and up-to-date information (4a-1). When exploring sites with patient discussions such as forums, YAs were also worried about encountering stories of patients with poor prognoses (4a-2).

Subtheme 4b: Source of information and support

Despite hesitancy toward searching online, many YAs found the internet an instrumental source of information and support. Many YAs felt the internet empowered them as they were able to do their own research and bring information to the table, particularly for rare cancers (4b-1). This helped enable shared decision-making. Online support groups and forums were vital in providing patients with vivid examples of other patients' experiences particularly regarding side-effects and strategies for dealing with them. Peer forums, particularly those that were age-specific, went beyond this and provided a platform for YAs to connect and relate to one another (4b-2).

Theme 5: Variability in fertility preservation discussions

Discussions around fertility and fertility preservation varied widely among participants. While for many patients fertility was brought up soon after diagnosis and options to preserve fertility discussed as a matter of urgency, eight patients described being uninformed about the consequences and options available (5a-1). With a number of patients, both men and women, fertility was not discussed before starting treatment. In a few cases, patients felt they had to push the clinical team to discuss fertility and consider treatment options. Among those who did discuss fertility, quite a few felt the decision was rushed and made without a full understanding of the consequences (5a-2). Most YAs who felt they were not fully informed about potential fertility preservation options and wanted children in the future felt a sense of regret after treatment.

Theme 6: Psychological and emotional support

Subtheme 6a: Need for formal psychological support

A majority of participants described an unmet need for access to formal psychological support (6a-1). While this varied with regards to the timing and type of support needed, many patients felt that psychological support is something that should be offered routinely by the clinical team. While many YAs felt the need for one-to-one counselling, they also wanted access to therapy that could help them cope during treatment, such as cognitive behavioural therapy, relationship counselling, family support, including advice around talking to children, and psychological support for loved ones (6a-2; 6a-3). Participants struggled to access services due to long wait times, a lack of cancer-specific therapists and a lack of awareness of how and where to access services (6a-4).

Subtheme 6b: Peer support

YAs had mixed interest in peer support from other young cancer patients. As mentioned above, YAs appreciated online forums for the opportunity to learn from the experiences of others and share their own experiences. Age-specific peer support, particularly from local charities and informal meetings in hospital, also reduced feelings of isolation (6b-1). However, many YAs were uninterested in formal peer support groups. Participants felt they lacked the time with young families and jobs and received adequate support from friends and family. Some YAs felt attending a support group was daunting or an admission of illness (6b-2). YAs also found that many hospital support groups included mostly older patients where the experiences and challenges were too dissimilar (6b-3).

Theme 7: Sign-posting to relevant resources

Subtheme 7a: Financial information and support

Many patients found a lack of information about sources of financial advice and support (7a-1). As patients incurred large travel costs, paid high mortgages and experienced a decrease in income, this was a source of distress for YAs. Participants found financial advice difficult to navigate and often needed support from charities to complete applications. YAs felt cancer-specific details, such as the exemption from prescription charges as a cancer patient, should be shared routinely by the clinical team.

Subtheme 7b: Diet and exercise

Individually tailored diet and exercise advice was a priority for YAs. Patients wanted to take action to help them recover from treatment. Many patients were disappointed by the dietary advice from doctors to maintain weight rather than specific recommendations related to their disease (7b-1). YAs often felt courses on physical exercise were not vigorous enough, geared toward much older, less active patients (7b-2). Some participants were nervous that physical activity could cause damage and wanted tailored advice. Again, recovery and regaining function was paramount to YAs to move forward from the cancer diagnosis.

Table 4. Coding hierarchy.

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
1. Prolonged diagnosis	1a. Patient interval	*Attribute symptoms to something less sinister*	1a-1	*I was thinking oh loss of energy, bruises but I just thought that was because I've got two young children who jump all over me so everything that was happening I just put it down to something else. (female 708, haematological cancer, in curative treatment)*
		Surrounding life circumstances	1a-2	*When you're young, you might be starting a new job, you don't want to take time off because you think it's going to be nothing. You move house, and then you're in a different area code so you have to get re-registered. (female 919, breast cancer, completed curative treatment)*
	1b. Care interval	*Cancer uncommon in young adults*	1b-1	*They were just calling me unfit and thinking that because I'm a young person, you don't suspect these things. (female 709, haematological cancer, in curative treatment)*
		Non-specific or atypical symptom presentation	1b-2	*I have been going to my GP for over five years for my symptoms, obviously the blood coming out of my, you know, in your stool was the first one, and swollen belly and stuff. But obviously because of my age and because, throughout all of this, I had never really sort of lost my appetite they are kind of thinking it's probably not cancer. (male 805, gastrointestinal cancer, in curative treatment)*
2. Navigating the healthcare system	2a. First interaction with the healthcare system	*Overwhelmed by practical aspects of healthcare system*	2a-1	*As a new patient, you haven't got a clue what is happening around you and things are moving at 100mph and it's hard to catch your breath and work out what's going on… this nurse started talking to us about everything really quite quickly. And you'll do this, and you'll do this, and you'll come into here… I felt out of control and I felt really scared because she's going through this as if it's nothing. Because she does it every day, she's not realising this is new to me. (female 928, breast cancer, in curative treatment)*
		No personal experience of illness	2a-2	*The only thing that I felt a little not in the know of is right at the very beginning because that's the time when you're most overwhelmed by it. You're unlikely to have known anybody or very few people who've gone through it. (male 816, germ cell tumour, completed curative treatment)*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
	2b. Need to be self-advocate	*Lack of healthcare provider continuity*	2b-1	*I find it very difficult to communicate with them. Most of the time I don't even see my consultant. I see someone else. I see someone new every day, so I can't even. I feel like I have to start all over again, which is difficult. (female 154, sarcoma, in treatment with unknown intent)*
		Need to be pro-active	2b-2	*It feels like, if you don't take charge of that as a patient, it, then, it doesn't feel like anyone is in charge of it. (male 115, sarcoma, in treatment with unknown intent)*
	2c. Appreciation of healthcare professionals	*Appreciate familiarity in healthcare staff*	2c-1	*I just feel more cared for… sometimes I just get a phone call from my nurse and she's saying, just checking to see everything's okay, do you need help with anything in terms of appointments. That makes a huge difference. (male 885, CNS tumour, completed treatment with unknown intent)*
		Reassured by time given for detailed discussions	2c-2	*He explained everything that was going to be done. He explained the process, what the suspicions were… And he did it in quite a lot of detail and I was actually very appreciative of that. In particular he did a lot to try to put me at ease. (male 886, CNS tumour, completed curative treatment)*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
3. Healthcare patient communication	3a. More clinical detail	*Want full and accurate information*	3a-1	*Initially I was drip-fed information and I suppose a lot of people probably couldn't handle it. Maybe I couldn't have handled it, I don't know at the time. But now, I still feel like I don't know enough… I know it's spread to the bones in my back, but I need to know which bones. I don't know. (female 503, lung cancer, in palliative treatment)*
		Information gives agency	3a-2	*You do get this sort of information in the letters… but actually having some sort of agency, and a bit more detailed knowledge on the options, the pathway itself, would be incredibly helpful. Because you're very much directed when you're diagnosed, and I think there's sort of an assumption that when you're diagnosed you're a bit too blinded by the diagnosis to be able to make some sort of, you know, a judgement. (female 970, breast cancer, in curative treatment)*
		Access to medical records	3a-3	*It's nice that I know that I could just go back to that [scan] and look at it again. I haven't bothered to, but it was a question that popped into my head and the fact that I had at my fingertips, the answer—somewhere, my filing's not that good—that is nice. You feel much more empowered (female 222, gastrointestinal cancer, completed curative treatment)*
	3b. Impact of side-effects	*Impact on daily life*	3b-1	*Yes, information about how you're likely to feel, how tired you're likely to feel, how spaced out you are. I was very spaced out on some of the tablets. Yes, things like that because that's quite surprising. Left looking after a baby and a three-and-a-half year old and you're not quite there because you're sort of floating around a bit. (female 200, gastrointestinal cancer, completed curative treatment)*
		Experience of side-effects	3b-2	*With the side effects thing as well, you go for chemo and then you like go home, and you have got like your thermometer, you are ready, but you don't really know what is a side effect, and what isn't. (female 801, gynaecological cancer, in curative treatment)*
		Long-term effects	3b-3	*Being younger, we probably do want to be able to fix things or feel a bit more in control of recovery. Just don't want to feel like you're going to have these problems for 40 years. So those are the things that I actually worry about a bit. So the effects, the late effects, of having radiotherapy. (female 603, gynaecological cancer, completed curative treatment)*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
4. Internet double-edged sword	4a. Overwhelming	*Information not relevant to individual clinical situations*	4a-1	*Pieces of information we get online are not necessarily accurate. And they might just give you a general look, but in your own case they become suddenly imprecise and scary. (male 138, sarcoma, completed curative treatment)*
		'Funnel of negativity'	4a-2	*A lot of people do sometimes just go on because you have had a shit day and whereas people won't go on and say yes today was brilliant and I have had no side effects. So, you can get a lot more of a funnel of negativity. (female 919, breast cancer, completed curative treatment)*
	4b. Source of information and support	*Information about treatment options and experiences from peers*	4b-1	*I read a lot on that forum about treatment options and all those things. So that's what helped me, actually, quite a lot… and also a little bit of – how do you say it – psychological… Yes, you know, there are a lot of people who are about the same age as you, and who also have that problem, so I think that also helps. (male 149, sarcoma, in curative treatment)*
		Peer support	4b-2	*When it's online, you feel like you can connect any time. So, I think that's what I find with the forum. At any time that I need some support or advice I can literally just ask there and then, and there's always somebody that's there. And the same if other people have got a problem, it's nice that I can share my experience with them, as well. (female 652, breast cancer, completed palliative treatment)*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
5. Fertility preservation	5a. Variability in discussions	*Not fully informed*	5a-1	*He kind of just sat down and broached the subject of getting pregnant, which caught me off guard a lot because it wasn't something I was… well, am considering at this point in my life, not for a few years but he then was like, just to let you know, we highly recommend that someone in your position does not think about getting pregnant for at least the first three years.… It might have been something I wanted to think about prior to that. I guess that kind of choice is then taken away from me, which is something I wasn't expecting at all. (female 402, melanoma, completed curative treatment)*
		Rushed	5a-2	*It felt really like rushed and a bit like I didn't really have a choice as well. It's hard to make decisions when you're swamped with information and they just want to get you under treatment. (female 605, gynaecological cancer, completed treatment with unknown intent)*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
6. Psychological and emotional support	6a. Need for formal psychological support	*Formal counselling*	6a-1	*I was referred to a psychologist… That actually really helped to just let it all out and I think that's the most I've ever cried, got really emotional about the prospect of losing my job, not having kids, not being in a relationship, not getting married, not having a husband and not owning a house and all of that stuff. (female 883, CNS tumour, in treatment with unknown intent)*
		Coping strategies	6a-2	*I really wanted something like CBT and I just didn't know where to get it… They said, oh, why don't you try psychology and I did that, but I didn't feel I really needed psychology. It was more I, kind of, wanted someone to say right, here are some strategies to deal with this particular period, how it might take your mind off the pain or whatever, but I never managed to find it. (female 202, gastrointestinal cancer, completed curative treatment)*
		Relationship and family support	6a-3	*The only thing that might have been nice was, sort of, the support for your spouse and family and, you know, talking to kids about it and stuff. That would probably be the only thing that was slightly difficult. (female 200, gastrointestinal cancer, completed curative treatment)*
		Barriers	6a-4	*It would've been really beneficial if it had just been a default practice that you have an appointment with someone to talk to… To actually go and sort that out independently, myself, is quite a big thing when you're going through a traumatic time. (female 813, urological cancer, in curative treatment)*
	6b. Peer support	*Reduce isolation*	6b-1	*I would like to know how many people is of my age at the hospital being treated because it would be nice to meet them… I have no idea if there is anyone else. (female 126, sarcoma, in treatment with unknown intent)*
		Want to avoid cancer	6b-2	*I didn't really want to speak to anyone who had the same thing because I just wanted to block the whole situation out… I didn't want to go to any support groups. I didn't want counselling. I just wanted my life to get back to normal, like it's never happened. But looking back on it now, I guess I just didn't want to be weak. (male 872, CNS tumour, completed curative treatment)*

Table 4. Continued

Theme	Subtheme	Code	In-text reference	Exemplary excerpt (labelled with participant characteristics and study identification number)
		Barriers	6b-3	*There's a support group for women who had cervical cancer and I went last year I think. I just… I didn't really like it. I went to go and I looked into the window, and everybody in there was at least 70 or older. And I was just like: I'm so much younger. I just didn't go in. I just thought: I can't. I've got nothing to relate to about this. (female 603, gynaecological cancer, completed curative treatment)*
7. Sign-posting to relevant resources	7a. Financial information and support	*Lack of information*	7a-1	*It was also quite difficult financially… and I don't feel there was any support there available, I didn't find any support. I did look and I asked people for help but no, there was nothing forthcoming. (male 705, haematological cancer, completed palliative treatment)*
		Burdensome applications	7a-2	*Access to Work alone took me and my previous boss almost two weeks to prepare. It's a 40 odd pages thing. I had to count the steps I have to make and achieve to come out to explain why they took a tangerine out of your leg and still you're not able to walk very well. It's just ridiculous. Calculate alternative routes on a GPS. (male 138, sarcoma, completed curative treatment)*
	7b. Diet and exercise	*Appetite for tailored dietary advice*	7b-1	*I spoke to the dietician and they were able to sort of talk through what sort of lower fibre food, soluble fibre and all that kind of stuff which was helpful. But I do think… I did feel a bit, you know, they want to be helpful and they're lovely. Their primary concern is that you're not losing weight. (female 672, lung cancer, in palliative treatment)*
		Need for age-appropriate rehabilitation	7b-2	*It was geared towards post-menopausal women in their sixties. It was not geared towards younger women who have been more active, and want to continue being active, and for people who have children, and needing a coping strategy for lifting, bathing, changing children. (female 970, breast cancer, in curative treatment)*

CNS Central nervous system

DISCUSSION

YAs lacked guidance in navigating health and supportive care services and had an appetite for more clinical information and health behaviour advice. Most challenges broadly relate to health information needs, suggesting that services for YAs may be initially improved by providing timely, age-tailored information. This is the first study to explore healthcare experiences specifically in YAs treated in adult cancer services in the UK.

Participants highlighted issues coordinating their care and navigating the healthcare system. This is not surprising given cancer services are designed for older adults with previous illness experience. While third sector organisations fill local gaps in practical and emotional support for YAs, the health system and information needs shared across institutions suggest YAs would benefit from support integrated into clinical services. This may require increasing capacity in psychological services or developing stronger links with the third sector organisations. The National Institute for Health and Care Excellence (NICE) recommends identifying a skilled key worker to support TYAs in coordinating their care, providing information and assessing and meeting holistic needs.[20] This recommendation could be extended to YAs in adult services to ensure provision of age-specific information and access to relevant support. TYAs who choose to undertake cancer treatment in adult services are still reviewed by TYA-specific multi-disciplinary teams.[21] Similar joint care could provide a model for providing specialist input to YAs in an adult setting.

This specialist input may be particularly important for addressing the variability seen in discussing fertility. Previous research has found failure to discuss fertility risks before anti-cancer treatment can be associated with poor mental health.[22,23] The variability contrasts a UK survey which found most oncologists reported discussing fertility risks with all patients, suggesting patient-clinician communication may be an issue.[24] Alternatively, perceived lack of knowledge about resources and referrals, patient characteristics, such as poor prognosis or prior children, and time constraints may result in inconsistent discussions by clinicians.[25] These barriers may be exacerbated in adult settings where clinicians have high caseloads and rarely treat young patients, with most new patients over age 60.[26] Discussing potential fertility loss and fertility preservation is important for any YA where the cancer or treatment may affect fertility to improve post-treatment quality of life, particularly with a fertility specialist where possible.[27] Instating clinical practice interventions such as quality indicators, resources and education may improve the likelihood of clinicians discussing fertility preservation with patients where appropriate by encouraging the discussions to become routine practice.[28]

There was also a clear need for tailored information about diet and exercise. Consumer trends suggest young people are more concerned with health and well-being.[29] This may translate to a greater interest in tailored advice for health behaviours. Recent surveys have shown that few clinicians are aware of nutritional guidance or provide tailored advice.[30,31] Given emerging evidence that physical exercise can reduce mortality, recurrence and adverse side-effects, physical activity advice should also be shared as standard care, particularly with YAs who are likely to have been active before diagnosis.[32] Third party organisations may provide more relevant health and information services for YAs than the standard hospital services. New patients may benefit from information about these organisations or actively linking them into the services. An age-specialist key worker may again be helpful in filling this role.

The emphasis on the need for information by YAs may be driven by a desire for control. Information is seen as a form of cognitive control and information-seeking a type of problem-focused coping.[33] Previous research has found that perceived control may mediate active coping and improve well-being in some circumstances, suggesting that enabling YAs to access information may promote quality of life.[34] Providing access to full and accurate clinical information beyond summary letters, whether through digital systems or directly sharing medical records or results if desired, may help YAs gain a sense of control. Guidance about trusted online sources for further information should be provided soon after diagnosis with warnings that prognosis and potential symptoms may vary greatly from what is presented online depending on clinical situation. Again the skilled key worker would be beneficial in these circumstances to direct any concerns arising from the clinical or online information.

While this explorative analysis exposes the need for additional age-tailored support, we could not determine the prevalence of the issues due to the semi-structured nature of the interviews and focus groups. The sample also overrepresented less common cancers with poor prognoses which may have over-emphasized certain topics such as the overwhelming nature of online information or the need for psychological support.

YA patient involvement in data analysis was integral to accurately interpreting and presenting the results, particularly with the large and diverse sample. Adequate funding for time and travel, authorship and training materials helped promote active and successful involvement. The dataset size and limited availability of qualitative software due to licence costs restricted the point at which we could involve patients. Future projects should involve patients throughout the full research cycle.

Clinical implications

Previous research has found that TYAs similarly deal with extended times to diagnosis, particularly for brain tumours, lymphomas and sarcomas, and that emergency presentation is unnecessary in a third of cases.[35] Evidence from this study and the paper by Dommett suggest that referrals from primary care for suspected cancers in young people should be encouraged and organisational delays, such as errors in referrals, must be reduced for timely investigations.

Efforts need to identify optimal pathways for provision of age-tailored information and access to relevant services for YAs in adult cancer settings. NICE guidelines provide excellent recommendations for age-specific multi-disciplinary care for children and TYAs.[14] Patients and providers should review these guidelines to determine whether they should apply to YAs. While dedicated in-patient units may not be necessary for YAs as most are treated in outpatient settings, YAs are faced with similar challenges as TYAs and would likely benefit from elements of the national TYA network of cancer services. Practical recommendations discussed in this paper for the challenging experiences identified are presented in Figure 1.

CONCLUSIONS

YAs with cancer lack guidance in navigating health and supportive care services and access to some relevant age-specific information and support. YAs would likely benefit from elements of the TYA cancer services focusing on providing tailored information and access to age-relevant services.

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CHAPTER 4

The prolonged diagnostic pathway of young adults (aged 25-39) with cancer in the United Kingdom: results from the Young Adult Cancer Patient Journey Study

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Journal of Clinical Medicine. 2021;10:4646. doi: 10.3390/jcm10204646

ABSTRACT

Purpose

Teenagers and young adults (TYAs; aged 13–24) experience prolonged intervals to cancer diagnosis. Insight into diagnostic intervals in young adults (YAs; aged 25–39) and subgroups at risk for long intervals is lacking. We investigated the diagnostic pathway of YA cancer patients, examined patient and tumour characteristics associated with its length, and compared the patient interval length of our sample with a TYA cohort.

Methods

In this cross-sectional survey YAs diagnosed with cancer in the UK in the past five years completed a questionnaire describing their patient (time from first symptom to first doctor consultation) and healthcare interval (from first consultation until consultation with a cancer specialist), sociodemographic, and clinical characteristics. Associations between characteristics and interval length were examined and compared with previously published data in TYAs.

Results

Among 341 YAs the patient interval lasted ≥2 weeks, ≥1 month, and ≥3 months in 60%, 42%, and 21%, respectively, compared to 48%, 27%, and 12% in the TYA group. The healthcare interval lasted ≥2 weeks, ≥1 month, and ≥3 months in 62%, 40%, and 17% of YA patients, respectively. YAs with melanoma or cervical cancer were most likely to experience long intervals, whereas YAs with breast cancer and leukaemia were most likely to experience short intervals.

Conclusions

Most YAs were not seen by a cancer specialist within 2 weeks of GP consultation. Interval lengths in YAs were associated with cancer diagnosis. Patient intervals were longer among YAs than among TYAs. Our study highlights long diagnostic pathways among YAs and calls for more awareness among healthcare professionals about malignancies in this age group.

INTRODUCTION

Cancer in adolescence and young adulthood (AYA), defined as patients aged 15–39 at cancer diagnosis, is uncommon, accounting for 5% of all cancer diagnoses.[1] Leukaemia, lymphoma, testicular cancer, and thyroid cancer are the most common cancers among 15 to 24-year-olds, while breast cancer and melanoma are most common among 25–39-year-olds.[2]

AYA cancer patients face unique developmental, physical, and psychosocial issues that make adjustment to their disease and health maintenance challenging.[3] AYAs describe unsatisfactory care experiences such as lack of recognition of their autonomy by healthcare providers (HCPs), lack of peer support, and inappropriate care environments.[4,5] To address these issues, the United Kingdom (UK) has rapidly expanded the availability of dedicated services for teenagers and young adults (TYA) ages 13 to 24. In contrast, no age-specific care services are available for young adult (YA) cancer patients aged 25 to 39 years.

Historically, progress in survival for AYAs has lagged behind both children and older adults, at least partly due to a prolonged diagnostic pathway.[6–8] Recently, we and others showed this gap in survival has closed for most, but not all tumours.[9,10] Early diagnosis of cancer is key to facilitate the start of treatment and can improve psychosocial and clinical outcomes.[11–13] The cause of prolonged diagnosis among AYA is likely to be multifactorial and may include a lack of awareness amongst AYAs and HCPs, heterogeneous and non-specific symptoms, and the rarity of cancer at this age.[14,15] Reducing time to diagnosis is a key area for improving cancer care in the National Health Service.[16] The BRIGHTLIGHT study, assessing specialist care for TYAs with cancer in England,[17] is the largest study among TYA patients looking at diagnostic timeliness.[15] In this study, over a quarter of participants (27%) waited more than one month to approach an HCP about symptoms.[15]

Although age-specific guidelines to improve diagnostic timeliness in TYAs have been developed in the UK, for YAs, no specific guidance exists.[18] Information regarding YA's diagnostic pathway is lacking and often obscured in studies of older adults where most patients are over age 50. As life events and the distribution of cancer types among YAs are distinct compared to older adults, available evidence cannot be extrapolated to YAs.

To improve healthcare services for YAs, we aim to describe the diagnostic pathway of patients aged 25–39 at diagnosis, identify factors associated with a prolonged pathway, compare the time from first symptom to doctor consultation in YAs with that in TYAs, and describe suggestions made by YAs to improve the diagnostic pathway.

METHODS

Study Design and Participants

In this cross-sectional observational study, we invited all surviving patients diagnosed with cancer (ICD–10 codes C00–C97) aged 25–39 years treated at a participating trust (The Royal Marsden Hospital NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust, University Hospital Southampton NHS Foundation Trust, Barts Health NHS Trust, Imperial College Healthcare NHS Trust, and East and North Hertfordshire NHS Trust). Patients were eligible if they were diagnosed in the last 5 years, able to communicate in English, and could complete questionnaires independently. Patients with a previous cancer diagnosis were excluded.

Ethical Approval

The Royal Marsden and Institute of Cancer Research Joint Committee on Clinical Research reviewed and sponsored the study (CCR4648). The Research Ethics Committee and Health Research Authority in the UK approved the study nationally (17/LO/0219).

Recruitment and Data Collection

Eligible patients received a letter from their treating physician explaining the purpose of the study. Patients provided informed consent before taking part. Data collection was conducted from May 2018 until March 2019 using PROFILES (www.profilesregistry.nl, accessed on date 05-10-2021), a web-based system designed to collect patient-reported outcomes in cancer trials. Questionnaires could be completed online or upon request by pencil and paper.

Study Measures

Whilst the study was primarily designed to examine unmet supportive care needs of YAs, this paper describes secondary analyses to explore the diagnostic pathway of participants.

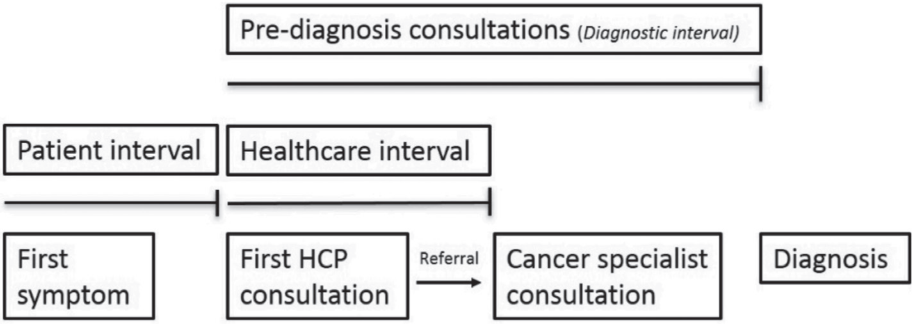
Demographic and Clinical Variables

The questionnaire package contained socio-demographic items, including age at diagnosis, gender, ethnicity, relationship status, educational level, and gross income per annum. Patients also self-reported clinical data including tumour type and comorbidities.

Diagnostic Pathway

The questionnaire package included a number of items about the diagnostic pathway, including items developed by the BRIGHTLIGHT group to assess the diagnostic pathway of TYAs.15,19 We explored the patient and healthcare intervals and the number of pre-diagnosis consultations as a surrogate marker of diagnostic timeliness (Figure 1). The patient interval, as defined previously,20 encompasses the time between the first symptom and first consultation with an HCP. The healthcare interval is the time from the first HCP consultation until the first consultation with a cancer specialist. Interval items had categorical response options of under 1 week, 1–2 weeks, 2–4 weeks, 1–3 months, 3–6 months, 6–12 months, more than 12 months, or ‘I don’t know’. The number of pre-diagnosis consultations was measured with response options 0, 1, 2–3, or ‘4 times or more’.

Figure 1. Diagnostic pathway.



An additional question assessed whether participants felt they were taken seriously by the first doctor they spoke to: “On a scale of 1 to 10, do you think your symptoms or concerns were taken seriously the first time you spoke to a doctor?”. A single free-text question asked for patient opinions on appropriate ways to reduce the time from symptom presentation to diagnosis.

Statistical Analysis

Descriptive statistics were reported for participants' demographic and clinical data, patient and healthcare interval lengths, the number of consultations, and whether patients felt they were taken seriously. Mean and standard deviation are reported for continuous variables. Frequency and percentage are reported for categorical variables. For patient and healthcare intervals, we dichotomized interval lengths at three separate thresholds: <2 weeks versus ≥2 weeks, <1 month versus ≥1 month, and <3 months versus ≥3 months.

Available data from patients at the Royal Marsden Hospital NHS Foundation Trust was used for a non-responder analysis. Age at diagnosis, current age, cancer type, and years from diagnosis were captured for non-responders. The characteristics of responders and non-responders were compared using independent samples t-tests for continuous data and chi-square tests for categorical data.

We performed univariate logistic regression analyses to detect associations between categorical independent variables and the length of the patient and healthcare intervals dichotomized at 1 month following previous studies.[15,21] Odds ratios (OR) and 95% confidence intervals (95% CI) are presented. Independent samples t-tests were performed for continuous variables. We did not perform multivariable analysis because there were too few observations in each cancer type.

The number of pre-referral consultations is an indicator of diagnostic timeliness as patients experiencing more pre-referral consultations have longer intervals from symptom presentation to diagnosis.[22] We argue that two consultations are usually needed before referral, thus ≥4 consultations best reflect a prolonged interval. Therefore, we dichotomized diagnostic timeliness into <4 or ≥4 consultations. Fisher's exact tests were performed to test associations between categorical variables and the number of consultations before diagnosis.

To compare our results with TYA patient intervals, we used data published by the BRIGHTLIGHT study group.[15] We were unable to compare the healthcare interval or number of consultations, as definitions and cut-off points between the two cohorts differed. We grouped carcinomas and combined all germ-cell tumours to make direct comparisons with the BRIGHTLIGHT cohort. Groups with too few observations or not occurring in both cohorts were excluded from the analysis. We reported frequency and percentage of patient intervals in both groups and tested the differences using X2 tests. As we had no access to the raw data from the BRIGHTLIGHT study, tests were limited to univariate analysis. Associations between patient characteristics and age group were restricted to single levels of the patient. If the expected number within a cell was smaller than five, Fisher's exact tests were performed.

All missing data were assumed to be missing at random and only complete cases were analysed. All statistical analyses were performed using IBM SPSS 25.0 (IBM, Armonk, NY, USA). Two-sided p-values of <0.05 were considered statistically significant.

Qualitative Analysis

We analysed free-text responses using inductive coding followed by axial coding to group participants' answers.[23] Two investigators independently coded the data (VS and OH). We describe the number of times each recommendation occurred.

RESULTS

Participants

Of the 1657 invited patients, 347 completed the questionnaire (response rate 21%); 341 participants had complete healthcare interval data and were included in the analysis. The mean age was 33.3 years, 108 (32%) were male, and 288 (84%) were white (Table 1). Breast cancer and testicular cancer were the most common diagnoses. The mean time between diagnosis and questionnaire completion was 2.9 years (standard deviation 1.7).

Table 1. Participant characteristics at time of survey.

Participant Characteristics (N=341)	**Mean (SD)**
Age at Diagnosis in Years	33.3 (4.3)
	Number (%)
Gender	
Male	108 (32)
Female	233 (68)
Ethnic group	
White	288 (84)
Non-White	53(16)
Cancer diagnosis	
Breast cancer	113 (33)
Leukaemia	9 (3)
Lymphoma	27 (8)
Sarcoma	22 (7)
Testicular cancer	52 (15)
Ovarian cancer	13 (4)

Table 1. Continued

	Number (%)
Melanoma	8 (2)
Thyroid cancer	20 (6)
Colorectal cancer	14 (4)
Cervical cancer	32 (9)
Other	30 (9)
Missing	1 (0)
Patient interval length (n=307; non-exclusive)	
>2 weeks	185 (60)
>1 month	129 (42)
>3 months	63 (21)
Healthcare interval length (n=341; non-exclusive)	
>2 weeks	210 (62)
>1 month	135 (40)
>3 months	59 (17)
Presence of symptom upon presentation	
Symptomatic	320 (94)
Asymptomatic	21 (6)
Relationship status	
Single	58 (17)
In a relationship	83 (24)
Married/civil partnership	189 (55)
Divorced	11 (3)
Educational level	
No education or primary school	2 (1)
Secondary school	32 (9)
Vocational	14 (4)
College	66 (19)
University	201 (59)
Other	26 (8)
Gross income per annum	
GBP < 20 000	88 (26)
GBP 20 000–30 000	51 (15)
GBP > 30 000	162 (48)
Missing	40 (12)
Comorbidities	
0	177 (52)
1	114 (33)
≥2	50 (15)

Non-responder Analysis

Responders and non-responders did not differ in age at diagnosis, current age, years from diagnosis, or cancer type (Appendix A).

Patient Interval

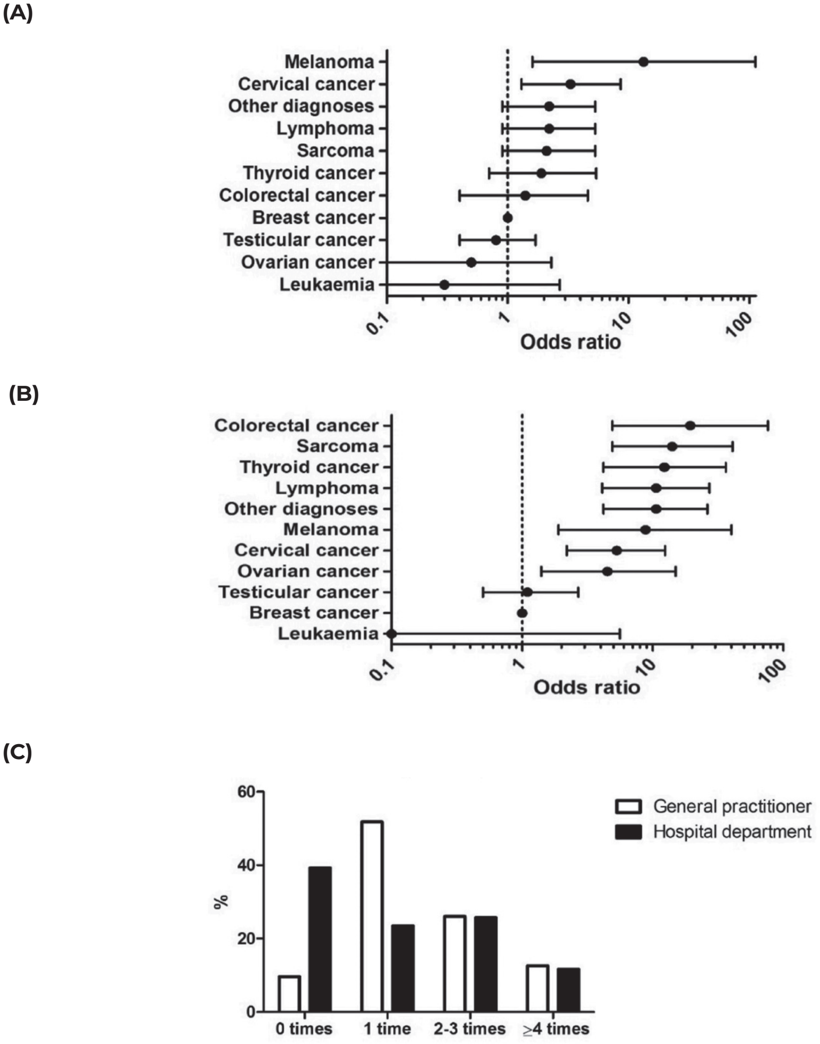
Patient interval data was completed by 307 participants. Seventy-eight percent first told a doctor about their symptoms, mostly their general practitioner (GP) (84%). A minority of patients were admitted as an emergency (4%) or were detected through screening (6%). Those detected through screening had breast (n=2) or cervical cancer (n=16). Half the participants with cervical cancer (n=16) were not detected through screening. The majority (68%) of patients felt they were taken seriously by the first doctor they spoke to.Although 94% of participants experienced symptoms, the majority (60%) waited longer than two weeks before consulting a doctor. In 42% and 21% of cases, participants waited longer than one and three months, respectively (Table 1). Reasons for delaying included waiting to see whether symptoms would disappear spontaneously, thinking there was no need to go to the doctor, being too busy, and not wanting to bother the doctor unnecessarily. Patients with melanoma and cervical cancer had significantly higher odds of experiencing a patient interval greater than one month compared to those with breast cancer (Figure 2A). Gender, age, and ethnicity were not associated with patient interval length (Table 2).

Healthcare Interval

Most patients (62%) had a healthcare interval ≥2 weeks. Forty percent of patient intervals were ≥1 month and 17% ≥3 months (Table 1). Compared to breast cancer, all other cancer types except for leukaemia and testicular cancer had significantly higher odds of experiencing a healthcare interval ≥1 month (Figure 2B). Gender, ethnicity, and the presence of a symptom were not associated with healthcare interval length. Patients with an interval ≥1 month were significantly younger than patients with an interval <1 month (Table 2).

Before receiving a diagnosis, 90% of patients spoke to their GP, 14% to an A&E doctor, 61% to a hospital doctor not in A&E, 9% to a walk-in centre clinician, 2% to a polyclinic doctor, and 12% to another doctor. A considerable number of participants (13%) spoke to their GP or a hospital doctor other than in A&E (12%) ≥4 times before diagnosis (Figure 2C).

Figure 2. (A) Odds ratios of patient interval ≥1 month by diagnosis. (B) Odds ratios of healthcare interval ≥1 month by diagnosis. (C) Number of pre-diagnosis consultations.



The number of consultations, regardless of location, was not associated with age, gender, or symptom presence (Table 3). Cancer type was associated with >4 GP consultations and >4 hospital doctor consultations. Participants diagnosed with leukaemia, sarcoma, ovarian cancer, thyroid cancer, colorectal cancer, and "other diagnoses" most often had >4 GP consultations. Participants diagnosed with leukaemia, lymphoma, sarcoma, testicular cancer, ovarian cancer, and "other diagnoses" most often had >4 hospital doctor consultations.

Table 2. Participant characteristics by interval length.

	Patient Interval (n=307)			**Healthcare Interval (n=341)**		
	<1 Month	**≥1 Month**		**<1 Month**	**>1 Month**	
	Mean (SD)	**Mean (SD)**	***p*-Value[#]**	**Mean (SD)**	**Mean (SD)**	***p*-Value[#]**
Age at diagnosis in years	33.5 (4.3)	33.2 (4.4)	0.6	33.7 (4.2)	32.7 (4.3)	0.03
	n (%)	**n (%)**	**OR (95% CI)**	**n (%)**	**n (%)**	**OR (95% CI)**
All participants	178 (58)	129 (42)	NA	206 (60)	135 (40)	
Gender						
Male	57 (55)	46 (45)	1 (ref)	68 (63)	40 (37)	1 (ref)
Female	121 (59)	83 (41)	0.9 (0.5–1.4)	138 (59)	95 (41)	1.2 (0.7–1.9)
Ethnic group						
White	149 (57)	111 (43)	1 (ref)	172 (60)	116 (40)	1 (ref)
Non-White	29 (62)	18 (38)	0.8 (0.4–1.6)	34 (64)	19 (36)	0.8 (0.5–1.5)
Cancer diagnosis						
Breast cancer	72 (66)	38 (34)	1 (ref)	95 (84)	18 (16)	1 (ref)
Leukaemia	6 (86)	1 (14)	0.3 (0.0–2.7)	8 (89)	1 (11)	0.1 (0.1–5.6)
Lymphoma	12 (46)	14 (54)	2.2 (0.9–5.3)	9 (33)	18 (67)	10.6 (4.1–27.2)^
Sarcoma	9 (47)	10 (53)	2.1 (0.9–5.3)	6 (27)	16 (73)	14.1 (4.9–40.8)^
Testicular cancer	35 (70)	15 (30)	0.8 (0.41–7)	43 (83)	9 (17)	1.1 (0.5–2.7)
Ovarian cancer	8 (80)	2 (20)	0.5 (0.12–3)	7 (54)	6 (46)	4.5 (1.4–15.0)^
Melanoma	1 (12)	7 (88)	13.3 (1.6–111.8)^	3 (38)	5 (63)	8.8 (1.9–40.1)^
Thyroid cancer	8 (50)	8 (50)	1.9 (0.7–5.4)	6 (30)	14 (70)	12.3 (4.2–36.3)^
Colorectal cancer	7 (58)	5 (42)	1.4 (0.4–4.6)	3 (21)	11 (79)	19.4 (4.9–76.3)^
Cervical cancer	8 (36)	14 (64)	3.3 (1.3–8.6)^	16 (50)	16 (50)	5.3 (2.2–12.4)^
Other	12 (46)	12 (46)	2.2 (0.9–5.3)	10 (33)	20 (67)	10.6 (4.2–26.3)^
Presence of symptom upon presentation						
Symptomatic						
Asymptomatic	178 (58)	129 (42)	NA	190 (59)	130 (41)	1 (ref)
	NA	NA		16 (76)	5 (24)	0.5 (0.1–1.3)

[#] Independent samples t-test; **NA** Not applicable; ^p<0.0; **OR** Odds ratio; **CI** Confidence interval; **Ref** Reference category; **n** Number of observations in sub-group

Table 3. Participant characteristics with four or more pre-diagnosis consultations.

	≥4 GP Consultations		≥4 Hospital Consultations	
	Mean (SD)		**Mean (SD)**	
Age at diagnosis in years	32.3 (4.5)#		33.0 (4.3)#	
	Number (%)~	**p-Value***	**Number (%)~**	**p-Value***
All participants	42 (13)		37 (12)	
Gender		0.593		0.349
Male	11 (11)		14 (14)	
Female	31 (14)		23 (11)	
Ethnic group		1		1
White	36 (13)		31 (12)	
Non-White	6 (12)		6 (12)	
Cancer diagnosis		0.006**		0.000**
Breast cancer	5 (5)		3 (3)	
Leukaemia	2 (25)		4 (50)	
Lymphoma	4 (15)		7 (27)	
Sarcoma	5 (23)		3 (14)	
Testicular cancer	2 (4)		6 (12)	
Ovarian cancer	3 (23)		2 (15)	
Melanoma	1 (13)		0 (0)	
Thyroid cancer	5 (25)		2 (11)	
Colorectal cancer	4 (29)		1 (7)	
Cervical cancer	4 (13)		2 (7)	
Other	7 (25)		7 (29)	
Presence of symptoms at presentation		1		0.706
Symptomatic	40 (13)		36 (12)	
Asymptomatic	2 (11)		1 (6)	

~Percentages do not add up to 100% as data per column is arranged as proportion of patients with certain characteristics within a certain time interval; *Fisher's exact test; **X2 test; #Independent samples t-test showed no differences between age and number of consultations; **GP General practitioner**

Comparison of Findings with TYA Population

The BRIGHTLIGHT cohort included 830 TYAs aged 12–24 at primary cancer diagnosis [15]. Their median age was 20 years, 55% were male, and 88% were white. Participants were diagnosed with lymphoma (32%), germ-cell tumours (19%), leukaemia (13%), non-skin carcinomas (12%), bone cancer (10%), soft tissue sarcomas (6%), central nervous system neoplasms (4%), melanoma and skin carcinoma (4%), and unspecified (1%) (Table 4).

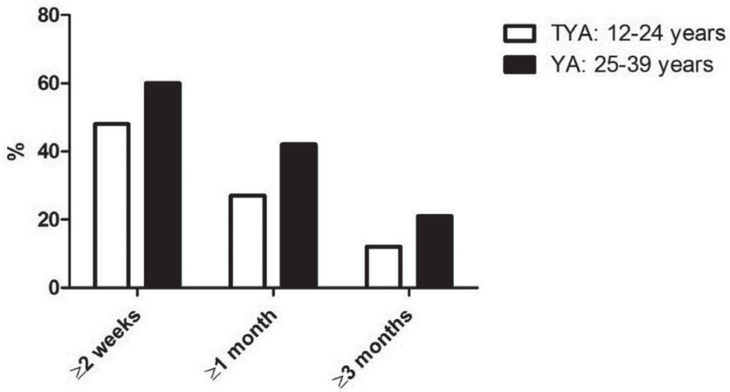
Complete patient interval data were reported for 748 TYAs. Compared to 341 YA participants, 48% versus 60% had a patient interval ≥2 weeks, 27% versus 42% ≥1 month, and 12% versus 21% ≥3 months, for TYA versus YA patients, respectively (Figure 3).

Table 4. Characteristics of TYA and YA populations.

	TYA 12–24 years	YA 25–39 years
	Number (%)	**Number (%)**
All participants	748 (100)	307 (100)
Gender		
Male	419 (56)	103 (34)
Female	329 (44)	204 (66)
Ethnic group		
White	657 (88)	260 (85)
Non-White	91 (12)	47 (15)
Cancer diagnosis		
Leukaemia	89 (12)	7 (2)
Lymphoma	248 (33)	26 (9)
Soft tissue sarcoma	41 (5)	19 (6)
Germ cell tumours	147 (20)	52 (17)
Melanoma	28 (4)	8 (3)
Carcinomas	87 (12)	152 (50)

TYA Teenagers and young adults; **YA** Young adults

Figure 3. Proportion of participants by patient and interval length.



Among males, white respondents, and patients with lymphoma, YAs were significantly more likely to have a patient interval ≥1 month than TYA participants (Table 5). YAs were also significantly more likely to have a >2-week patient interval compared to TYAs among males and white patients, though this association was not significant among cancer diagnosis groups (Appendix A). When dichotomized at three months, YAs were significantly more likely to have a longer patient interval than TYA participants among males, white patients, or those diagnosed with lymphoma or sarcoma (Appendix A).

Table 5. Comparison of patient interval of TYA population with YA population.

	TYA (n=748)		YA (n=307)		TYA vs. YA
	<1 Month	>1 Month	<1 Month	>1 Month	>1 Month
	n (%)	n (%)	n (%)	n (%)	X2 p-Value
All participants	544 (73)	204 (27)	178 (58)	129 (42)	-
Gender					
Male	641 (74)	107 (26)	57 (55)	46 (45)	0
Female	651 (71)	97 (29)	121 (59)	83 (41)	0.12
Ethnic group					
White	566 (72)	182 (28)	149 (57)	111 (43)	0
Non-White	726 (76)	22 (24)	29 (62)	18 (38)	0.21
Cancer diagnosis					
Leukaemia	726 (75)	22 (25)	6 (86)	1 (14)	0.36
Lymphoma	682 (73)	66 (27)	12 (46)	14 (54)	0.01
Soft tissue sarcoma	735 (68)	13 (32)	9 (47)	10 (53)	0.28
Germ cell tumours	712 (76)	36 (24)	37 (71)	15 (29)	0.69
Melanoma	734 (50)	14 (50)	1 (13)	7 (88)	0.06
Carcinomas	720 (68)	28 (32)	93 (61)	59 (39)	0.66

TYA Teenagers and young adults; **YA** Young adults; **n** Number of observations in sub-group

Suggestions for Improving the Diagnostic Pathway

Many patients (39%) gave a total of 191 suggestions to improve the diagnostic pathway. Themes included raising awareness of cancer in YAs and taking young people seriously, communication, and reducing passive waiting times. Table 6 shows exemplary quotes.

The majority (39%) of recommendations were about raising awareness among HCPs and YAs that age should not preclude cancer and taking YAs seriously (Table 3). Nearly a quarter (21%) suggested better communication, such as providing more information about investigations, not skirting around cancer suspicions, and not giving false reassurance. One in six (16%) thought the healthcare interval length could be reduced by shortening wait times for examinations, referrals and appointments, and sharing more information between institutions and departments.

Table 6. Quotes supporting qualitative analyses.

Theme	Quotations
Raising awareness and taking young people seriously	"I didn't come across many well-informed doctors before I was admitted to the ***. I think cancer was dismissed as a possible reason because I was relatively young and otherwise fit and healthy. No one took my tumour markers despite me having lumps/swelling. Perhaps my only suggestion is raising awareness with all doctors that age is not a reason to discount cancer if they can't immediately identify the cause of a symptom. A blood test may have cut down my wait significantly."
	"I rarely felt like I was being listened to and taken seriously as an individual who knew their own body. The GP only took me seriously when I found that a pre-existing lump in my breast had grown almost overnight, by which time it was too late. My sense was that the emergency/rapid response care was very good; but the preventative care and taking a holistic look at my symptoms in the early stages was completely overlooked."
Communication	"I didn't realize they could tell you on the day that its cancerous, I thought you had to wait for the results, so I was very unprepared and alone (without my husband/parent)."
	"My consultant sent me for a fine needle aspiration but told me this was fairly routine. I was not told this was a test for cancer. I feel that I should have been given at least some mild warning of the possibility of cancer by the consultant."
Reducing passive waiting times	"Reducing the wait between being referred to seeing a specialist or having tests. It's a very stressful and scary time."
	"Share test results/scan info between trusts so tests do not have to repeated."

A small number of remarks were about the patient interval, recommending that YAs should not wait to contact their GP with abnormalities and be persistent about getting a diagnosis (9%).

There were no major differences between groups, but participants with a healthcare interval ≥1 month more often remarked about raising awareness and being taken seriously (57%) and reducing waiting times for examinations, referrals, and appointments (50%).

DISCUSSION

In this study, we investigated the diagnostic pathway of YA cancer patients, examined patient and tumour characteristics associated with the length of the diagnostic pathway, compared the patient interval length of our sample with a TYA cohort, and reported patients' suggestions for improving the diagnostic pathway.

Both patient and healthcare intervals were long among a substantial proportion of participants. Forty-two percent of participants had patient intervals ≥1 month and 21% ≥3 months. Healthcare intervals were ≥1 month for 40% and ≥3 months for 17% of participants. Gender and ethnicity were not associated with diagnostic intervals or the number of consultations before diagnosis. Age was only associated with the healthcare interval, where age was slightly lower among patients with a >1 month interval. Remarkably, symptom presence at diagnosis did not influence healthcare interval length nor the number of GP or hospital doctor consultations.

Subtype-specific cancer diagnosis was associated with both patient and healthcare interval length and number of pre-diagnosis consultations. YAs with melanoma were most likely to wait ≥1 month before consulting a doctor but never had ≥4 hospital doctor consultations, as expected with identifiable presenting symptoms (an itching or bleeding pigmented lesion) of this cancer. The finding that identifiable presenting symptoms may lead to a short patient interval is supported by a sub-analysis of the BRIGHTLIGHT cohort, which shows 38% of participants with mole changes had a patient interval > 1 month.[24]

YAs with cervical cancer were more likely to wait ≥1 month as well, and some had ≥4 GP consultations. Notably, half of these patients were not detected through screening. However, in the NHS one in four women skip cervical screening, with the proportion increasing to one in three among those aged 25 to 29.[25] Unfortunately, our study did not ask cervical cancer patients not detected through screening whether they participated in the screening program. We therefore cannot conclude whether these were interval carcinomas occurring between two screening dates.

In breast cancer, one might expect a short patient interval as breast cancer patients form a distinct group compared to other cancer patients, given the general knowledge about the disease and its symptoms in the population. However, a third waited more than one month before consulting a doctor. We hypothesize this may be due to YAs having busy lives and not recognizing symptoms as caused by malignancy. Two participants with breast cancer reported being diagnosed through screening, possibly in a screening program for a hereditary cancer syndrome. The standard NHS screening program for breast cancer starts at age 50. Regarding the breast cancer healthcare interval, it is unsurprising that few participants had >4 GP (5%) or hospital (3%) consultations.

The NICE two-week-wait rule (TWW) states patients with a suspicion of cancer should be referred to a specialist in two weeks and additional investigations, including biopsies, should be carried out on one day.[26] Therefore, one would expect the healthcare interval to be shorter than two weeks for most participants. However, the healthcare interval lasted ≥2 weeks in 43% of YAs, and ≥1 month in 16%. As expected, few had a healthcare interval ≥3 months (2%). It is known that younger patients present less often via the TWW, and more often via non-TWW referrals or in emergency presentations, however, this may not be directly correlated with the healthcare interval, as the majority of patients will be diagnosed through emergency presentation.[27]

Participants with diagnoses other than breast cancer were more likely to experience a healthcare interval ≥1 month. The only exception was leukaemia, though these patients had many pre-diagnosis GP and hospital consultations. The need to perform additional investigations in leukaemia patients to confirm the diagnosis may explain the high number, but most of these investigations can be undertaken and interpreted relatively quickly. Alternatively, patients with leukaemia often present as an emergency, although this percentage is higher in TYAs than YAs.[27]

Comparison with existing literature is difficult, as studies focusing solely on YAs 25–39 years of age are rare. This study enabled a direct comparison of YA and TYA patient intervals with findings from the BRIGHTLIGHT study. This showed that YAs in our study, in general, had longer patient intervals. Age-related factors may contribute to this difference, such as differing life priorities (e.g., having a job, taking care of children). The distribution of diagnoses may play an important role as well: the proportion of participants diagnosed with leukaemia and lymphoma was larger in the TYA group, whereas carcinomas were diagnosed more often in the YA group. Participants who were male or white were more at risk of a longer patient interval when aged 25–39, compared to those aged 12–24. Furthermore, those diagnosed with lymphoma with a patient interval ≥1 month, or ≥3 months, were also more likely to be older. This was also true for patients with soft tissue sarcoma who had a patient interval ≥3 months. These findings are relevant and call for actions to increase awareness among YAs to reduce the patient interval.

Our findings support those of a European study, showing diagnostic routes among those aged 15–29 vary substantially, and an American study with patients aged 15–29 that found cancer diagnosis was significantly associated with interval length, whereas ethnicity, age, and gender were not.[28] Similarly, a National Cancer Intelligence Network report found that cancer diagnosis played a major role in determining how TYAs were likely to be referred.[27]

A Danish study amongst AYAs (aged 15–39) reported GP consultations increased several months before cancer diagnosis, possibly reflecting low awareness of patients and HCPs that symptoms may be due to malignancy.[29]

Although 68% of participants felt they were taken seriously in their first consultation, most suggestions to improve the diagnostic pathway were about taking YAs seriously, and not rejecting cancer as a possibility due to age. Additional recommendations were made about communication, and reducing passive waiting time, e.g., for additional examinations, referrals, or requesting information from other institutions. There were no major differences by interval length and most recommendations were not age specific.

To our knowledge, this is the first study to examine the diagnostic pathway of YA cancer patients, with various cancer diagnoses. However, this study has several limitations. First, intervals and the number of consultations were self-reported, potentially introducing recall bias. A generally consistent finding is that as the recall time increases, the ability to recall events degrades.[30] However, significant events, such as a cancer diagnosis, are less likely to be forgotten.[30] Furthermore, estimating the duration of an event is extremely stable.[31,32] To minimize the effect of recall bias, patients were asked to report the duration of intervals instead of dates, and questions were anchored to a life event (the cancer diagnosis).

Second, the study may be subject to selection bias as only 21% of invited participants responded, which is not unusual for studies among young adults with cancer. Data for the non-responder analysis was unfortunately only available from a selection of patients. However, this analysis does not show any differences in terms of age, time since diagnosis, or diagnosis.

Another cause of selection bias is the survivorship population in which we conducted our study. Not only will these people have had different tumour characteristics (e.g., lower stage at diagnosis), but they may also have had a different diagnostic pathway. Our results should thus be interpreted with this in mind.

Third, the distribution of tumours does not accurately reflect the incidence of cancers in YAs in the population.[10] For males, the most common cancers among YAs in the UK are testicular cancer, melanoma, and gastrointestinal tumours. For females, these are breast cancer, melanoma, and tumours of the genitourinary tract. Lymphoma and sarcoma are therefore overrepresented in our study, whilst melanoma and gastro-intestinal tumour may be underrepresented. We invited patients from hospitals in the Southeast, East, and London regions, who may have relatively more TWW referrals than those diagnosed in the North East.[27] Interval length may be underestimated when compared to the whole of England. Lastly, as subgroups were small, we were unable to perform adjusted analyses and the results should therefore be interpreted with caution.

Our findings highlight that cancer is still seen as a disease of the elderly. We recommend increasing awareness and gain better insight in the diagnostic pathway of patients aged 25–39 and raise awareness in the general public and among health care professionals to shorten time to diagnoses. Further research with a larger population is needed to confirm our findings with respect to identified risk groups, and to study the impact of a prolonged diagnostic pathway on clinical and patient-reported outcomes for YAs.

CONCLUSIONS

Patient and healthcare interval length is long in a substantial proportion of YA cancer patients. Diagnostic intervals were associated with cancer diagnosis, with YAs with melanoma or cervical cancer experiencing a long time to diagnosis, and YAs with breast cancer and leukaemia experiencing a short diagnostic pathway. Compared to the TYA population, YA patients who were male, white, or diagnosed with lymphoma or STS, were more likely to experience a prolonged patient interval. Participants recommended improving the diagnostic pathway by raising awareness, enhancing communication, and reducing passive waiting time.

Take home message

The diagnostic pathway of YAs should be studied further and awareness about cancer in this age group should be increased. Healthcare providers should be aware of cancer incidence among young adults and provide adequate information and support for this age group.

Appendix A. Responders versus non-responders the Royal Marsden NHS Foundation Trust.

	Responders (n=209)	Non-responders (n=690)
	Mean (SD)	**Mean (SD)**
Age at diagnosis in years	33.17 (4.41)	32.77 (4.32)
Age at time of study	35.82 (4.63)	35.42 (4.52)
Years from diagnosis	3.79 (1.78)	3.23 (1.77)
	Number	**Number**
Cancer diagnosis		
Breast cancer	56	151
Leukaemia	5	16
Lymphoma	9	44
Sarcoma	27	92
Testicular cancer	31	134
Ovarian cancer	7	10
Melanoma	11	25
Thyroid cancer	23	90
Colorectal cancer	10	35
Other	11	24
Missing	19	69

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CHAPTER 5

Describing unmet supportive care needs among young adults with cancer (25-39 years) and the relationship with health-related quality of life, psychological distress and illness cognitions.

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Journal of Clinical Medicine. 2021;10:4449. doi: 10.3390/jcm10194449

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ABSTRACT

Purpose

Few studies describe supportive care needs among young adults (YAs) with cancer ages 25 to 39 using validated questionnaires. Previous findings identified the need for psychological and information support and suggest gender, age, psychological distress and coping may be associated with greater need for this support.

Methods

To substantiate these findings, this study aimed to (1) describe the supportive care needs of YAs in each domain of the Supportive Care Needs Survey and (2) explore the relationship between unmet supportive care needs and clinical and demo-graphic factors, health-related quality of life, psychological distress, illness cognitions and service needs using latent class analysis. Clinical teams from six hospitals in England invited eligible patients to a cross-sectional survey by post.

Results

317 participants completed the survey online or on paper. YAs expressed the most need in the psychological and sexuality domains. Using latent class analysis, we identified three classes of YAs based on level of supportive care need: no need (53.3%), low need (28.3%) and moderate need (18.4%). In each class, median domain scores in each domain were similar. Low and moderate need classes were associated with worse health-related quality of life and greater helplessness. Unmet service needs were associated with the moderate need class only.

Conclusions

Patients with unmet supportive care needs should be offered holistic care across supportive care domains.

INTRODUCTION

A growing body of research has highlighted specific psychosocial issues experienced by young adults (YAs) ages 25 to 39 with cancer, such as difficulty balancing work or childcare with treatment, financial distress and social isolation from friends and family.[1,2] However, evidence on whether YAs need access to support services for the issues experienced is lacking. In cancer, supportive care refers to 'the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement'.[3] Simply measuring the prevalence or severity of problems assumes that patients who experience issues have a need for supportive care. Needs assessments directly measure if a patient perceives a need for help and the magnitude of the desire for help.[4]

Three systematic reviews including qualitative and quantitative studies have looked at supportive care needs among adolescents and YAs and identified a need for age-appropriate information, facilities and communication, access to emotional support, contact with peers and fertility information and services.[5–7] However, many studies used qualitative data and few quantitative studies used validated measures of need. Additionally, most studies focused on younger patients ages 15 to 24, who have better access to age-tailored psychosocial support in the countries where the studies were conducted.

One more recent study included adolescents and YAs ages 18 to 39 and used the Supportive Care Needs Survey (SCNS). The SCNS is a validated measure comprised of common issues among cancer patients in five domains of need: psychological, health system and information, patient care and support, physical and daily living and sexuality needs.[8] Met needs are the issues that patients report are not applicable or 'satisfied', while unmet needs are the issues where patients report they have some degree of need. This study found the highest unmet supportive care needs were in the psychological and information domains. Higher unmet needs in some domains were associated with female gender, older age, increased distress and poorer coping with the disease. These findings generally support recent research into adolescent and YA care advocating for more age-appropriate information and psychosocial support.[9]

Unmet supportive care needs in previous studies have been associated with lower health-related quality of life (HRQoL) and higher psychological distress.[10–13] Contrary to expectation, one study exploring the relationship between function, symptoms and supportive care needs found patients with low function and high symptoms did not always have high unmet supportive care needs.[14] This may reflect variable access to psychosocial support services or differences in cognitive processing. Variable access to support services can lead to 'service need' where a patient is unable to use a certain desired service (i.e. psychology or physiotherapy). This differs from supportive care need which relates to support for specific issues or problems common among patients with cancer (i.e. anxiety or pain). Illness cognitions, the beliefs or perceptions patients have about their disease and its treatment, may be related to a patient's HRQoL.[15] The relationship between illness cognition, service need and supportive care need has not yet been explored among YAs with cancer.

To substantiate the unmet supportive care needs of YAs ages 25 to 39 and examine the relationship with clinical and demographic factors and other psychosocial concepts, we conducted a multi-centre cross-sectional survey. Our main objectives were to (1) describe the unmet supportive care needs among YAs, in each SCNS domain and (2) explore the relationship between supportive care need and

clinical and demographic factors, HRQoL, psychological distress, illness cognitions and service need using latent class analysis.

METHODS

Study design

We conducted a multi-centre, cross-sectional survey.

Study population and procedures

Clinical teams from six hospitals across Southeast England identified potential participants in clinic lists and local databases. Eligible patients were diagnosed with any cancer type between age 25 and 39 between May 2013 and May 2018. Patients were excluded if previously diagnosed with cancer before age 25 or before May 2013, unable to read or write in English or mentally or physically unfit (e.g. severe cognitive disability or nearing end-of-life) as determined by the clinical team. Eligible patients who relapsed or received a second primary diagnosis were not excluded. The clinical team invited patients by letter to take part in the survey between May 2018 and October 2019. Participants that did not respond within one month were posted a reminder letter. Participants could choose to complete the survey online using PROFILES, a web-based system for collecting patient-reported outcomes in cancer research, or return a paper version by post.[16]

All participants completed an informed consent form either online or on paper returned with the survey. The study was reviewed and approved by The Royal Marsden NHS Foundation Trust and Institute of Cancer Research Joint Committee for Clinical Research (CCR4648), a London Research Ethics Committee and the UK Health Research Authority (17/LO/0219).

Measures

All items and measures in the survey were self-report. Demographic and clinical items included current age, age at diagnosis, gender, ethnicity, education, cancer diagnosis, treatments, current treatment status and current treatment intent. Here anti-hormonal treatments were considered active therapy.

Supportive Care Needs

We used the SCNS long form, a 59-item instrument that measures supportive care needs among people with cancer.[4] Each item asks patients about a common issue or problem experienced by patients with cancer that can be potentially ameliorated by supportive care. It is a well-validated measure used extensively in cancer populations. The measure has five domains (psychological, health system and information, physical and daily living, patient care and support and sexuality needs) and 4 single items that do not belong to a domain (talking to other people, changes in others' attitudes or behaviour toward you, financial concerns, transport). Items are scored from 1 to 5 (1 not applicable, 2 satisfied, 3 low need, 4 moderate need and 5 high need). Domain scores are the average score of items in each domain and can range from 1-5. Domain scores were calculated if at least half the items were complete. Participants with missing domain scores were excluded. Domain scores for each participant were then dichotomised with scores >2 indicating 'unmet need' as the scoring manual recommends. At an item level, we dichotomised responses with scores >2 indicating 'unmet need' and present the ten most common issues of all 59 items. Cronbach's alpha was calculated to determine internal reliability in the sample.

Quality of Life

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC-QLQ-C30) is a 30-item instrument developed to assess HRQoL in patients with cancer.[17]

The measure has been widely used in clinical trials and has robust psychometric properties. The EORTC-QLQC30 includes five functional scales (physical, emotional, cognitive, role and social functioning), eight symptom scales (fatigue, pain, nausea and vomiting, dyspnoea, insomnia, appetite loss, constipation and diarrhoea) and a global quality of life score. All domains are scored if at least half the items are complete and are transformed to a standardised score of 0-100 with higher scores indicating better function or quality of life or higher symptom burden. A summary score, which has shown to be a strong prognostic factor for survival, was calculated using the mean of all scale scores except global quality of life and financial impact following the recommendation by Giesinger *et al*.[18]

Psychological Distress

The Hospital Anxiety and Depression Scale is a 14-item instrument used extensively in cancer research with robust evidence of validity.[19,20] The measure is comprised of two scales (anxiety and depression) made of seven items each. Items are scored from 0-3. Scale scores, the summed item total, can range from 0-21. Higher scores indicate worse anxiety or depression. Scores greater than eight indicate borderline abnormal anxiety or depression.[19,21]

Illness Cognition

Illness cognitions were measured using the Illness Cognition Questionnaire, an 18-item instrument comprised of three, six-item scales: helplessness, acceptance and perceived benefits.[22] The helplessness scale measures negative perception of the disease as uncontrollable, unpredictable or unchangeable. Acceptance measures the level that a patient acknowledges the illness and perceives the ability to live with the effects of the condition. Perceived benefits measures the amount a patient finds positive meaning in the disease. Items are scored on a 1-4 scale and scores are the summed totals ranging between six and 24 with higher scores representing greater helplessness, acceptance or perceived benefits.

Service Needs

The amount to which YAs were able to use desired support services was measured using a non-validated questionnaire adapted from the Adolescent and Young Adult Health Outcomes and Patient Experience Study.[23] Patients were presented with 16 relevant services including physiotherapy, pain management, psychology and complementary services (supplementary material table 1). For each item, patients were asked to indicate if they had needed the service and, if yes, if they had used the service. The number of services that were needed but not used were summed to give the total number of unmet service needs for each participant. The total number of service needs could range from 0-16. This is another measure of need which asks patients to explicitly report the need and use of specific services rather than the need for support with issues or problems reported in the SCNS. Using both measures allowed us to explore whether service need is related to supportive care need.

Statistical analysis

Descriptive statistics were calculated for demographic and clinical items and questionnaires. We compared the characteristics of included and excluded participants to identify potential bias using independent samples t-tests in the case of continuous variables and chi-squared tests with adjusted residuals in the case of categorical variables.

All continuous variables are presented using mean and standard deviation or median and interquartile range where skewed. Frequency and percentage are reported for categorical variables. P-values were considered significant at the point 0.05 level.

Latent class analysis

To explore the pattern of responses across SCNS domains and analyse supportive care need as a single outcome to avoid type I errors, we used latent class analysis.[24] Latent class analysis assumes one or more unobserved categorical variables are responsible for response patterns, which it uses to probabilistically assign individuals to classes and provide information about how individuals are likely to respond to each of the domains given class assignment. Individuals with similar response patterns will tend to be assigned to the same latent class. Researchers then assign each class a qualitative description based on literature, experience and theory. In a previous study in adults, authors found that level of supportive care need categorised cancer patients into three classes: low need, moderate need and high need.[25]

Latent class models with increasing numbers of classes were fit from a 1-class to a 5-class model. Model selection was based on minimising the Bayesian Information Criteria (BIC) and Akaike's Information Criteria (AIC), increasing the entropy and ease of interpretation (i.e. classes make sense from a rational perspective). We determined the 3-class model was optimal and defined the latent variable as the level of supportive care need. Classes were labelled no need, low need and moderate need as responses tended to cluster by similar degree of need across supportive care domains, similar to the previous study in adults. Detailed information regarding model fit and selection can be found in supplementary material 2.

Covariates

The relationships between level of supportive care need and clinical and demographic characteristics, psychosocial factors and access to services was explored in univariable latent class regression models. Diagnosis was dichotomised [breast vs. non-breast] due to small numbers in non-breast cancer diagnoses groups. Variables significantly associated with the level of supportive care need were added to a multi-variable latent class regression model using forward selection. Variables were included in the final model if they reduced the AIC and BIC. Collinearity of covariates was tested in a correlation matrix.

Analysis was conducted in R version 4.0.2.3.

RESULTS

Three hundred and forty-seven YAs took part in the survey of 1,683 (20.6%) potential participants. Of the respondents, 317 participants completed at least half of each domain in the SCNS and were included in the analysis. Participants were on average 33.3 years old (SD + 4.2) at diagnosis and 2.9 years from diagnosis (SD + 1.6) (Table 1). Most participants were female (N=219; 69.1%), white (N=272; 85.8%), and receiving follow-up care and monitoring but no longer receiving anti-cancer treatment (N=242; 76.3%). Participants excluded from analysis were no different in age at diagnosis (t=0.58; p=0.560), current age (t=0.56; p=0.578), time from diagnosis (t=0.02; p=0.986), gender (X^2=0.07; p=0.785), or cancer type (X^2=6.49; p=0.592) from those included. They were, however, more likely to be from 'other' ethnic groups (X^2=15.07; p=0.005; adjusted residual=3.25) or have missing treatment status information (X^2=32.98; p<0.001; adjusted residual=5.66). The majority of respondents (53.3%) were in the no need class, while 28.3% were in the low need class and 18.4% were in the moderate need class.

Table 1. Summary of patient-reported demographic and clinical characteristics in total sample and stratified by level of supportive care need.

	Total YAs (N=317)	No need (n=168)	Low need (n=98)	Moderate need (n=51)
	Mean [SD]			
Mean age at diagnosis in years	33.3 [4.2]	33.0 [4.3]	33.6 [4.1]	33.7 [4.1]
Mean current age in years	36.2 [4.5]	36.2 [4.6]	36.2 [4.6]	36.0 [4.3]
Years from diagnosis	2.9 [1.6]	3.2 [1.6]	2.6 [1.7]	2.3 [1.5]
	Frequency (%)			
Gender				
Female	219 (69.1)	106 (48.4)	74 (33.8)	39 (17.8)
Male	98 (30.9)	62 (63.3)	24 (24.5)	12 (12.2)
Ethnicity				
White	272 (85.8)	147 (54.0)	88 (32.4)	37 (13.6)
Asian/Asian British	26 (8.2)	13 (50.0)	6 (23.1)	7 (26.9)
Mixed/Multiple ethnic groups	12 (3.8)	6 (50.0)	2 (16.7)	4 (33.3)
Black/African/Caribbean/Black British	3 (1.0)	1 (33.3)	1 (33.3)	1 (33.3)
Other ethnic group	4 (1.3)	1 (25.0)	1 (25.0)	2 (25.0)
Educational attainment				
University	205 (64.7)	109 (53.2)	60 (29.3)	36 (17.6)
College / diploma	59 (18.6)	27 (45.8)	22 (37.3)	10 (16.9)
Secondary school	31 (9.8)	20 (64.5)	7 (22.6)	4 (12.9)
Vocational qualification	16 (5.05)	9 (56.2)	6 (37.5)	1 (6.25)
Primary school	2 (0.6)	1 (50.0)	1 (50.0)	0 (0.0)
Other	4 (1.3)	2 (50.0)	2 (50.0)	0 (0.0)
Diagnosis				
Breast cancer	102 (32.2)	39 (38.2)	41 (40.2)	22 (21.6)
Testicular cancers	47 (14.8)	31 (66.0)	13 (27.7)	3 (6.4)
Gynaecological cancers	45 (14.2)	21 (46.7)	15 (33.3)	9 (20.0)
Haematological cancers	37 (11.7)	20 (54.1)	11 (29.7)	6 (16.2)
Sarcomas	26 (8.2)	23 (88.5)	2 (7.7)	1 (3.8)
Head & neck cancers*	23 (7.3)	16 (69.6)	5 (21.7)	2 (8.7)
Gastrointestinal cancers	14 (4.4)	5 (35.7)	6 (42.9)	6 (21.4)
Melanoma	11 (3.5)	9 (81.8)	1 (9.1)	1 (9.1)
Other	12 (3.8)	4 (33.3)	4 (33.3)	4 (33.3)
Treatments received (non-exclusive)				
Surgery	250 (78.9)	135 (54.0)	78 (31.2)	37 (14.8)
Chemotherapy	184 (58.0)	81 (44.0)	68 (33.7)	35 (19.0)
Radiotherapy	144 (45.4)	71 (49.3)	48 (33.3)	25 (17.4)
Hormone therapy	66 (20.8)	29 (43.9)	26 (39.4)	11 (16.7)
Clinical trial therapy	34 (10.7)	15 (44.1)	12 (35.3)	7 (20.6)
Complementary therapy	29 (9.2)	11 (37.9)	11 (37.9)	7 (24.1)
Targeted therapy	28 (8.8)	12 (42.9)	11 (39.3)	5 (17.9)
Immunotherapy	19 (6.0)	7 (36.8)	8 (42.1)	4 (21.1)

Table 1. Continued

	Frequency (%)			
Active surveillance	13 (4.1)	9 (69.2)	2 (15.4)	2 (15.4)
Stem cell transplant	7 (2.2)	6 (85.7)	1 (14.3)	0 (0.0)
Other	29 (9.2)	15 (51.7)	10 (34.5)	4 (13.8)
Current treatment status				
On follow-up	242 (76.3)	150 (62.0)	65 (26.9)	27 (11.2)
On treatment	75 (23.7)	18 (24.0)	33 (44.0)	24 (32.0)
Current treatment intent				
Curative	244 (77.0)	137 (56.1)	75 (30.7)	32 (13.1)
Palliative	46 (14.5)	18 (39.1)	15 (32.6)	13 (28.3)
Unknown	25 (7.9)	12 (48.0)	7 (28.0)	6 (24.0)
Missing	2 (0.6)	1 (50.0)	1 (50.0)	0 (0.0)

YA Young adult; **SD** Standard deviation; *Head and neck cancer comprised of thyroid cancer and other malignancies in the head and neck not further defined

Supportive care needs

Respondents had the highest need in the psychological domain, where 42.0% of all respondents had unmet need (domain score > 2), followed by the sexuality domain, where 36.3% reported unmet need (Table 2). When stratified by latent class, at least 60% of participants in the moderate need class had unmet need in each domain. This contrasts the no need class where less than 12% of patients had unmet need in each domain. Cronbach's alpha for all domains was at least 0.88 indicating good internal reliability.

At the item level, uncertainty about the future and fear of cancer recurrence (FCR) were the most common unmet needs for all patients regardless of class (Table 3). Even in the no need class where unmet need was uncommon, a third of patients reported unmet need for uncertainty about the future and a fifth of patients reported unmet need for FCR.

Due to the high domain scores in the sexuality domain, we further explored these single items. Support with changes in sexual feelings was unmet in 76.5% (n=39) of moderate need patients, 52.0% (n=51) of low need patients and 11.0% (n=19) of no need patients. Support with changes in sexual relationships was unmet for 80.4% (n=41) of moderate need patients 49.0% (n=48) of low need patients and 11.0% (n=19) of no need patients.

Table 2. Overall domain scores and proportion with unmet need (domain score >2) in each supportive care need domain and single item stratified by predicted latent class.

Domain	Total YAs (n=317)		No need (n=168)		Low need (n=98)		Moderate need (n=51)	
	Median DS (IQR)	Number with DS >2 (%)	Median DS (IQR)	Number with DS >2 (%)	Median DS (IQR)	Number with DS >2 (%)	Median DS (IQR)	Number with DS >2 (%)
Psychological (22 items)	1.8 (1.2-2.7)	133 (42.0)	1.2 (1.0-1.6)	0 (0.0)	2.5 (2.2-3.0)	83 (84.7)	3.3 (2.9-3.6)	50 (98.0)
Health system & information (15 items)	1.5 (1.0-2.3)	107 (33.8)	1.1 (1.0-1.4)	6 (3.6)	2.1 (1.7-2.5)	50 (51.0)	3.2 (2.7-3.7)	51 (100.0)
Physical and daily living (7 items)	1.3 (1.0-2.1)	87 (27.4)	1.0 (1.0-1.3)	0 (0.0)	2.1 (1.6-2.6)	56 (57.1)	2.6 (1.8-3.3)	31 (60.8)
Patient care and support (8 items)	1.3 (1.0-2.0)	59 (18.6)	1.0 (1.0-1.3)	1 (0.6)	1.6 (1.1-2.0)	7 (7.1)	2.6 (2.3-3.3)	51 (100.0)
Sexuality (3 items)	1.7 (1.0-3.0)	115 (36.3)	1.0 (1.0-1.7)	19 (11.3)	2.3 (1.1-3.3)	53 (54.1)	3.7 (2.7-4.2)	43 (84.3)
Talking to other people (1 item)	2.0 (1.0-3.0)	103 (32.6)	1.0 (1.0-2.0)	17 (10.1)	3.0 (2.0-3.0)	52 (53.1)	3.0 (2.0-4.0)	34 (68.0)
Changes in others' attitudes or behaviour toward you (1 item)	1.0 (1.0-3.0)	94 (29.7)	1.0 (1.0-1.0)	11 (6.5)	2.0 (1.0-3.0)	47 (48.)	3.0 (2.0-4.0)	36 (70.6)
Financial concerns (1 item)	1.0 (1.0-3.0)	93 (29.3)	1.0 (1.0-1.0)	11 (6.5)	2.0 (1.0-3.0)	48 (49.0)	3.0 (2.0-5.0)	34 (66.7)
Transport (1 item)	1.0 (1.0-2.0)	42 (13.2)	1.0 (1.0-1.0)	2 (1.2)	2.0 (1.0-2.0)	13 (13.3)	3.0 (2.0-3.0)	27 (52.9)

IQR Interquartile range; **DS** Domain score

Table 3. Ten most common unmet supportive care needs stratified by level of supportive care need.

	10 most common unmet needs in no need class			10 most common unmet needs in low need class			10 most common unmet needs in moderate need class		
	Number (%)	**Item**	**Domain**	**Number (%)**	**Item**	**Domain**	**Number (%)**	**Item**	**Domain**
1	60 (35.7)	Fears about the cancer returning	Psychological	80 (81.6)	Fears about the cancer returning	Psychological	49 (96.1)	Uncertainty about the future	Psychological
2	35 (20.8)	Uncertainty about the future	Psychological	77 (78.6)	Uncertainty about the future	Psychological	43 (84.3)	Fears about the cancer returning	Psychological
3	27 (16.1)	Anxiety	Psychological	74 (75.5)	Feelings of sadness	Psychological	42 (82.4)	Feelings of sadness	Psychological
4	24 (14.3)	Fears about the cancer spreading	Psychological	73 (74.5)	Anxiety	Psychological	42 (82.4)	Fears about the cancer spreading	Psychological
5	23 (13.7)	Feelings of sadness	Psychological	70 (71.4)	Feeling down or depressed	Psychological	42 (82.4)	Learning to feel in control of your situation	Psychological
6	23 (13.7)	To talk to someone who has been through a similar experience	Health system & information	68 (69.4)	Fears about the cancer spreading	Psychological	42 (82.4)	Keeping a positive outlook	Psychological
7	22 (13.1)	Lack of energy and tiredness	Physical & daily living	62 (63.3)	Lack of energy and tiredness	Physical & daily living	42 (82.4)	Access to professional counselling if you, family or friends need it	Health system & information
8	21 (12.5)	Feeling down or depressed	Psychological	59 (60.2)	Learning to feel in control of your situation	Psychological	41 (80.4)	Finding meaning in this experience	Psychological
9	19 (11.3)	Changes in sexual feelings	Sexuality	56 (57.1)	Keeping a positive outlook	Psychological	41 (80.4)	Changes to your usual routine and lifestyle	Psychological
10	19 (11.3)	Changes in your sexual relationships	Sexuality	55 (56.1)	Feelings about death and dying	Psychological	41 (80.4)	Changes in your sexual relationships	Sexuality
							41 (80.4)	Making the most of your time	Psychological

YA Young adult

Covariates

Median and interquartile range of the EORTC-QLQ-C30 summary, anxiety, depression, acceptance, helplessness and perceived benefits scores and number of unmet service needs are presented in table four. For each outcome, the median score was worst in the moderate need class and best in the no need class.

Table 4. Summary of psychosocial and service use outcomes in total sample and stratified by level of supportive care need.

	Total YAs (N=317)	No need (n=168)	Low need (n=98)	Moderate need (n=51)
	Median [IQR]			
[*]**EORTC-QLQ-C30 summary score** (n=310)	89.0 [74.8-95.5]	94.4 [89.2-98.1]	78.9 [65.4-89.3]	71.7 [58.4-82.9]
[+]**Acceptance** (n=314)	16.0 [13.0-19.0]	17.0 [15.0-20.0]	14.0 [12.0-16.0]	13.0 [12.0-16.0]
[+]**Helplessness** (n=314)	8.0 [6.0-11.0]	6.0 [6.0-8.0]	10.0 [7.0-13.0]	12.0 [9.0-14.5]
[+]**Perceived benefits** (n=314)	18.0 [13.0-22.0]	18.0 [13.0-22.0]	18.0 [13.0-22.0]	17.0 [12.0-22.0]
[#]**Unmet service needs** (n=287)	2.0 [0.0-4.0]	1.0 [0.0-2.0]	3.0 [1.0-5.0]	5.0 [2.0-6.0]
	Frequency (%)			
[‡]**Anxiety**				
Score < 8	167 (52.7)	117 (70.1)	39 (23.4)	11 (6.59)
Score > 8	150 (47.3)	51 (34.0)	59 (39.3)	40 (26.7)
[‡]**Depression**				
Score < 8	252 (79.5)	159 (63.1)	66 (26.2)	27 (10.7)
Score > 8	65 (20.5)	9 (13.8)	32 (49.2)	24 (36.9)

YA Young adult; **IQR** Interquartile range; [*]European Organisation for Research and Treatment of Cancer Quality of Life Core Module score summarising all scales except the financial impact scale and global quality of life; [‡]Scale from the Hospital Anxiety and Depression Scale; [+]Scale from the Illness Cognitions Questionnaire; [#]Total number of unmet service needs from service need questionnaire

Breast vs non-breast diagnosis, white vs non-white ethnicity, time from diagnosis, chemotherapy, treatment status, treatment intent, diarrhoea (data not shown), all other EORTC-QLQ-C30 scale scores (data not shown), the EORTC-QLQ-C30 the summary score, anxiety, depression, helplessness, acceptance and number of unmet service needs were significantly associated with level of supportive care need in univariate analysis (Table 5). As all EORTC-QLQ-C30 scale scores had a strong association with level of supportive care need, the summary score was added to the multivariable model instead of individual scores.

Table 5. Univariable models with covariates significantly associated with level of supportive care need.

Variable	Class comparison	OR	DF	OR CI	p-value
In follow-up / on treatment (ref)	low / no need	0.24	12	(0.09, 0.59)	0.005^{**}
	moderate / no need	0.10	12	(0.04, 0.25)	$<0.001^{**}$
Non-breast diagnosis / breast diagnosis (ref)	low / no need	2.91	12	(1.42, 5.99)	0.007^{**}
	moderate / no need	2.34	12	(1.07, 5.12)	0.035^{*}
Non-white ethnicity / white ethnicity (ref)	low / no need	0.65	12	(0.20, 2.11)	0.444
	moderate / no need	3.11	12	(1.26, 7.68)	0.018^{*}
Treatment intent **Palliative / curative** (ref)	low / no need	1.32	10	(0.44, 3.91)	0.587
	moderate / no need	3.23	10	(1.21, 8.63)	0.024^{*}
I don't know / curative (ref)	low / no need	1.00	10	(0.26, 3.89)	0.996
	moderate / no need	2.24	10	(0.65, 7.68)	0.175
Years from diagnosis	low / no need	0.82	12	(0.67, 1.00)	0.050
	moderate / no need	0.68	12	(0.53, 0.89)	0.008^{**}
Chemotherapy received / no chemotherapy (ref)	low / no need	3.67	12	(1.64, 8.23)	0.004^{**}
	moderate / no need	2.03	12	(0.96, 4.28)	0.060
EORTC-QLQ-C30 summary score*	low / no need	0.87	12	(0.84, 0.91)	$<0.001^{**}$
	moderate / no need	0.85	12	(0.81, 0.89)	$<0.001^{**}$
Anxiety‡ **> 8 / Anxiety < 8** (ref)	low / no need	3.26	12	(1.64, 6.51)	0.003^{**}
	moderate / no need	16.54	12	(4.50, 60.83)	0.001^{**}
Depression‡ **> 8 / Depression < 8** (ref)	low / no need	8.85	12	(3.22, 24.33)	0.001^{**}
	moderate / no need	20.38	12	(6.48, 64.08)	$<0.001^{**}$
Helplessness^{+}	low / no need	1.72	12	(1.44, 2.06)	$<0.001^{**}$
	moderate / no need	1.98	12	(1.61, 2.45)	$<0.001^{**}$
Acceptance^{+}	low / no need	0.82	12	(0.74, 0.90)	0.001^{**}
	moderate / no need	0.80	12	(0.72, 0.88)	$<0.001^{**}$
Unmet service needs$^{\#}$	low / no need	1.31	12	(1.13, 1.45)	0.002^{**}
	moderate / no need	1.70	12	(1.51, 2.00)	$<0.001^{**}$

OR Odds ratio; **DF** Degrees of freedom; **CI** Confidence interval; **ref** Reference value; *European Organisation for Research and Treatment of Cancer Quality of Life Core Module score summarising all scales except the financial impact scale and global quality of life; $^{+}$Scale from the Illness Cognitions Questionnaire; ‡Scale from the Hospital Anxiety and Depression Scale; #Total number of unmet service needs from service need questionnaire; *p-value significant to 0.05 level; **p-value significant to 0.01 level

After forward selection the final multiple regression model included the EORTC-QLQ-C30 summary score, number of unmet service needs and acceptance. Compared to patients in the no need class, patients in the low need class had significantly lower odds of a higher EORTC-QLQ-C30 summary score and significantly higher odds of a higher helplessness score (Table 6). Compared to patients in the no need class, patients in the moderate need class had significantly lower odds of a higher EORTC-QLQ-C30 summary score and significantly higher odds of more unmet service needs. The odds of having higher acceptance were lower in the low and moderate need classes compared to the no need class, but these were not significant.

Table 6. Final multivariable regression showing covariate relationships with level of supportive care need.

Variable	Class comparison	OR	OR CI	p-value
EORTC-QLQ-C30 Summary score*	low / no need	0.92	(0.88, 0.98)	0.012*
	moderate / no need	0.90	(0.85, 0.96)	0.008**
Helplessness+	low / no need	1.34	(1.04, 1.73)	0.030*
	moderate / no need	1.42	(1.03, 1.95)	0.035*
Unmet service needs#	low / no need	1.18	(0.97, 1.44)	0.082
	moderate / no need	1.57	(1.21, 2.04)	0.005**
Acceptance+	low / no need	0.93	(0.81, 1.06)	0.202
	moderate / no need	0.86	(0.73, 1.02)	0.074
Model Characteristics: AIC 1141.547 **| BIC** 1232.683 **| Residual DF** 6 **| Observations** 283				

OR Odds ratio; **DF** Degrees of freedom; **CI** Confidence interval; **AIC** Akaike's Information Criteria; **BIC** Bayesian Information Criteria (BIC); *European Organisation for Research and Treatment of Cancer Quality of Life Core Module score summarising all scales except the financial impact scale and global quality of life; +Scale from the Illness Cognitions Questionnaire; #Total number of unmet service needs from service need questionnaire; *p-value significant to 0.05 level; **p-value significant to 0.01 level

DISCUSSION

Our results suggest that about half of YAs with cancer have unmet supportive care needs. Among these patients, the degree of need for help is generally low to moderate. Our results substantiate the common unmet need for psychological support among YAs. Evidence suggests a number of interventions are effective at improving psychological wellbeing among adolescents and YAs with cancer including peer support, technology-based interventions and skill-based interventions which could be implemented to address this gap.[26]

The most common psychological issues were uncertainty about the future and FCR. In this study, about half the participants experienced FCR, aligning with previous research that found between 29% and 85% of adolescents and YAs experience FCR to some extent.[27] A recent meta-analysis showed that psychological interventions can have small but significant and sustained effects on FCR, particularly contemporary cognitive behavioural therapies.[28] While interventions for uncertainty, which often include informational support have shown positive effects, a systematic review found these studies to be at unknown or high risk of bias.[29] Further rigorous research should be conducted to evaluate potential psychological support for uncertainty.

Our results also highlight the common unmet need for support in the sexuality domain. Specifically, respondents reported unmet need for support with changes in sexual feelings and relationships. One recent study found that around half of YAs experience sexual dysfunction after diagnosis which persists for at least two years.[30] However, research from the clinician perspective suggests providers inconsistently identify sexuality as an unmet need.[31] Our study demonstrates the relatively high unmet need for support with sexuality and sexual functioning among YAs compared to other domains and should motivate providers to address this gap. Expert consensus suggests early initiation of discussion regarding sexual health counselling is important and that peer support may be an effective intervention for this population.[32]

Similar to the previous findings in adults with cancer, the latent class analysis identified three classes of participants distinguished by level of supportive care need.[25] However, in this study where we further explored the responses in each class, we found the degree of unmet need in each class ranged from none to moderate rather than low to high. While in general the unmet needs were not high, participants tended to have a similar degree of unmet need across domains. This suggests that resources should be targeted to those with supportive care needs in a holistic, multidisciplinary approach. One study found that using a conversation aid called a ‘Snapshot’ with adolescents and YAs helped identify psychosocial issues.[33] This could be a useful tool to identify supportive care needs across domains in this population.

The relationship between diagnosis and level of supportive care need could not be explored in-depth due to small numbers in each group. However, the proportion of patients in each class for most diagnoses followed a similar pattern with the highest proportion of patients in the no need class. This concurs with the findings of a previous systematic review which found unmet supportive care needs did not differ by cancer type when included in mixed studies.[34] Treatment status, however, made a big difference for the level of supportive care need where the majority of those on treatment had unmet needs compared to the minority of those on follow-up. This also corroborated the results of the previous review which found patients on treatment had the highest unmet supportive care needs.[34] However, in the multivariable model, cancer type and treatment status were no longer significantly associated with level of supportive care need. It is also interesting to note that 8% of patients reported they did not know the intent of their treatment. It is difficult to interpret the reason patients reported unknown treatment intent but this may have contributed to an observed higher information and psychological need in this group.

In multivariable analysis, the moderate need class was independently associated with lower HRQoL, more helplessness and more unmet service needs. This suggests that service needs do indeed play a role in unmet supportive care needs. While causality cannot be determined due to the cross-sectional design of the study, it is reasonable to expect that improving access to services would reduce the degree of unmet supportive care need for those with moderate need. This finding also suggests, however, that HRQoL and helplessness play a role in unmet supportive care needs regardless of access to services. This implies that increasing services alone will not resolve all supportive care needs. We hypothesise this may be the case because the SCNS measures issues that services may not consistently resolve. For example, 'changes to daily routine and lifestyle' may occur regardless of professional support due to cognitive or functional changes. Another example is 'fatigue' where there is uncertainty around effective interventions for YAs.[35] Addressing these issues will rely on reducing the initial impact of cancer and its treatment by finding kinder treatments and improving early diagnosis. Including patient reported outcomes important to YAs in clinical trials and focusing on this specific population in analysis will help identify treatments with lesser impact on the issues important to this population.

Limitations

The low response to this study should be taken into consideration when evaluating the results of this exploratory analysis. Low response is more common in studies focusing on adolescents and YAs and it is recognised that recruitment in this population takes considerable resource.[36] Future researchers could employ a combined approach of in clinic and postal invitations to increase the proportion of responses. The low response may have introduced response bias which includes overrepresentation of white females with breast cancer. Although, breast cancer is the most common cancer among YAs, particularly between 35 and 39 years, which may account in part for the high proportion in this study.[37] Incomplete data further reduced the sample size in the multiple regression model. The inclusion of many different cancer types allowed us to explore the supportive care needs of YAs across diagnoses. However, broad diagnostic categories and relatively low numbers in some groups limited our ability to explore differences by cancer type. The diagnoses and treatments presented here may also suffer from some level of inaccuracy as participants self-reported the information.

CONCLUSIONS

YAs with cancer need additional psychological support, particularly for fear of cancer recurrence and uncertainty. Sexual needs have high importance relative to other domains in YAs and deserve special attention as this is often overlooked in routine care. Patients with unmet supportive care needs should be offered holistic care across the supportive care domains. Improving access to support services will likely reduce supportive care needs, particularly by targeting YAs with moderate need. However, some needs identified in the SCNS may not be effectively resolved by current services or interventions. Future studies should further explore the relationship between supportive care needs, HRQoL and illness cognitions in specific supportive care domains and longitudinally to better understand causation.

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CHAPTER 6

Identifying health-related quality of life cut-off scores that indicate the need for supportive care in young adults with cancer.

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Quality of Life Research. 2022; 31: 2717-2727. doi: 10.1007/s11136-022-03139-6

ABSTRACT

Purpose

Using patient-reported outcomes in routine cancer care may improve health outcomes. However, a lack of information about which scores are problematic in specific populations can impede use. To facilitate interpretation of the European Organisation for Research and Treatment of Cancer Core Questionnaire (EORTC QLQ-C30), we identified cut-off scores that indicate need for support by comparing each scale to relevant items from the Supportive Care Needs Survey (SCNS-LF59) in a young adult (YA) population.

Methods

We conducted a cross-sectional survey among YAs with cancer ages 25-39 at diagnosis. Participants completed the EORTC QLQ-C30 and SCNS-LF59. Patient, clinician and research experts matched supportive care needs from the SCNS-LF59 to quality of life domains of the EORTC QLQ-C30. We evaluated the EORTC QLQ-C30 domain score's ability to detect patients with need using receiver operator characteristic (ROC) analysis, calculating the area under the ROC curve and sensitivity and specificity for selected cut-offs. Cut-offs were chosen by maximising Youden's J statistic and ensuring sensitivity passed 0.70. Sensitivity analyses were conducted to examine the variability of the cut-off scores by treatment status.

Results

Three hundred and forty-seven YAs took part in the survey. Six experts matched SCNS-LF59 items to ten EORTC QLQ-C30 domains. The AUC ranged from 0.78-0.87. Cut-offs selected ranged from 8 (Nausea and Vomiting and Pain) to 97 (Physical Functioning). All had adequate sensitivity (above 0.70) except the Financial Difficulties scale (0.64). Specificity ranged from 0.61-0.88. Four of the cut-off scores differed by treatment status.

Conclusion

Cut-offs with adequate sensitivity were calculated for nine EORTC QLQ-C30 scales for use with YAs with cancer. Cut-offs are key to interpretability and use of the EORTC QLQ-C30 in routine care to identify patients with supportive care need.

INTRODUCTION

Interest in using patient-reported outcomes (PROs) in routine cancer care has increased dramatically in recent years.[1] PROs are direct reports from patients about symptoms, function or wellbeing with respect to a condition or treatment without interpretation by a clinician or anyone else.[2] Evidence suggests that using PROs in routine care may improve patient-clinician communication, quality of life, symptom burden, patient satisfaction and even survival.[3–7] In these cases, PROs are essentially used as screening tools to help identify problems for further discussion with a clinician that might otherwise go unaddressed.

Despite the potential benefit, using PROs in routine care can be challenging due to difficulty interpreting scores which are usually presented as a range of numerical values (i.e. 0-100).[8] In cancer, most PROs have been designed for use in research where analysis can focus on group comparisons or change over time. However, in routine care, clinicians need to interpret scores at an individual level at a single time point. This requires an understanding of which scores are considered moderate or severe and require clinical attention. We can aid this interpretation by defining a 'cut-off' score, the threshold above or below which the scores are problematic.

The European Organisation for Research and Treatment of Cancer Quality of Life Core Questionnaire (EORTC QLQ-C30) is one of the PROs most commonly used in routine care.[3] However, research defining cut-offs for the questionnaire domains is limited.

Giesinger *et al*. identified cut-offs for functional and symptom domains by comparing patient scale scores on the EORTC QLQ-C30 to their responses on three external questions designed to reflect clinical importance ('Has your symptom/problem limited your daily life?', 'Have you needed any help or care because of your symptom/problem?' and 'Has your symptom/problem caused you or your family/partner to worry?').[9,10] Clinical importance was conceptualised as the need for clinical interaction, incorporating the presence of symptoms or problems that are limiting, the need for help or care and worries about the issues.

Snyder *et al*. instead took a more focused approach to screen for supportive care needs by comparing EORTC QLQ-C30 domain scores to selected items from a validated measure of supportive care need among cancer patients.[11–13] However, the short form of the Supportive Care Needs Survey (SCNS) used had a limited number of items that were conceptually similar to the EORTC QLQ-C30 domains.

This meant the authors could only calculate adequate cut-offs for six of the 15 scales. Additionally, the sample included mostly older adults (mean age 61), which could limit generalisability. Cut-offs may be different among younger people as patients may have higher expectations for function and symptoms. For example, the optimal cut-off for social functioning in the study by Giesinger *et al*. for patients younger than 60 was 16 points lower than the optimal cut-off for older patients.[14] The lack of inclusion of young adults (YAs) in these studies likely obscures important differences in the identification of problematic scores.

Stronger evidence for cut-offs indicating the need for support for each domain will facilitate its use in standard cancer care as a screening tool for supportive care. We aim here to expand on the analysis by Snyder *et al*. to identify additional cut-offs on EORTC QLQ-C30 scale scores in a population of young adults (YAs) diagnosed with cancer between the ages of 25 and 39. We will replicate the analysis using the SCNS Long Form (SCNS-LF59) to utilise questions not found in the short form that may be relevant to additional EORTC QLQ-C30 scale scores (i.e. Nausea and Vomiting) and to the younger population (i.e. 'fear of losing independence').

MATERIALS AND METHODS

Study population and procedures

We conducted a multi-centre, cross-sectional survey where clinical teams invited potential participants by post between May 2018 and March 2019. Patients were eligible if they received a first primary cancer diagnosis of any type between the ages of 25 and 39 at one of the six participating centres in Southeast England between May 2013 and May 2018. Patients were excluded if the treating clinician determined they had severe cognitive disability or were physically too unwell (i.e. nearing end of life). Patients could complete the questionnaires by paper or online using PROFILES, a web-based system for the collection of patient reported outcomes in cancer research.[15] To use the data for exploratory analyses, no formal sample size was calculated a priori but we aimed to enrol 350 patients based on number of eligible YAs at participating centres and expected 25% response.[16]

Measures

Participants reported demographic and clinical information including current age, age at diagnosis, gender, ethnicity, education, work status, cancer diagnosis, treatments, treatment status and treatment intent.

Supportive Care Needs

Participants completed the SCNS-LF59 as a measure of supportive care need.[17] This instrument includes 59 items which comprise five domains (psychological, health system and information, physical and daily living, patient care and support, and sexuality needs) and four single items (talking to other people, changes in others' attitudes or behaviour towards you, financial concerns, transport). Response categories range from one to five and correspond to not applicable, satisfied, low need, moderate need and high need. Domain scores, calculated only if at least half the items are complete, are the average of all items in each domain.

Quality of Life

Participants completed the EORTC QLQ-C30 to measure cancer-related quality of life.[18] The EORTC QLQ-C30 is a 30-item instrument with 15 scales in total: five functional scales (physical, emotional, cognitive, role, and social functioning), nine symptom scales (fatigue, pain, nausea and vomiting, dyspnoea, insomnia, appetite loss, constipation, diarrhoea and financial difficulties) and a global quality of life score. Scales are scored according to the manual if at least half the items are complete.[19] Scores range from 0-100. Higher scores on functional scales indicate better function, higher scores on the global quality of life scale indicates better quality of life, and higher scores on symptom scales indicate worse symptom burden.

Anchor selection

To determine the cut-offs, each EORTC QLQ-C30 scale needed to be compared to a conceptually similar single item, composite item or domain from the SCNS-LF59, referred to as an anchor. To ensure selected anchors were strong conceptual matches to the EORTC QLQ-C30 scales, we involved six experts in a multi-round rating process.

Potential anchors previously suggested by Snyder at al. for each EORTC QLQ-C30 scale formed the starting point. New items found in the SCNS-LF59 compared to the short form were added as potential anchors to relevant scales based on conceptual similarity by the lead author (EL). Potential anchors were then reduced to a single anchor per scale in an iterative process with patient, clinician and researcher experts.

Experts were identified and approached based on previous collaborations on YA oncology and quality of life projects. Experts were provided with an overview of the study's aims, methods, samples of the EORTC QLQ-C30 and SCNS-LF59 and a Microsoft Excel template for rating the anchors. The template first showed which items belonged to each scale in the EORTC QLQ-C30 and SCNS-LF59 to familiarise the experts with the questionnaires at item and domain-level. The template then had a page, which showed all the potential anchors for each EORTC QLQ-C30 scale. Instructions were discussed by phone where possible.

In the first round, experts were asked to independently rate each potential anchor in order of best conceptual fit, excluding items they thought did not fit entirely. If an expert thought the combination of every item in a domain matched the scale well, the domain could be selected and all single items excluded. Experts were also encouraged to add further potential anchors from the SCNS-LF59 if identified. The ratings were then returned and combined into a single document with each rating labelled only with a coded ID number for review by the lead author (EL).

Where there was majority agreement (4/6) that an anchor should be excluded, it was recorded as 'excluded', highlighted in red and grouped together. Where there was majority agreement that an anchor should be included, it was recorded as 'included', highlighted in green and grouped together. If there was agreement that a domain should be used as an anchor, it was included and all single items comprising that domain were excluded and treated as above. Newly suggested potential anchors were added in red text and grouped together with items that did not reach agreement for inclusion or exclusion. The spreadsheet with all the results was then presented back to the experts for a second round of ratings where they were asked specifically to rate the newly proposed items and those that had not reach agreement in the first round. This process continued until agreement was reached for each anchor.

Statistical analysis

Descriptive statistics were calculated for demographic and clinical variables. Mean and standard deviation are presented for continuous variables. Frequency and percentages are presented for categorical variables. Patients with incomplete data were excluded.

First we dichotomised each anchor from the SCNS-LF59 selected by the experts. Scores >2 indicate need while scores <2 indicate no need. Where more than one single item was chosen as an anchor, we calculated and dichotomised the mean score of the single items.

Cut-offs were evaluated using receiver operating characteristic (ROC) analysis, which allows us to evaluate the performance of a numerical test to classify subjects on a binary outcome.[20] The area under the ROC curve (AUC) indicates how well the numerical test can discriminate between the two binary outcomes levels.[21] Sensitivity (true positive rate) and specificity (true negative rate) can then be calculated for different thresholds to understand the accuracy of the test. Here, the EORTC QLQ-C30 scale scores form our numerical predictors and our binary outcomes are supportive care need on the specific anchors chosen (need vs no need). Sensitivity here indicates the proportion of individuals that score worse than the cut-off that truly have supportive care need on the anchor (score >2). Specificity indicates the proportion of individuals that score better than the cut-off that truly do not have supportive care need on the anchor (score < 2).

We then calculated the AUC to determine the EORTC QLQ-C30 scale scores' ability to discriminate between patients with need and those with no need on the selected anchors.[21] There is no agreed definition for an adequate AUC score, though evidence suggests that values below 0.70 indicate poor discrimination, values between 0.70 and 0.80 indicate acceptable discrimination and values above 0.80 indicate excellent discrimination.[22] If the AUC was below 0.70, cut-offs with sensitivity and specificity were not calculated. This AUC indicates the EORTC QLQ-C30 score would not adequately identify patients with and without need on the chosen anchor and should not be used as a screening tool.

Where the AUC exceeded 0.70, we calculated the cut-offs with associated sensitivities and specificities. We selected the optimal cut-off by maximising Youden's J statistic (the sum of sensitivity and specificity minus one). If the statistics for two adjacent thresholds differed by less than 0.05 we selected the threshold with the higher sensitivity following the methods described by Giesinger *et al*.[14] Where the sensitivity for the cut-off these parameters indicated was below 0.70, we chose the closest threshold with a sensitivity above this value where possible.

Sensitivity Analysis

Invariance by treatment status

For EORTC QLQ-C30 scores with agreed anchors, we conducted sensitivity analyses to explore variability in diagnostic accuracy and optimal cut-off scores by treatment status (on treatment vs. on follow-up). To determine the diagnostic accuracy, we calculated the AUC for each EORTC QLQ-C30 scale separately for patients on treatment and on follow-up. To examine variability in optimal cut-off scores, we used a multivariate logistic regression model for each chosen pair of SCNS-LF59 anchors and EORTC QLQ-C30 domains. In each model, the SCNS-LF59 binary anchor was included as the dependent variable. The EORTC QLQ-C30 domain score and treatment status were included as independent variables. If treatment status was significantly associated with the anchor ($p<0.01$), this indicated the optimal cut-off score was different between groups. In these cases, we calculated the cut-off score separately for patients on treatment and on follow-up and chose the optimal scores based on the criteria mentioned above. We also calculated the sensitivity and specificity of the new cut-off scores and compared them to the total sample.

Invariance by anchor selection method

Previous analyses selected anchors based on the highest AUC rather than expert opinion. To explore the impact of including multidisciplinary experts in the selection of anchors, we repeated the analysis using the anchors with the highest AUC and compared the findings where the anchors differed.

RESULTS

Sample characteristics

A total of 347 YAs completed the survey of 1,683 (20.6%) YAs invited between May 2018 and October 2019. Three hundred and thirteen participants had complete data and were included in analysis. On average, YAs were 33.3 years old (SD 4.2) at diagnosis and 2.8 years from diagnosis (SD 1.6) (Table 1). The majority of participants were female (N=216; 69.0%), of white descent (N=268; 85.6%) and university educated (N=202; 64.5%). Participants most commonly had breast cancer (N=100; 31.9%), were on follow-up (N=238; 76.0%) and were treated with curative intent (N=244; 76.7%).

Table 1. Summary of demographic and clinical participant details.

Participant characteristics (N=313)	**Mean [SD]**	**Range**
Mean age at diagnosis in years	33.3 [4.2]	25-39
Mean current age in years	36.1 [4.5]	26-45
Years from diagnosis	2.8 [1.6]	0-7
	Number (%)	
Gender		
Female	216 (69.0)	
Male	97 (31.0)	
Ethnicity		
White	268 (85.6)	
Asian/Asian British	26 (8.3)	
Mixed/Multiple ethnic groups	12 (3.8)	
Black/African/Caribbean/Black British	3 (1.0)	
Other ethnic group	4 (1.3)	
Educational attainment		
University	202 (64.5)	
College / diploma	59 (18.8)	
Secondary school	30 (9.6)	
Vocational qualification	16 (5.1)	
Primary school	2 (0.6)	
Other	4 (1.3)	
Diagnosis		
Breast cancer	100 (31.9)	
Testicular cancer	47 (15.0)	
Gynaecological cancers	44 (14.1)	
Haematological malignancies	36 (11.5)	
Sarcomas	26 (8.3)	
Head & neck cancers	23 (7.4)	
Gastrointestinal cancers	14 (4.5)	
Melanoma	11 (3.5)	
Other	12 (3.8)	
Treatments received (non-exclusive)		
Surgery	247 (78.9)	
Chemotherapy	182 (58.1)	
Radiotherapy	141 (45.0)	
Hormone therapy	64 (20.4)	
Clinical trial therapy	34 (10.9)	
Complementary therapy	28 (9.0)	
Targeted therapy	28 (9.0)	
Immunotherapy	18 (5.6)	
Active surveillance	13 (4.2)	
Stem cell transplant	7 (2.2)	
Other	29 (9.3)	
Current treatment status		
On follow-up	238 (76.0)	
On treatment	75 (24.0)	
Treatment intent		
Curative	244 (76.7)	
Palliative	46 (14.7)	
Unknown	25 (8.0)	
Missing	2 (0.6)	

SD Standard deviation

Cut-offs for Supportive Care Need

Six experts chose to take part in anchor selection including two YA patients from the United Kingdom, two clinical psychologists from Austria and two quality of life researchers from Austria and the Netherlands. Experts agreed on anchors for ten of the 15 of the EORTC QLQ-C30 scales after two rounds of ratings (Table 2). All potential anchors were excluded for Cognitive Functioning, Dyspnoea, Constipation, Appetite Loss and Diarrhoea as the SCNS-LF59 lacked items with similar content. The AUC for each agreed anchor ranged from 0.78-0.87 (Table 2). The highest AUCs were observed for Nausea and Vomiting (0.867) and Pain (0.865) and the lowest AUCs were observed for Financial Difficulties (0.776) and Global Quality of Life (0.781).

Cut-offs for the functioning scales and Global Quality of Life, where higher scores indicate better functioning, ranged from 71 for Global Quality of Life and Emotional Functioning to 97 for Physical Functioning (Table 2). Cut-offs for the symptom scales, where higher scores indicate more problems, ranged from 8 for Nausea and Vomiting and Pain to 17 for Insomnia and Financial Difficulties. Sensitivity ranged from 0.64 for Financial Difficulties to 0.88 for Pain (Table 2). Specificity ranged from 0.61 for Physical Functioning to 0.88 for Nausea and Vomiting and Financial Difficulties (Table 2).

The proportion of patients with need on the chosen anchors for each scale ranged from 9.3% on Nausea and Vomiting to 42.2% on Emotional Functioning (Table 3). The largest difference in EORTC QLQ-C30 mean score between patients with and without need in effect size was found for Nausea and Vomiting (Cohen's d=-1.74) and Pain (Cohen's d=-1.44) and the smallest difference was found for Emotional Functioning (Cohen's d=1.00) and Global Quality of Life (Cohen's d=1.11).

Sensitivity Analysis

Invariance by treatment status

We examined the diagnostic accuracy and optimal cut-off scores by treatment status for the ten EORTC QLQ-C30 scales with agreed anchors. All 20 AUCs were above 0.70 indicating acceptable discrimination (Table 4). AUCs for both groups were above 0.80 indicating excellent discrimination for Role Functioning, Nausea and Vomiting, and Pain. AUCs were also above 0.80 for Emotional Functioning and Insomnia for patients on treatment and Fatigue for patients on follow-up.

Table 2. Results of the receiver operating characteristic (ROC) analysis for scales with agreed anchors and cut-off scores.

EORTC QLQ-C30 Scale	SCNS-LF59 Anchor	Cut-Off Score	AUC (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)
Global Quality of Life	Feeling unwell a lot of the time + Not being able to do the things you used to do	**71**	0.78 (0.71-0.85)	0.78 (0.68-0.86)	0.69 (0.64-0.75)
Physical Functioning	Physical and daily living needs	**97**	0.79 (0.73-0.85)	0.80 (0.71-0.89)	0.61 (0.54-0.67)
Role Functioning	Not being able to do the things you used to do	**92**	0.84 (0.78-0.89)	0.82 (0.74-0.91)	0.74 (0.67-0.79)
Emotional Functioning	Psychological needs	**71**	0.79 (0.74-0.84)	0.71 (0.64-0.79)	0.70 (0.64-0.77)
Social Functioning	Changes to usual routine and lifestyle + Changes in other peoples attitudes towards you	**92**	0.81 (0.75-0.86)	0.82 (0.75-0.90)	0.70 (0.64-0.77)
Fatigue	Lack of energy/tiredness	**28**	0.84 (0.79-0.88)	0.78 (0.69-0.85)	0.79 (0.73-0.85)
Nausea and Vomiting	Nausea/vomiting	**8**	0.87 (0.79-0.94)	0.83 (0.69-0.97)	0.88 (0.84-0.92)
Pain	Pain	**8**	0.87 (0.82-0.91)	0.88 (0.79-0.95)	0.74 (0.69-0.80)
Insomnia	Not sleeping well	**17**	0.83 (0.78-0.88)	0.87 (0.80-0.93)	0.66 (0.60-0.72)
Financial Difficulties	Concerns about your financial situation	**17**	0.78 (0.72-0.83)	0.64 (0.54-0.74)	0.88 (0.84-0.92)

EORTC QLQ-C30 European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; **SCNS-LF59** Supportive Care Needs Survey Long Form 59; **SD** Standard deviation; **AUC** Area under the ROC curve; **CI** Confidence interval

Table 3. Number of patients with and without supportive care need on each SCNS-LF59 anchor and corresponding EORTC QLQ-C30 scale score.

		Respondents with no need on SCNS-LF59 anchor		Respondents with need on SCNS-LF59 anchor			
EORTC QLQ-C30 Scale	**SCNS-LF59 Anchor**	**Number (%)**	**Mean EORTC QLQ-C30 scale score (SD)**	**Number (%)**	**Mean EORTC QLQ-C30 scale score (SD)**	**Difference in mean score**	**Effect size***
Global Quality of Life[+]	Feeling unwell a lot of the time + Not being able to do the things you used to do	240 (76.9)	78.3 (16.3)	72 (23.1)	55.2 (24.5)	23.1	1.11
Physical Functioning[+]	Physical and daily living needs	226 (72.2)	95.1 (7.8)	87 (27.8)	75.6 (23.1)	19.5	1.20
Role Functioning[+]	Not being able to do the things you used to do	227 (72.8)	91.6 (17.7)	85 (27.2)	53.9 (32.7)	37.6	1.33
Emotional Functioning[+]	Psychological needs	181 (57.8)	80.8 (18.9)	132 (42.2)	54.9 (26.8)	25.8	1.00
Social Functioning[+]	Changes to usual routine and lifestyle + Changes in other peoples attitudes towards you	217 (69.3)	89.6 (19.2)	96 (30.7)	58.2 (30.8)	31.4	1.14
Fatigue[-]	Lack of energy/tiredness	192 (61.5)	17.0 (20.7)	120 (38.5)	49.3 (27.8)	-32.3	-1.14
Nausea and Vomiting[-]	Nausea/vomiting	283 (90.7)	3.1 (10.6)	29 (9.3)	28.2 (24.0)	-25.0	-1.74
Pain[-]	Pain	239 (76.6)	7.5 (15.2)	73 (23.3)	42.9 (29.8)	-35.5	-1.44
Insomnia[-]	Not sleeping well	222 (72.1)	15.2 (24.5)	86 (27.9)	55.8 (32.9)	-40.6	-1.25
Financial Difficulties[-]	Concerns about your financial situation	221 (70.6)	5.4 (16.5)	92 (29.4)	40.9 (37.3)	-35.5	-1.21

*Cohen's d based on pooled standard deviation; [+]Higher scores indicate better functioning or quality of life; [-]Better scores indicate worse symptom burden; **EORTC QLQ-C30** European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; **SCNS-LF59** Supportive Care Needs Survey Long Form 59; **SD** Standard deviation

Table 4. Results of the sensitivity analyses for scales with optimal cut-off scores that vary by treatment status.

EORTC QLQ-C30 Scale	SCNS-LF59 Anchor	Group	Cut-Off Score	AUC (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)
Global Quality of Life	Feeling unwell a lot of the time + Not being able to do the things you used to do	Total	**71**	0.78 (0.71-0.85)	0.78 (0.68-0.86)	0.69 (0.64-0.75)
		On TX	**63**	0.78 (0.67-0.89)	0.73 (0.58-0.88)	0.83 (0.71-0.93)
		On FU	**71**	0.75 (0.66-0.85)	0.74 (0.59-0.87)	0.72 (0.65-0.78)
Physical Functioning	Physical and daily living needs	Total	**97**	0.79 (0.73-0.85)	0.80 (0.71-0.89)	0.61 (0.54-0.67)
		On TX	**90**	0.75 (0.64-0.86)	0.74 (0.61-0.87)	0.59 (0.43-0.76)
		On FU	**97**	0.77 (0.69-0.85)	0.76 (0.63-0.88)	0.64 (0.57-0.71)
Emotional Functioning	Psychological needs	Total	**71**	0.79 (0.74-0.84)	0.71 (0.64-0.79)	0.70 (0.64-0.77)
		On TX	**71**	0.83 (0.73-0.93)	0.74 (0.63-0.85)	0.76 (0.57-0.90)
		On FU	**79**	0.76 (0.70-0.83)	0.79 (0.71-0.88)	0.55 (0.48-0.63)
Financial Difficulties	Concerns about your financial situation	Total	**17**	0.78 (0.72-0.83)	0.64 (0.54-0.74)	0.88 (0.84-0.92)
		On TX	**17**	0.79 (0.70-0.88)	0.70 (0.55-0.85)	0.80 (0.66-0.91)
		On FU	**17**	0.75 (0.68-0.83)	0.60 (0.46-0.73)	0.90 (0.85-0.94)

EORTC QLQ-C30 European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; **SCNS-LF59** Supportive Care Needs Survey Long Form 59; **AUC** Area under the ROC curve; **CI** Confidence interval; **TX** Treatment; **FU** Follow-up

Cut-off scores differed by group for four domains ($p<0.01$). The optimal cut-off scores for patients on treatment were lower than those for the total sample on Global Quality of Life and Physical Functioning (Table 4). For the on treatment group, the optimal cut-off score on Financial Difficulties was the same but sensitivity reached the acceptable threshold. For Emotional Functioning, the optimal cut-off score for patients on follow-up was higher than for the total sample and had better sensitivity.

Invariance by anchor selection method

The anchors for four scales (Global Quality of Life, Physical Functioning, Emotional Functioning and Social Functioning) differed when chosen according to the highest AUC rather than expert opinion (Table 5). The AUC for the composite anchor chosen by experts for 'Global Quality of Life' was higher than the single SCNS-LF59 item with the highest AUC (0.781 vs 0.761, respectively). The expert chosen anchor also had slightly higher sensitivity (0.78 vs 0.74, respectively), though the cut-off was the same. The AUCs of all other anchors selected by experts were lower than those chosen according to AUC.

The cut-offs for two scales (Physical Functioning and Emotional Functioning) differed when chosen according to the highest AUC rather than expert opinion. The cut-off for Physical Functioning was less severe using the anchor chosen by the experts compared to the anchor chosen according to highest AUC (97 vs 90, respectively). However, these cut-offs had similar sensitivity (0.80 vs 0.79, respectively). The cut-off for Emotional Functioning was more severe when using the anchor chosen by experts compared to the anchor chosen according to highest AUC (71 vs 79, respectively). Sensitivity for the anchor chosen by experts was lower than for Emotional Functioning than the anchor chosen according to highest AUC (0.71 vs 0.88, respectively).

Table 5. Comparison of anchors selected using expert rationale compared to selection according to highest area under the receiver operator characteristic (ROC) curve.

EORTC QLQ-C30 Scale	Method	SCNS-LF59 Anchor	Cut-Off Score	AUC (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)
Global Quality of Life	Expert	Feeling unwell a lot of the time + Not being able to do the things you used to do	**71**	0.78 (0.71-0.85)	0.78 (0.68-0.86)	0.69 (0.64-0.75)
	AUC	Changes to usual routine and lifestyle	**71**	0.76 (0.70-0.82)	0.74 (0.66-0.83)	0.72 (0.72-0.78)
Physical Functioning	Expert	Physical and daily living needs	**97**	0.79 (0.73-0.85)	0.80 (0.71-0.89)	0.61 (0.54-0.67)
	AUC	Work around the home	**90**	0.82 (0.74-0.89)	0.79 (0.79-0.98)	0.75 (0.49-0.55)
Emotional Functioning	Expert	Psychological needs	**71**	0.79 (0.74-0.84)	0.71 (0.64-0.79)	0.70 (0.64-0.77)
	AUC	Feelings of sadness	**79**	0.85 (0.81-0.90)	0.88 (0.82-0.93)	0.63 (0.55-0.70)
Social Functioning	Expert	Changes to usual routine and lifestyle + Changes in other peoples attitudes towards you	**92**	0.81 (0.75-0.86)	0.82 (0.75-0.90)	0.70 (0.64-0.77)
	AUC	Changes to usual routine and lifestyle	**92**	0.84 (0.79-0.88)	0.86 (0.79-0.93)	0.71 (0.65-0.77)

EORTC QLQ-C30 European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; **SCNS-LF59** Supportive Care Needs Survey Long Form 59; **SD** Standard deviation**; AUC** Area under the ROC curve; **CI** Confidence interval

DISCUSSION

We identified cut-offs for ten of the 15 EORTC QLQ-C30 scales with adequate to exceptional ability to discriminate between YA cancer patients with and without need for support. Most cut-offs identified here have good sensitivity, indicating that the majority of patients who score worse than the threshold will have a true need for support. This is the first study to establish cut-offs for a major PRO measure for YAs with cancer.

The exception is 'Financial Difficulties' which did not meet the requirement for sensitivity of at least 0.70. Using the threshold of 17 on 'Financial Difficulties' will miss about 35% of YAs that need support. This was surprising given the similarity in content between the EORTC QLQ-C30 scale and the SCNS-LF59 anchor. This may reflect inconsistencies in patient's perception of the healthcare system's ability to provide support for financial concerns. If a respondent felt the healthcare team would be unable to provide support, they may not report that they have 'need' even if they have financial issues. Financial toxicity is high among YAs compared to older adults and about a third of patients had need for financial concerns in this study.[23] Future research should prioritise developing appropriate methods to identify and address financial toxicity among YAs.

The sensitivity analyses showed that four of the ten optimal cut-off scores differed between YAs on treatment and YAs on follow-up. Given the relatively small number of patients on treatment in our sample, this work should be considered valid for patients on follow-up and replicated in YAs on treatment to determine the most appropriate scores to use for this group. While the optimal Emotional Functioning cut-off score for patients on follow-up was found to be higher than the score for the total sample, it may be preferable to use the lower score in a screening setting to ensure all patients with psychological need are captured.

Excluding the cut-off for Financial Difficulties given its poor sensitivity, we were able to identify three more cut-offs compared to Snyder *et al*.'s previous analysis.[11,12] These new cut-offs for Social Functioning, Nausea and Vomiting and Insomnia were identified using items in the SCNS-LF59 not previously included in the SCNS short form.

The cut-offs identified here were similar to those identified by Snyder *et al*. except for emotional and role functioning, where we identified more lower or worse scores as the cut-offs. This may reflect differences between adults and YAs. YAs may have more informal emotional support from friends and family than older adults which may translate into less perceived need for formal support from the healthcare team resulting in more lower cut-offs. Alternatively, YAs may not report the need for support if they think no relevant services in the healthcare system can address the issue. This may explain the wore score for role functioning which was anchored to ‘Not being able to do the things you used to do’ in our study compared to ‘Work around the home’ in prior studies.

In contrast, the cut-offs identified by Giesinger *et al*. were similar or lower. This likely reflects the different conceptualisation of the cut-offs. A symptom or functional problem may need to be more severe to be worrying or life limiting than to be interested in support. This may also reflect the fact that YAs may have higher expectations towards their level of functioning compared to older adults. In addition, our sample was largely comprised of survivors no longer on treatment who may again have higher expectations for symptoms and functional status compared to patients on treatment, and thus report supportive care needs at less severe scores.

These cut-offs can facilitate clinical interpretation for use of the EORTC QLQ-C30 in routine care by indicating which scores require clinical attention. For example, the scores can be integrated into the medical record by presenting clinicians with graphs highlighting the scores that indicate supportive care is needed.[24] The involvement of YA patients, clinical psychologists and health researchers ensured matching SCNS-LF59 anchors to EORTC QLQ-C30 scales was based on theory and experience rather than statistics alone. It was interesting to find that the composite anchor for Global Quality of Life had a higher AUC than any single item alone, supporting the selection of anchors based on expert rationale rather than statistical methods. Although including patient, clinician and researcher experts in the selection of anchors results in similar cut-offs compared to relying on the selection of anchors using statistical methods, namely maximising the AUC.

In Physical Functioning, the cut-off was less severe though with similar sensitivity when the anchor was selected by experts. Particularly as this is a young population, any reduction in physical function may be more likely to be unusual and more damaging to quality of life and therefore require more clinical attention. For example, the most vigorous item on the Physical Functioning scale is taking a long walk. Older patients may have such limitations for other reasons while the inability to perform such basic activities may be more concerning for a young person. Therefore, the cut-off score of 97 defined by the expert chosen anchor would be recommended. In contrast, the Emotional Functioning cut-off was more severe when the anchor was chosen by experts. This may reflect that emotional function is more than feeling sad (the anchor with the highest AUC) and that sadness alone when experiencing a cancer diagnosis does not necessitate support. However, the AUC and sensitivity for the expert chosen anchor is much lower than the AUC-defined anchor. As these cut-off scores would be used in a screening setting, we would recommend taking the cautious approach and using the less severe cut-off score of 79.

These cut-offs are beneficial in that they are simple for clinicians to use to identify supportive care need using the EORTC QLQ-C30 in routine care. However, screening tools always have a trade-off between sensitivity and specificity. This means the EORTC QLQ-C30 will falsely indicate some patients have need and falsely indicate others do not have need. Here we favoured sensitivity over specificity by setting a minimum requirement of 0.70 sensitivity. This means patients with need are unlikely to be missed. Favouring sensitivity does, however, increase the number of false positives. In this context, this seems favourable as the result of a positive is a clinical discussion rather than invasive investigation, however, this could lead to alert fatigue for the clinician. Trials that have used similar approaches have not found a significant increase in workload, however, alert fatigue would need to be explored in an empirical evaluation of the cut-offs.[3]

Limitations

As a few of the scales in the EORTC QLQ-C30 are made up of only one or two items, there is limited precision in the measurement of the concept and therefore, the potential thresholds. This contributes to large differences between sensitivity and specificity, meaning that to achieve adequate sensitivity, there will be lower specificity and potentially a high number of false positives. False positives could lead to 'burnout' and rejection of the use of such a screening method in clinical practice. Using a quality of life instrument with higher precision may improve the sensitivity and specificity of the cut-offs as seen in the development of cut-offs for the computer adaptive test version of the EORTC QLQ-C30 in further work by Giesinger *et al*.[9]

Further work to compare and validate cut-offs to determine the most appropriate instruments and thresholds is necessary given the potential impact of their use in practice. While the SCNS-LF59 is well validated in cancer populations, it may miss some supportive care needs specific to YAs such as support returning to work, managing childcare or physical activity advice. In addition, the SCNS-LF59 is a self-report of need, which may be influenced by other factors such as knowledge of the availability of support or beliefs about the effectiveness of services. However, we view the use of a self-report measure of need as a strength as it is face valid, clinically relevant and values patient views. This ensures we take a patient-centred approach to supportive care provision.

The survey had a low response rate which may limit the generalisability of the study. In particular, the survey favoured female YAs with a high level of education, no longer on treatment and those with breast cancer. YAs included in this sample may have been higher functioning than the broader population of YAs with cancer leading to higher cut-off scores than necessary in general practice. The high proportion of females means the findings may not generalise well to males, although previous studies have found cut-off scores do not vary by gender.[9,14] Future research should aim to validate these findings.

CONCLUSIONS

We identified nine appropriate cut-offs for supportive care needs on the EORTC QLQ-C30 for YAs with cancer in follow-up. This is the first study to establish cut-offs for a major PRO measure for YAs with cancer. The use of these thresholds will facilitate the measurement of quality of life routinely in cancer care to help identify those with need. Further investigation to empirically compare these cut-offs to others is necessary to select the most appropriate metrics depending on the purpose and population. Additional research is also needed to look at cut-off scores for clinically significant changes in longitudinal measurement in clinical care.

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CHAPTER 7

Cancer care and wellbeing in adolescents and young adults during the coronavirus disease 2019 pandemic: A UK sarcoma perspective.

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Cancer. 2020;126::5359-5360. doi: 10.1002/cncr.3321

COMMENTARY

Adolescents and young adults (AYAs) with cancer face particular psychosocial challenges which may be amplified by the COVID-19 pandemic. Kosir *et al*. examined the impact of the pandemic on cancer care and wellbeing in AYAs in an online survey.[1] The authors highlight increased levels of anxiety in AYAs and used qualitative data to provide unique insight into possible contributing factors to reduced wellbeing during the pandemic.

In the first month of lockdown we surveyed 350 sarcoma patients from two London institutions, including 60 AYAs ages 16-39 (52% male).[2] Consistent with the heightened anxiety found by Kosir *et al*., AYAs were significantly more likely than adults to report the pandemic had an impact on their emotional wellbeing (60% vs. 38%; p=0.002) and had significantly lower emotional functioning (EORTC-QLQ-C30) to a clinically relevant level (mean 63.1 vs. 74.6; p=0.001). This indicates that adverse psychosocial outcomes during the pandemic may be more prevalent in AYAs than in adults with cancer.

Based on their qualitative results, Kosir *et al*. hypothesized that anxiety in AYAs was predominantly driven by health and cancer-related concerns. Conversely, we found no significant difference in the level of worry about potential impact of COVID-19 on health in AYAs versus adults (ten-point scale; mean 5.37 {SD2.66} vs. 5.94 {SD2.50}; p=0.112), and mean cancer worry was slightly higher in adults compared to AYAs (mean 5.64 {SD2.5} vs. 4.91 {SD2.8}; p=0.054). Modifications to care were similar in AYAs and adults, including the proportion of telemedicine appointments (65% vs. 60%) and treatment postponements (2% vs. 10%). These data indicate that care modifications, COVID-19 or cancer-related worry may not entirely explain the higher impact on emotional wellbeing in AYAs.

Kosir *et al*. reported that half the participants felt more isolated during the pandemic, however, its impact on anxiety was not explored in depth. The UK Office for National Statistics reported a strong association between loneliness and anxiety in the general population during the pandemic.[3] In our study, loneliness was higher in AYAs (33%) than adults (22%), despite 92% of AYAs living with others. AYAs reporting loneliness had significantly lower emotional functioning than those not reporting loneliness, suggesting this may be a strong contributor to reduced wellbeing (mean 52.9 vs. 68.1; p=0.048). Lower emotional functioning was also seen in lonely adults (mean 54.9 vs. 80.3; $p<0.001$), showing the pervasive impact of loneliness across all ages.

A sense of belonging amongst peers and the ability to maintain connections is important for AYAs to reduce social isolation and emotional distress.[4,5] Pre-pandemic, AYAs with cancer may have cherished the opportunity to take their chemotherapy infusion in a backpack to the movies with friends. The pandemic has isolated AYAs with longer, more intensive shielding compared to peers. However, widespread social distancing restrictions may have narrowed the AYA-peer gap, as noted by some AYAs in Kosir *et al.*'s study.

Considering emotional distress in healthy AYAs provides context to the experiences of young people with cancer. A repeated cross-sectional study comparing clinical and community cohorts of young people ages 14 to 28 found that clinical cohorts had slightly higher mental health symptoms but community cohorts experienced greater deterioration during the pandemic.[6] Similarly, a Dutch study of over 4000 cancer survivors and matched normative participants found slightly higher levels of depression and loneliness in the general population.[7] These studies suggest that levels of distress may be similar, or even higher, in healthy populations.

The authors acknowledge several limitations to their study, such as the high proportion of females (87%), and participants from different healthcare systems and continents. Female gender is predictive of increased psychological distress across the cancer disease trajectory and has been associated with higher anxiety during the pandemic.[3,8,9] A significantly higher proportion of female AYAs in our study reported that COVID-19 had impacted their emotional wellbeing compared to males (76% vs. 45%; $p=0.015$). Additional limitations include the lack of information on cancer type and stage which lead to differing levels of anxiety and health-related quality of life in AYAs.[9] There was also a high proportion of AYAs (37%) who reported pre-existing mental health conditions and may be particularly sensitive to disruption caused by the pandemic.

Wellbeing in AYAs with cancer may be acutely impacted by the pandemic compared to adults, though their concerns likely overlap with healthy AYAs. Evidence-based interventions such as practical skills sessions that strengthen social support, emotional wellbeing and resilience should be rapidly integrated into care to reduce loneliness.[10] Age appropriate resources are crucial to sustain emotional wellbeing and safety in AYAs during periods of social isolation.

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CHAPTER 8

General Discussion

BIOPSYCHOSOCIAL ISSUES

Adolescents and young adults (AYAs) ages 15 to 39 face a number of unique challenges when diagnosed with cancer compared to children and adults. This work has shown that even within this group, young adults (YAs) ages 25 to 39 have specific needs that may differ from teenagers and young adults (TYAs) ages 15 to 24. Furthermore, issues experienced by all age groups can cause a different burden and need for support among YAs due to the increased family and work responsibilities in this life stage compared to younger patients and the generally more precarious financial and social situation compared to older adults. As YAs over age 25 are treated in services designed for older adults despite the unique biopsychosocial issues they face, many YAs have unmet supportive care needs. These include psychological support addressing loneliness, uncertainty and anxiety, practical support with childcare, difficulty accessing financial assistance and returning to work, and support with romantic relationships. Not all YAs have strong need for support, so identifying which patients do have need is an important first step. We have established cut-off scores on a health-related quality of life measure commonly used in routine care to help identify YAs with supportive care needs to address these gaps in future.

Early diagnosis

In our qualitative work, many YAs described lengthy periods of time between first symptom and diagnosis and viewed the diagnostic experience negatively. Prior research has shown that longer time to diagnosis is consistently associated with poor outcomes such as advanced or metastatic disease and higher treatment burden.[1–3] Furthermore, negative perceptions of the experience are associated with poorer quality of life.[4] When probing further into the diagnostic pathway, YAs in the qualitative work described both patient and healthcare system factors contributing to the extended timeline. According to our survey data, the patient interval (time from first symptom to first healthcare consultation) and healthcare interval (time from first consultation to diagnosis) were similar in length with roughly 15-20% of YAs experiencing more than three-month intervals. The literature shows that the time to diagnosis is longest for AYAs compared to children and older adults, however, it is unknown whether this differs within the age group.[1]

Compared to YAs, other UK-based research shows patient intervals for TYAs are much shorter while healthcare intervals are similar or slightly longer.[5,6] The difference in the time prior to first consultation may reflect less parental involvement among YAs and difficulty accessing healthcare services. Evidence shows YAs believe they would wait longer to consult a healthcare professional about a cancer warning sign than TYAs and YAs recognise fewer warning signs than older adults.[7] Longer healthcare intervals among TYAs may be due to the difference in cancers that arise in the two groups. Cancers in YAs, such as breast and melanoma, have more specific symptoms at presentation which aid diagnosis compared to common cancers in TYAs, such as CNS and haematological cancers, which have non-specific symptoms.[8]

Efforts to improve early diagnosis should take the different extent of contributing factors into account for YAs and TYAs. Specifically, work to improve awareness of cancer signs and symptoms may be more critical among YAs. However, this is a major gap in current public health policy. The most widespread cancer awareness campaigns led by government organisations and Cancer Research UK all target people over age 50.[9] A research briefing for a recent UK government debate includes a majority of articles from the Teenage Cancer Trust, focusing on TYAs.[10] Only two articles on bowel and cervical cancers were inclusive of (though not focused on) YAs.[11,12] Further advocacy is needed to highlight the issue at the government level and run targeted campaigns to raise cancer awareness among YAs.

Psychological challenges

In the qualitative component of our work, YAs described feeling uncertain about future plans, interpersonal relationships and potential clinical outcomes similar to previous work among AYAs across the age range.[13,14] However, YAs in this work emphasised uncertainty in *current circumstances*. Participants described the diagnosis interrupting changing jobs, moving house, establishing new relationships and caring for young children. Uncertainty may cause additional distress for YAs as it seems to commonly be a time of major upheaval and change. Over half the YAs in the cross-sectional survey reported needing support for feelings of uncertainty and fear of cancer recurrence, demonstrating the high prevalence in this group. This aligns with previous research which suggests younger patients have a higher need for support with fear of recurrence compared to older adults.[15] Our study found fear of cancer recurrence is associated with higher information needs suggesting more age-appropriate information may be necessary. Interventions including information support to reduce uncertainty and fear of recurrence may have a small but lasting positive effect.[16,17] Psychological interventions aimed at reducing fear of recurrence should be incorporated into supportive care services for YAs.

YAs described feeling emotionally distant from healthy peers, due to a lack of understanding about severe illness. This is a common issue in the literature for TYAs,[18–20] and has been described in research grouping patients ages 15 to 39.[21] As the stages of development theory suggests the priorities of YAs shift from peer to family relationships, one may expect changes in friendships would have a lesser impact in this group.[22] However, evidence from this project builds on the limited findings that YAs are also distressed by weakened friendships after a cancer diagnosis.[23] The 'Teen Cancer Trust Blueprint of Care' for TYAs recommends healthcare providers discuss the potential negative impact of cancer on relationships to normalise the experience.[24] To our knowledge this is currently not recognised as an issue in adult NHS services. Macmillan, one of the largest cancer charities with information in most NHS hospitals, does not list changing friendships among the impacts of cancer.[25] YAs would benefit from healthcare providers receiving training to help normalise the issue as well.

Anxiety and distress came up as a very common issue in both the qualitative and quantitative components of this research. A large body of evidence shows younger age is a risk factor for anxiety after a cancer diagnosis among adults, but most studies have defined age categories using broad ranges.[26,27] In our cross-sectional survey, 47% of YAs had at least borderline anxiety using the Hospital Anxiety and Depression Scale with a cut-off score of 9 validated in cancer patients.[28] A recent study of younger AYAs in the UK, which used a lower cut off of 8, found 33% of AYAs ages 13-18 and 44% of AYAs 19-24 had at least borderline anxiety.[29] Taking the difference in cut-off score into account, our findings suggest a higher proportion of YAs likely have anxiety compared to TYAs. While some anxiety is expected and reasonable after a cancer diagnosis, healthcare providers should screen for problematic levels of distress and refer YAs to appropriately trained psychologists or occupational therapists.

Social challenges

YAs described feeling physically isolated from friends and family. Parents of young children 'missed out' on their lives due to hospital stays, periods of illness and the need to isolate to avoid infection. The 'Teen Cancer Trust Blueprint of Care' for TYAs recommends flexible visiting hours to ensure friends can visit outside of work or school hours.[24] In contrast, visiting hours are limited in adult services and restrictions on children visiting parents may even be in place depending on the hospital and ward.[30] Due to the COVID-19 pandemic, this has been further restricted to one visitor per day for a maximum of two hours in most places. In North America, only one in six hospitals have childcare support.[31] Expanding access to in-hospital childcare may in part relieve the issue. Guidelines for clinicians working with parents of children have been developed to provide advice on handling hospital visits and facilitating communication about illness and end-of-life.[32] Training should be expanded in adult services or nurse specialists with age-specific training should be available to YAs to provide support and advice. In-depth qualitative work should be undertaken to understand the psychological impact of these limitations on YAs and to explore potential solutions if needed.

As the COVID-19 pandemic occurred during the course of this work, the government-imposed lockdown provided an opportunity to explore how physical isolation impacts age groups differently. Unfortunately, our small sample size prevented subgroup analysis among AYAs cohorts, but our research showed that about a third of AYAs experienced loneliness compared to a fifth of adults and that loneliness was associated with lower wellbeing. A review of social support and adolescent cancer survivors found evidence that a lack of social support is associated with higher distress.[33] The greater impact of social isolation on AYAs compared to adults may in part explain the higher levels of distress among YAs and younger AYAs. This further substantiates the need to YAs with cancer in maintaining relationships during treatment and recovery.

Practical challenges

Given the backdrop of increased responsibility, it is unsurprising YAs emphasized difficulties juggling work, finances and childcare with treatment and side effects. One study from Germany on AYAs found over half the participants employed at diagnosis needed more than 6 months off work.[34] In our qualitative data, we found some YAs felt pressed to return to work before full recovery due to financial concerns, while other described the drop in income difficult to manage. Some evidence suggests financial toxicity is more common in YAs with cancer than TYAs.[35] We are unaware of research comparing YAs with older adults, but one study reported that 50% more patients under 65 years old experienced financial hardship compared to patients over 65.[36] In our survey, roughly 30% of participants reported experiencing financial difficulties. Advice on financial support is only a small component of recommended care for TYAs.[24] Support in adult services largely depends on referrals to cancer charities, such as Macmillan Cancer Support or Maggie's, which have comprehensive information and some in-person benefits advisors.[37,38] However, YAs in our qualitative work found accessing the support, navigating services and completing the forms challenging while undergoing treatment. Advocacy work needs to be undertaken to reduce these key barriers at a government and service provision level.

YAs also found managing childcare with appointments and recovery challenging. In the outpatient setting, unpredictable waits and the inability to select appointment times posed a challenge to arranging care. While recovering from surgeries, participants were unsure how physically active they could be in lifting, carrying and playing with children. The physical and emotional toll of cancer and its treatment place additional strain on parents who feel torn between providing care for children and accepting the need for care themselves.[39] Increasing access to childcare may reduce the psychological impact on YAs and promote recovery. However, limited support currently exists. Patients must largely depend on government benefits if eligible or small cancer charities for limited childcare support.[40]

Symptom management

Key side effects described by YAs in the qualitative work were fatigue and cognitive deficits. In the cross-sectional survey, nearly 40% of participants reported a need for support with lack of energy or tiredness. A recent review showed nearly 40% of AYA survivors experience cognitive deficits and that YAs may be more likely to experience impairments than TYAs.[41] While these side effects are common among all cancer patients, they may reduce YAs ability to return to work and ultimately have large psychosocial impacs.[42,43] In the qualitative work, YAs indicated that fatigue contributed to social isolation and limited their ability to return to work. Similarly, cognitive impairments impinged on YAs ability to undertake the same type or amount of work. As a result, many YAs felt this change in ability to work due to side effects made them question their identity as a young person. This seems to reflect Erikson's 'middle-aged' life stage where individuals must achieve competency in work or parenthood to gain a sense of generativity.[22] When achieving this goal is interrupted by cancer and or its treatment it may threaten one's sense of self. Support from occupational therapists who understand the psychosocial impact of reduced work ability would help improve resilience to change and establish a 'new normal'.[44] However, the limited evidence available suggests this is likely available to less than 15% of patients.[45,46]

SUPPORTIVE CARE NEEDS AND PSYCHOSOCIAL INTERVENTIONS

Early diagnosis

The long period from symptom onset to contacting a health professional among YAs warrants intervention as discussed above. Awareness of symptoms common among YAs is low as cancer is not 'supposed' to arise during young adulthood, particularly as these can be different from the cancers that occur in older adults.[47] YAs in our qualitative work described attributing symptoms to other life events such as work stress or pregnancy. Public campaigns may encourage patients to discuss symptoms with healthcare providers as these have shown promise in the general population in the past.[48] YAs also described delays accessing care due to time constraints and lack of registration at a general practitioner, for example after moving house. Barriers to accessing care can be reduced by improving the ease of registration and providing remote consultations.

In both our qualitative and quantitative work, YAs often had a high number of consultations prior to diagnosis. Poorer cancer survival in the UK compared to other European countries has been in part attributed to lower availability and willingness to use diagnostic interventions.[49] Observational studies show that increased use of cancer diagnostics is associated with improved survival.[50] Campaigns with general practitioners to encourage the use of investigative tests have also shown promise with reduction in late stage diagnoses.[48] Campaigns could be tailored to cancer types common among YAs. Researchers have also suggested the use of clinical decision support tools, which could incorporate age, improve referral for investigation.[48] The use of these tools could reduce healthcare provider variability in referral and potential bias against cancer among YAs.[48]

Psychological needs

Nearly half the patients completing the supportive care needs instrument reported the need for psychological support and emotional issues were commonly discussed in the qualitative data. Evidence suggests YAs have greater psychological needs than younger AYAs.[51] While a direct comparison with older adults is unavailable, one study showed the average need for items relating to psychological support was 37%, lower than the 42% of YAs in our study.[52] In adults, information needs are more common than psychological needs.[53]

Providing access to psychological support should be a key goal for improving supportive care for YAs with cancer. The qualitative findings suggest access to psychological support is limited by a lack of knowledge about available services and long wait-times. Evidence from hospices in the UK similarly found access to psychological support was inadequate due to funding and staff limitations, however, recent commissioning guidance in London shows a commitment to improving psychosocial support for cancer patients.[54,55] The Healthy London Partnership recommends 'universal psychologically informed care' where all healthcare providers are expected to have a basic understanding of a patient's psychological needs.[55] However, as YAs have needs that differ from older adults, additional training of healthcare providers may be needed.

Social support needs

In the qualitative data we found YAs felt out of place in hospital when surrounded by older patients. However, despite this, patients had mixed interest in peer support from other YA cancer patients and it did not come up as an important need in the survey data. This contrasts previous research which found over three quarters of participants desired peer support, although some patients in this study were recruited through social media which may have led to a biased sample.[56] Some patients in the qualitative work described being too busy with family life, work and recovery, while others described wanting to avoid talking about cancer and the thought of becoming unwell. This suggests that the low interest in peer support may be in part due to avoidant coping styles, which are associated with poorer quality of life and more depressive symptoms.[57] This highlights the range of services that might be needed and the importance of screening or measuring psychosocial functioning to ensure patients receive the most appropriate care.

Young adult support groups are available through cancer charities in the UK such as SHINE Cancer Support, which specifically focuses on YAs and provides both in person and online groups, and Maggie's, which facilitates in-person groups for young people at various cancer centres throughout the country.[58,59] Providing online peer support groups may be important in this population given competing interests and responsibilities. This is true even more so now given the COVID-19 pandemic and the added requirement to shield and avoid infection, which we found may have been associated with loneliness in young people. Our qualitative findings also showed that some patients preferred online forums as sources of support, where stories and discussions from other young people are available to read at leisure. One study evaluating a YA-specific website with a social interaction component found the website improved feelings of 'connectedness' for 83% of respondents.[60] A mixed approach to providing peer support opportunities may be best for YAs.

Practical needs

Financial toxicity and the need to return to work is a priority for YAs. Participants in our qualitative work described a number of barriers to accessing financial support including limited knowledge about availability, burdensome paperwork and difficulties navigating grant applications. Reducing these logistical barriers to accessing financial support is an important first step in addressing this need, which is acutely experienced by YAs. Emerging evidence suggests enrolling patients and caregivers in financial navigation programs can improve access to financial support and reduce finance-related distress.[61,62] Return to work interventions that include multidimensional components, such as physical, psychoeducational and vocational aspects, can also lead to a small but significant improvement in return to work.[63] Enabling return to work may help address a number of psychosocial needs as financial and employment difficulties can be a source of chronic stress for YAs.[64] The patient group likely needs joint support from financial navigators and occupational therapists to holistically address the key issues. Financial navigation largely relies on the advisors at Maggie's charity which are unlikely to have the capacity to support all YAs in need.[38] Similarly, as described above, access to occupational therapy is limited.

Challenges managing childcare during treatment and recovery was also a common theme in our qualitative study. A study of supportive care needs including cancer patients of any age found that the need for childcare was not applicable for over 80% of respondents, demonstrating the need is specific to YAs.[52] The lack of availability of child-friendly areas in the hospital contributed to challenges attending appointments and feeling isolated during in-patient stays. Addressing the need for childcare would ease a major source of distress for YA parents with cancer. Adult services should consider creating child-friendly spaces to encourage visits during hospital stays and allay childcare difficulties.

Symptom management

Participants in our survey frequently reported lack of energy or tiredness, anxiety, feeling down or depressed, insomnia and fatigue as symptoms for which they needed support. As mentioned above, these side-effects can have a major psychosocial impact and result in low quality of life.[65] A number of mobile applications have been designed specifically for AYAs to help manage symptoms and side-effects of treatment. Initial evaluations have shown the tools are acceptable and usable.[66,67] Studies looking at the effect of the intervention on relevant outcomes have shown digital interventions can help improve perceived self-efficacy, patient-provider communication, pain management, anxiety, fear of recurrence, depression and fatigue.[68–71] However, much of this research was conducted with younger AYAs and would need to be repeated in YAs. Mobile technology may be a particularly effective mode of intervention for this age group and should be a key area for future research.

Sexual and reproductive health

In our qualitative work, YAs highlighted the importance of information about fertility and referrals to specialists. The inconsistency in the amount of information received was apparent. Lack of knowledge about referral pathways, bias around certain patient characteristics, like poor prognosis or prior children, and time constraints during clinics are clinician factors contributing to inconsistent discussions about fertility.[72] Referrals can be particularly complicated in the UK where availability of fertility treatments varies by clinical commissioning group.[73] Issues with patient-clinician communication may also contribute to the lack of perceived information about fertility, as most oncologists report discussing fertility.[74] Implementing quality metrics, providing clinician training and sharing patient educational resources can improve the consistency of fertility discussions by incorporating them in routine care.[75]

YAs reported relatively high sexuality needs compared to the other domains on the Supportive Care Needs Survey, particularly on changes in sexual feelings and sexual relationships. One recent study showed about half of YAs experience sexual dysfunction after treatment.[76] Sexual and reproductive health is an important topic for AYAs beyond fertility as, depending on the treatment, patients may be advised against becoming pregnant or at heightened risk of sexually transmitted infections.[77] Despite this, only half of clinicians in adult services think sexuality is an unmet need.[78] As adult services treat patients largely over age 50, discussions regarding sexual health may not be routine. In a study which included patients over age 18, only 14% of participants identified the need for sexuality support as important compared to 36% in our study.[52] Failure to stratify by age group likely underestimates the need for sexuality support in adult services. Training adult healthcare providers in sexual health issues, identifying a champion to receive age-tailored training or linking YAs with TYA providers are potential models for providing appropriate advice and support for people with minor problems. Information about sexual issues and dating are also provided by YA-specific cancer charities like SHINE Cancer Support.[79] Access to a psychosexual therapist may be necessary for moderate to severe problems. These services are available through the NHS but service provision is inconsistent.[80]

RECOMMENDATIONS FOR CLINICAL PRACTICE

Overall, YAs have a wide range of unmet supportive care needs. Many of these overlap with younger and older patients while others are unique to this patient group. The type and severity of need also varies among YAs. Although YAs with higher supportive care needs had lower quality of life, more unmet service needs and higher feelings of helplessness. Existing services do exist, though many would benefit from tailoring to YAs and others are location-dependent. Two key steps must be undertaken to address these unmet needs in clinical practice. First is to ensure clinical staff with age-specific training are aware of the potential needs of YAs, confident in carrying out needs assessments and knowledgeable in available services and referral pathways. Second is to routinely assess individuals in clinic to identify YAs with unmet supportive care needs.

Training in YA care is available but limited. Accredited training on the needs of YAs and information about useful services and support is provided by SHINE Cancer Support for healthcare professionals.[81] It is vital that someone with suitable training is involved in the care of YAs to ensure needs are adequately assessed and appropriate referrals are made. One of the key criticisms of the holistic needs assessment implemented nationally by the NHS was that clinicians undertaking the assessments lacked knowledge or the ability to address some of the issues raised.[82] In addition, patients and clinicians found contextual barriers limited usefulness of the tool such as lack of time, privacy and pre-existing relationship.[82] Individuals confident in carrying out such assessments with the time and support to do so are needed.

The best model of care must be carefully determined taking into account the incidence of cancer in YAs in local areas. It is unlikely that dedicated units would be possible given incidence is six times higher in YAs compared to TYAs and would effectively require six times the resources.[83] AYA specialists in Canada propose instituting AYA-specific clinical nurse specialists who are trained in age-related needs and can make the appropriate referrals.[84] In The Netherlands, the AYA 'Young and cancer' care network has a similar nurse-led model.[85] A similar approach could be implemented at adult medical centres to fill the gap of YA-specific care. A central team of CNSs with training in YA supportive care needs and knowledge of relevant local and national resources could provide cross-tumour support and supplement the current care model for patients within the YA age range. Alternatively or in addition, a regional model could be employed similar to the remote multi-disciplinary teams created for TYAs in the UK.[24] This would ensure clinical expertise in age-related issues could be shared across centres. This combined approach may be best given the small numbers of YAs relative to adult patients but the large number of YAs and associated resource implications relative to TYAs. An alternative or additional approach would be to extend the coverage of remote multi-disciplinary teams to some or all YAs to ensure they have the necessary clinical and allied health professional input.

In order to address the supportive care needs described above, healthcare professionals must be able to identify patients with need. Conversation aids, such as the Holistic Needs Assessment Concerns Checklist provided by Macmillan Cancer Support and Snapshot where patients tick boxes next to the issues they are concerned about, are a useful resource.[86,87] Evaluations have shown these interventions improve problem detection and discussion and there is some evidence they increase referral.[88] However, these tools are not validated and they lack qualitative information about the severity of need, which may make assessors feel unclear about which issues require clinical action. Furthermore, there is some evidence patients are reluctant to report issues if they feel healthcare providers are not able to address then.[82]

To address some of these issues, we have established age-specific cut-off scores on the European Organisation Research and Treatment for Cancer Quality of Life Core Questionnaire (EORTC QLQ-C30), a quality of life measure commonly used in routine care.[89,90] These cut-off scores provide clear indication for clinical action to encourage further discussion and referrals. Healthcare professionals can use this questionnaire as a screening tool for need while monitoring common quality of life issues such as emotional functioning, physical functioning and symptom levels. Using one or both methods would facilitate identifying which patients require further support.

LIMITATIONS AND SUGGESTIONS FOR FUTURE RESEARCH

The survey unfortunately had a low response, which potentially introduced selection bias and limits the generalizability of the findings. Evaluating the demographic characteristics of the survey sample, we under-sampled lower educated YAs, patients with minority ethnic backgrounds and potentially over-sample breast cancer patients. We also did not explore how needs and experiences differed for specific under-served groups such as transgender or non-binary YAs or non-cisgender individuals. The research was also limited to Southeast England. The qualitative sample was skewed toward tumour types with poor outcomes (i.e. sarcoma, central nervous system), which may have led to over-emphasis of issues relevant to patients with poor prognoses such as uncertainty of clinical outcomes. Finally, the cross-sectional nature of this research prevented us from looking at causality, but this mixed methods descriptive approach was an important first step in understanding the experiences and needs of YAs with cancer.

The Supportive Care Needs Survey may have missed important issues relevant to YAs such as return to work, childcare, fertility and health behaviours. This limited our ability to determine the prevalence of these specific YA needs. For example, diet and exercise came up in a number of qualitative interviews and was suggested as an area of improvement for supportive care services. However, the Supportive Care Needs Survey did not include any items related to specific health behaviours limiting our ability to explore the prevalence of these needs. Future research to develop a supportive care needs questionnaire specific to YAs would facilitate better evaluation of needs in this population.

Our work was strengthened by the combination of qualitative and quantitative data, which allowed us to explore issues not included in the questionnaire. For example, support returning to work was identified as a key need in our research despite not being examined in the quantitative survey. Similarly, fertility was identified as an important unmet need that was not covered in the survey data. Future studies could use the qualitative work to form part of the basis for a modified or novel supportive care needs survey.

Interestingly, in contrast, sexual health was an important supportive care need relative to the other domains. However, sexuality did not come up as an important issue in the qualitative interviews. This is likely due to hesitancy discussing sensitive topics with the interviewer. Future research should examine this issue in more depth, giving more consideration to ensuring patients feel comfortable to discuss the topic.

Effective interventions or services are available (though potentially in need of tailoring) for many of the needs identified among YAs. Once a valid and reliable measure of supportive care need is available for this population, longitudinal investigation should be conducted to evaluate whether these interventions address the needs. It is also important to examine the barriers and facilitators to uptake of relevant interventions from a patient and healthcare provider perspective to understand any access challenges.

This research represents an important step in identifying gaps in supportive care for YAs in the UK and methods to begin addressing these needs. YAs would benefit from additional age-specific support tailored to their phase of life.

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CHAPTER 9

Summary

SUMMARY

Adolescents and young adults (AYAs) with cancer ages 15-39 face unique medical, practical and psychosocial issues. In the United Kingdom, principal treatment centres and programmes have been designed to care for teenagers and young adult (TYA) patients aged 13-24 in an age-appropriate manner. However, for young adults (YAs) with cancer aged 25-39, little access to age-specific support is available. This thesis examines this possible gap by investigating YA care experiences and supportive care needs in a mixed methods programme of research.

We recruited YA patients diagnosed with any type of cancer between the ages of 25 and 39 in the last five years from six hospitals in Southeast England. These included 4 hospitals in London (Royal Marsden Hospital NHS Foundation Trust, Barts Health NHS Trust, Imperial College Healthcare NHS Trust,and East and North Hertfordshire NHS Trust) , the East Suffolk and North Essex NHS Foundation Trust in Ipswich, and the University Hospital Southampton NHS Foundation Trust in Southampton.We conducted qualitative interviews and focus groups to explore the psychosocial, practical and care experiences of YAs in-depth. This allowed us to examine issues not included in relevant questionnaires designed for older adults. We also conducted a cross-sectional survey measuring the diagnostic interval, supportive care needs and health-related quality of life of a more representative sample of patients. Patients were eligible if they were and were under the care of one of the participating centres. Clinical teams invited potential participants to the qualitative work in clinic between November 2017 and August 2018. We recruited a convenience sample with a view to including a range of tumour types across sites. Clinical teams invited potential participants to the qualitative part of the project by sending a survey by post between May 2018 and October 2019.

For the qualitative part of this study 152 patients were invited. Sixty five (42.8%) patients participated, 50 (76.9%) in individual interviews and 15 (23.1%) in five focus groups. For the quantitative part 1657 patients were invited and 347 completed the questionnaire (response rate 21%).

In **chapter two** we investigated the psychosocial experiences and practical challenges of YAs in the qualitative data. Transcripts were analysed using inductive thematic analysis. We involved two YA patients in the research team during the analytical process to ensure robustness. They shaped the results by feeding back

on the interpretation of the data, commenting on the importance of each theme and subtheme, and reviewing the wording of each theme. Sixty-five YAs took part in the qualitative interviews and focus groups. YAs were 33.6 years old on average at the time of participation. The majority of participants were female (N=39; 60.0%), white (N=50; 74.6%), university educated (N=45; 69.2%) and did not have children (N=38; 59.4%). The majority were in follow-up (N=37; 56.9%) and treated with curative intent (N=40; 66.7%). A range of tumour types were included, most commonly sarcomas (N=13; 20.0%), breast cancer (N=12; 18.5%) and central nervous system (CNS) tumours (N=12; 18.5%). Our findings included four themes and ten subthemes. The four themes encompassed competing responsibilities, retaining normalilty and identity as YA, facing isolation and coping with uncertainty. Participants struggled to balance work, childcare and financial solvency with treatment. The halt in family and work life as well as changes in body image and physical or cognitive ability threatened participants' identity and perceived 'normality' as a YA. However, these also stimulated positive changes including personal growth and the strengthening of relationships. YAs experienced social isolation from friends and family, including children. Many struggled to cope with uncertainty around treatment outcomes and disease recurrence. Overall, YAs face a number of specific psychosocial and practical challenges with the sudden halt of family and work life.

In **chapter three**, we again examined the qualitative data, now with the aim of understanding the healthcare experiences of YAs to gain insight into relevant supportive care needs. Data was analysed using thematic analysis. Results were shaped in an iterative process with the initial coders and four YA patients who did not participate in the study to improve the rigor of the analysis. Sixty-five YAs took part in the qualitative interviews and focus groups. Participants on average were 33.6 years at participation and 1.9 years from diagnosis. Most YAs were female (N=39; 60.0%), white (N=50; 74.6%), married (N=35; 53.8%), university educated (N=45; 69.2%) and did not have children (N=38; 59.4%). The majority of patients had completed treatment (N=37; 56.9%). We identified seven themes and 13 subthemes. YAs found navigating the healthcare system difficult and commonly experienced prolonged diagnostic pathways exemplified by misdiagnoses and multiple visits with various healthcare professionals. Participants felt under-informed about current clinical details and the long-term implications of side effects on daily life. YAs found online resources overwhelming but also a source of information and treatment support. Some patients regretted not discussing fertility before cancer treatment or felt uninformed or rushed when making fertility preservation decisions. A lack of age-tailored content or age-specific groups deterred YAs from accessing psychological support and rehabilitation services. The description of age-specific needs such as fertility support and the prioritisation of long-term health outcomes and physical functioning calls for provision of better age-specific information and access to existing relevant support for YAs treated in adult settings.

In **chapter four**, we examined the diagnostic interval of YAs using data from the cross-sectional observational study. Patients aged 25–39 years treated at one of the six participating trusts. Patients were eligible if they were diagnosed in the last 5 years, able to communicate in English, and could complete questionnaires independently. Patients with a previous cancer diagnosis were excluded. The questionnaire package included a number of items about the diagnostic pathway, including items developed by the BRIGHTLIGHT study group to assess the diagnostic pathway of TYAs. The BRIGHTLIGHT cohort included 830 TYAs aged 12–24 at primary cancer diagnosis. Their median age was 20 years, 55% were male, and 88% were white. Participants were diagnosed with lymphoma (32%), germ-cell tumours (19%), leukaemia (13%), non-skin carcinomas (12%), bone cancer (10%), soft tissue sarcomas (6%), central nervous system neoplasms (4%), melanoma and skin carcinoma (4%), and unspecified (1%) Data of our study could be compared with those of the BRIGHLIGHT study and in this way the impact of different phase of young adolescents and young adult life on outcomes could be studied. Data were analysed descriptively. 341 participants were included in complete-case analysis. The mean age was 33.3 years, 32% were male, and 84% were white. Breast cancer and testicular cancer were the most common diagnoses. The mean time between diagnosis and questionnaire completion was 2.9 years. Participants reported the length of their patient interval (time from first symptom to first doctor consultation) and healthcare interval (time from first consultation to first cancer specialist consultation) in the survey. Among 341 YAs the patient interval lasted ≥2 weeks, ≥1 month, and ≥3 months in 60%, 42%, and 21%, respectively, compared to 48%, 27%, and 12% in the TYA group, demonstrating an overall longer interval in the YA group. The healthcare interval lasted ≥2 weeks, ≥1 month, and ≥3 months in 62%, 40%, and 17% of YA patients, respectively. YAs with melanoma or cervical cancer were most likely to experience patient intervals of ≥ 1 month, whereas YAs with breast cancer and leukaemia were the least likely. This study highlights the long diagnostic pathways among YAs and calls for more awareness among healthcare professionals about malignancies in the young adult age group.

In **chapter five**, we used data from the cross-sectional survey to describe the supportive care needs of YAs and explore the relationship between unmet needs and clinical characteristics, demographic factors, health-related quality of life, psychological distress, illness cognitions and service needs. We conducted latent class analysis to identify groups of YAs at risk of unmet need and to reduce the

number statistical tests conducted. Latent class analysis assumes one or more unobserved variables are responsible for response patterns, which it uses to assign individuals to classes. Individuals with similar response patterns will be assigned to the same latent class, which is then assigned a qualitative description based on literature, experience and theory. Three hundred and seventeen participants were included in complete-case analysis. Participants were on average 33.3 years old at diagnosis and 2.9 years from diagnosis. Most participants were female (N=219; 69.1%), white (N=272; 85.8%), and receiving follow-up care and monitoring but no longer receiving anti-cancer treatment (N=242; 76.3%). We identified three classes of YAs based on level of supportive care need: no need (53.3%), low need (28.3%) and moderate need (18.4%). In each class, median domain scores in each domain were similar. YAs expressed the most need in the psychological and sexuality domains. Low and moderate need classes were associated with worse health-related quality of life and greater helplessness. Unmet service needs were associated with the moderate need class only (which was the highest level of need in our analysis). These results show about half of YAs treated in adult services have unmet supportive care needs and how that may negatively impact health-related quality of life.

In **chapter six**, we used data from the cross-sectional survey to identify cut-off scores on a common quality of life measure to enable its use as a screening tool among YAs for supportive care need. Using the EORTC QLQ-C30 and Supportive Care Needs Survey Long Form (SCNS-LF59) response data, we identified cut-off scores using receiver operator characteristic (ROC) analysis. Patient, clinician and research experts matched supportive care needs from the SCNS-LF59 to quality of life domains of the EORTC QLQ-C30. We then evaluated the EORTC QLQ-C30 domain score's ability to detect patients with need by calculating the area under the ROC curve, sensitivity and specificity for selected cut-offs. Cut-offs were chosen by maximising Youden's J statistic and ensuring sensitivity passed 0.70. Three-hundred and thirteen participants were included in complete-case analysis. On average, YAs were 33.3 years old (SD 4.2) at diagnosis and 2.8 years from diagnosis (SD 1.6). The majority of participants were female (N=216; 69.0%), of white descent

(N=268; 85.6%) and university educated (N=202; 64.5%). Participants most commonly had breast cancer (N=100; 31.9%), were on follow-up (N=238; 76.0%) and were treated with curative intent (N=244; 76.7%). Cut-offs with adequate sensitivity were calculated for Global Quality of Life (71), Physical Functioning (97), Role Functioning (92), Emotional Functioning (71), Social Functioning (92), Fatigue (28), Nausea and Vomiting (8), Pain (8) and Insomnia (17). Sensitivity analyses suggest these scores may only be valid for YAs on follow-up. These cut-off scores will enable the use of the EORTC QLQ-C30 in routine care to identify YA patients with supportive care need.

In **chapter seven**, we examined the impact of social isolation due to the government-imposed COVID-19 lockdown on wellbeing in AYAs ages 16 to 39 with sarcoma in a secondary analysis of cross-sectional survey data. We surveyed 350 patients with sarcoma from two London institutions during the first two months of the lockdown (23 March-23 May 2020). Sixty of these participants were AYAs (52% male). AYAs were significantly more likely than adults to report that the pandemic had an impact on their emotional wellbeing (60% vs 38%; P=.002), and had significantly lower emotional functioning to a clinically relevant level (mean score, 63.1 vs 74.6; P=.001). Loneliness was also higher in AYAs (33%) than in adults (22%). AYAs who reported feeling loneliness had significantly lower emotional functioning than those not reporting loneliness, suggesting this may be a strong factor associated with reduced well-eing (mean score, 52.9 vs 68.1; P=.048). However, as the data was cross-sectional causality cannot be determined. While small numbers prevented us from analysing the YA cohort within this group, these findings substantiate the need among YAs for support in maintaining relationships with healthy peers during a lock-down.

CHAPTER 10

Samenvatting

SAMENVATTING

Adolescenten en jongvolwassenen (AYA's) met kanker in de leeftijd van 15-39 jaar worden geconfronteerd met unieke medische, praktische en psychosociale uitdagingen. In het Verenigd Koninkrijk zijn behandelcentra ingericht en -programma's ontworpen om tieners en jongvolwassen (teenagers and young adults ,TYA) patiënten in de leeftijd van 13-24 jaar op een leeftijdsspecifieke manier te begeleiden. Voor jongvolwassenen (young adults, YAs) met kanker in de leeftijd van 25-39 jaar is er echter weinig toegang tot leeftijdsspecifieke ondersteuning beschikbaar. Dit proefschrift beschrijft het onderzoek dat is verricht bij jong volwassenen die tussen de 25-39 jaar gediagnostiseerd zijn met kanker. Het doel was om de psychosociale issues te onderzoeken waar zij mee geconfronteerd worden en om hun zorgervaringen en ondersteunende zorgbehoeftes te onderzoeken. Tevens hebben we onderzocht of we drempelwaarden van een bestaande veel gebruikte vragenlijst op het gebied van kwaliteit van leven, de EORTC QLQ-C30, zouden kunen gebruiken in de praktijk om zorg voor deze jong volwassen kanker patienten te kunnen verbeteren. Het onderzoek is verricht in het Verenigd Koningkrijk met behulp van van zogenaamd mixed methods-onderzoek, een combinatie van kwalitatief (interviews en focusgroepen) en kwantitatief (vragenlijsten) onderzoek.

YA-patiënten bij wie de diagnose kanker in de afgelopen vijf jaar was gesteld en die afkomstig waren uit zes ziekenhuizen in Zuidoost-Engeland werd gevraagd om deel te nemen aan onderzoek. To de zes ziekenhuizen behoorden vier ziekenhuizen in Londen, (Royal Marsden Hospital NHS Foundation Trust, Barts Health NHS Trust, Imperial College Healthcare NHS Trust en East and North Hertfordshire NHS Trust) en tevens the East Suffolk and North Essex NHS Foundation Trust in Ipswich en the University Hospital Southampton NHS Foundation Trust in Southampton. We voerden kwalitatief onderzoek uit door middel van interviews en focusgroepen om de psychosociale, praktische en zorgervaringen van YAs te uit te vragen. Daarmee is het mogelijk die zaken te onderzoeken en onderwerpen uit te diepen die niet zijn opgenomen in bestaande vragenlijsten die zijn ontworpen voor oudere volwassenen. Tevens is een cross-sectionele onderzoek uitgevoerd dat het diagnostische interval, de niet direct medische zorgbehoeften en de gezondheidsgerelateerde kwaliteit van leven in een veel grotere groep van YA patienten heeft gemeten. Patiënten kwamen hiervoor in aanmerking als ze onder behandeling waren of waren geweest van een van de eerder genoemde deelnemende ziekenhuizen. Tussen november 2017 en augustus 2018 werden potentiële deelnemers uitgenodigd voor het kwalitatieve onderzoek . We hebben hierbij zorg gedragen dat we YAs met verschillende tumortypes uitnodigden om deel te nemen. Tussen mei 2018 en oktober 2019 nodigden. klinische teams potentiële deelnemers per post uit voor het vragenlijst onderzoek.

Voor het kwalitatieve deel van het onderzoek werden 152 patiënten uitgenodigd. Vijfenzestig patiënten (42.8%) namen hieraan deel: 50 (76.9%) aan de interviews en 15 (23.1%) aan een focusgroep. Voor het kwantitatieve deel van het onderzoek werden 1657 patiënten uitgenodigd van wie 347 de vragenlijsten invulden en terugstuurden (response percentage 21%).

In **hoofdstuk twee** onderzochten we de psychosociale ervaringen en praktische uitdagingen van YAs op basis van de verkregen kwalitatieve data. Transcripties van het kwalitatieve onderzoek werden geanalyseerd met behulp van de zogenaamde inductieve thematische analyse. We hebben twee YA-patiënten in het onderzoeksteam betrokken tijdens het analyseproces om te zorgen dat de resultaten betekenisvol weergegeven zouden worden. Ze hebben feedback gegeven op de interpretatie van de onderzoeksresultaten en commentaar geleverd op het belang van elk thema en subthema en de wijze waarop de thema's verwoordwerden. Vijfenzestig YAs namen deel aan de kwalitatieve interviews en focusgroepen. YAs waren gemiddeld 33,6 jaar oud op het moment van deelname. De meerderheid van de deelnemers was vrouw (n=39; 60,0%), wit (n=50; 74,6%), universitair geschoold (n=45; 69,2%) en had geen kinderen (n=38; 59,4%). De meerderheid was in follow-up (n=37; 56,9%) en werd behandeld met curatieve intentie (n=40; 66,7%). Patienten die deelnamen aan de studies hadden een verscheidenheid aan tumortypen, sarcomen (n=13; 20,0%), borstkanker (n=12; 18,5%) en tumoren van het centrale zenuwstelsel (CZS) (n=12; 18,5%). Onze bevindingen omvatten vier thema's en tien subthema's. De vier hoofdthema's omvatten: tegenstrijdige verantwoordelijkheden, behoud van normaal leven and identiteit als jong volwassene, confrontatie met eenzaamheid en omgaan met onzekerheid. YAs hadden moeite om balans te krijgen tussen werk, kinderopvang en (opbouw van) een financiele buffer en hun behandeling. Ze ervoeren dat gezins- en professioneel leven een halt wordt toegeroepen, en samen met veranderingen in lichaamsbeeld en fysieke of cognitieve vaardigheden bedreigde dit de identiteit als ook de ervaren 'normaliteit' van een YA. Deze ervaringen brachten echter ook positieve veranderingen, waaronder persoonlijke groei en het versterken van relaties. YA's ervoeren sociaal isolement van vrienden en familie, inclusief kinderen. Velen worstelden om om te gaan met onzekerheid over behandelingsresultaten en kans op ziekterecidief. Concluderend worden YAs geconfronteerd met een aantal specifieke psychosociale en praktische uitdagingen die gepaard gaan met de door kanker en behandeling geinduceerde plotselinge halt in het gezins- en professionele leven.

In **hoofdstuk drie** hebben we opnieuw gekeken naar de kwalitatieve gegevens, nu met als doel de zorgervaringen van YA's te begrijpen om inzicht te krijgen in relevante ondersteunende zorgbehoeften. De gegevens werden geanalyseerd met behulp van thematische analyse. De resultaten kwamen tot stand door een iteratief proces met de initiële codeurs en vier YA-patiënten die niet deelnamen aan de studie om de sterkte van de analyse te verbeteren. Vijfenzestig YAs namen deel aan de kwalitatieve interviews en focusgroepen. Deelnemers waren gemiddeld 33,6 jaar bij deelname en 1,9 jaar na diagnose. De meeste YAs waren vrouw (n=39; 60,0%), wit (n=50; 74,6%), getrouwd (n=35; 53,8%), universitair geschoold (n=45; 69,2%) en hadden geen kinderen (n=38; 59,4%). De meerderheid van de patiënten had de behandeling voltooid (n=37; 56,9%). We identificeerden zeven thema's en 13 subthema's. YAs vonden het navigeren door het gezondheidszorgsysteem moeilijk en hadden vaak langdurige diagnostische trajecten gehad, met verkeerde diagnoses en meerdere bezoeken aan verschillende zorgverleners. Deelnemers voelden zich onvoldoende geïnformeerd over de huidige klinische details en de langetermijn implicaties van bijwerkingen op het dagelijks leven. YAs vonden online bronnen overweldigend, maar ook een bron van informatie en ondersteuning van hun behandeling. Sommige patiënten hadden spijt dat ze de vruchtbaarheid niet hadden besproken vóór de behandeling van kanker of voelden zich niet geïnformeerd of gehaast bij het nemen van beslissingen over mogelijk behoud van vruchtbaarheid. Een gebrek aan op leeftijd afgestemde inhoud of leeftijdsspecifieke groepen weerhield YAs ervan te vragen om psychologische ondersteuning en revalidatie. De beschreven leeftijdsspecifieke behoeften zoals het tijdig bespreken van mogelijkheden van behoud van vruchtbaarheid en van gezondheidsresultaten en fysiek functioneren op de lange termijn vragen om betere leeftijdsspecifieke informatie en ondersteuning voor YA's die in de volwassen setting worden behandeld.

In **hoofdstuk vier** onderzochten we het diagnostische interval van YAs met behulp van gegevens uit de cross-sectionele onderzoek. We onderzochten in de hierboven beschreven groep, waarbij patienten geen eerdere maligniteit gehad mochten hebben, de tijd het gekost had tot de uiteindelijke diagnose was gesteld. We gebruikten hiervoor o.a. ook vragen die in de zogenaamde BRIGHTLIGHT studie waren gebruikt, een studie die ook in de UK bij TYAs, dus de groep van jonge kankerpatienten van 12-24 jaar, was gebruikt. De BRIGHTLIGHT groep bestiond uit 830 patienten met een mediane leeftijd van 20 jaar, waarvan 55% man en 88% wit was. Belangrijkste diagnoses in de BRIGHLIGHT groep waren lymfomen, kiemceltumoren, leukemie, carcinomen en sarcomen. Resultaten van onze studie konden tot op zekere hoogte vergeleken worden met die van hen en op die manier kon de impact van het diagnostische traject in verschillende fases van adolelescentie en jong volwassenheid worden vergeleken. De gegevens werden beschrijvend geanalyseerd; 341 deelnemers werden opgenomen in een complete case-analyse. De gemiddelde leeftijd van de YA patienten was 33,3 jaar, 32% was mannelijk en 84% wit. Borstkanker en testiskanker waren de meest voorkomende diagnoses. De gemiddelde tijd tussen diagnose en het invullen van de vragenlijst was 2,9 jaar. Deelnemers rapporteerden de lengte van hun patiëntinterval (gedefinieerd als tijd van eerste symptoom tot eerste doktersconsult) en zorginterval (tijd van eerste consult tot eerste kankerspecialistconsult) in de enquête. Onder 341 YAs duurde het patiëntinterval ≥2 weken, ≥1 maand en ≥3 maanden in respectievelijk 60%, 42% en 21%, vergeleken met 48%, 27% en 12% in de TYA-groep. Het zorginterval duurde ≥2 weken, ≥1 maand en ≥3 maanden bij respectievelijk 62%, 40% en 17% van de YA-patiënten. YAs met melanoom of baarmoederhalskanker hadden de meeste kans op patiëntintervallen van ≥ 1 maand, terwijl YAs met borstkanker en leukemie het minst waarschijnlijk waren. Deze studie benadrukt de lange diagnostische paden onder YAs en roept op tot meer bewustzijn bij zorgprofessionals over de mogelijkheid van maligniteiten in deze leeftijdsgroep.

In **hoofdstuk vijf** gebruikten we gegevens uit de cross-sectionele studie om de ondersteunende zorgbehoeften van YAs te beschrijven en de relatie tussen onvervulde behoeften en klinische kenmerken, demografische factoren, gezondheidsgerelateerde kwaliteit van leven, psychologische nood, ziektecognities en servicebehoeften te onderzoeken. We voerden latente klassenanalyses uit om groepen YA's te identificeren die het risico liepen op onvervulde behoeften en om het aantal uitgevoerde statistische tests te verminderen. Latente klassenanalyse gaat ervan uit dat een of meer niet-geobserveerde variabelen verantwoordelijk zijn voor responspatronen, die worden gebruikt om individuen aan klassen toe te wijzen. Individuen met vergelijkbare responspatronen worden toegewezen aan dezelfde latente klasse, die vervolgens een kwalitatieve beschrijving krijgt toegewezen op basis van literatuur, ervaring en theorie. Driehonderdzeventien deelnemers werden meegenomen in de complete case-analyse. Deelnemers waren gemiddeld 33,3 jaar oud (bij diagnose en 2,9 jaar na diagnose. De meeste deelnemers waren vrouw (N= 219; 69,1%), blank (N=272; 85,8%), en ontvingen nazorg en monitoring, maar kregen geen anti-kankerbehandeling meer (N=242; 76,3%). We identificeerden drie klassen van YAs op basis van het niveau van ondersteunende zorgbehoefte: geen behoefte (53,3%), lage behoefte (28,3%) en matige behoefte (18,4%). In elke klasse waren de mediane domeinscores in elk domein vergelijkbaar. YAs gaven de meeste behoefte aan op psychologisch en seksualiteitsgebied. Lage en matige behoefteklassen werden geassocieerd met een slechtere gezondheidsgerelateerde kwaliteit van leven en grotere hulpeloosheid. Onvervulde behoeften in dienstverlening werden geassocieerd met de klasse met matige behoeften (wat het hoogste behoefteniveau was in deze analyse). Deze resultaten tonen aan dat ongeveer de helft van de YAs die worden behandeld in een omgeving met oudere volwassenen onvervulde ondersteunende zorgbehoeften heeft en toont aan hoe dat een negatieve invloed kan hebben op de gezondheidsgerelateerde kwaliteit van leven.

In **hoofdstuk zes** gebruikten we gegevens uit de cross-sectionele enquete om drempelwaarde scores te identificeren van een kwaliteit van leven meting om deze als mogelijk screeningsinstrument onder YAs voor ondersteunende zorgbehoeftes in de toekomst te kunnen gebruiken. Met behulp van de kwaliteiet van leven vragenlijst EORTC QLQ-C30 en Supportive Care Needs Survey Long Form (SCNS-LF59) responsegegevens identificeerden we drempelwaarde scores met behulp van ROC-analyse (receiver operator characteristic). Patiënten, clinici en onderzoeksexperts koppelden ondersteunende zorgbehoeften van de SCNS-LF59 aan kwaliteit van leven domeinen van de EORTC QLQ-C30. Vervolgens evalueerden we het vermogen van de EORTC QLQ-C30-domeinscores om patiënten met behoeften te detecteren door het gebied onder de ROC-curve, gevoeligheid en specificiteit voor geselecteerde drempelwaardes te berekenen. Drempelwaardes werden gekozen door de J-statistiek van Youden te maximaliseren en ervoor te zorgen dat de gevoeligheid 0,70 passeerde. Driehonderd dertien deelnemers werden meegenomen in de complete case-analyse. Gemiddeld waren YAs 33,3 jaar oud bij diagnose en 2,8 jaar na diagnose. De meerderheid van de deelnemers was vrouw (N=216; 69,0%), van blanke afkomst (N=268; 85,6%) en universitair geschoold (N=202; 64,5%). Deelnemers hadden het vaakst borstkanker (N=100; 31,9%), waren in follow-up (N=238; 76,0%) en werden behandeld met curatieve intentie (N=244; 76,7%). Drempelwaarden met voldoende gevoeligheid werden berekend voor Globale Kwaliteit van leven (71), fysiek functioneren (97), rolfunctioneren (92), emotioneel functioneren (71), sociaal functioneren (92), moeheid 28), misselijkheid en braken (8), pijn (8) en Islapeloosheid (17). Gevoeligheidsanalyses suggereren dat deze scores mogelijk alleen geldig zijn voor YAs in de follow-up na behandeling. Deze drempelwaarde scores zullen het gebruik van de EORTC QLQ-C30 in routinezorg mogelijk maken om YA-patiënten met ondersteunende zorgbehoeften te identificeren.

In **hoofdstuk zeven** onderzochten we de impact van sociaal isolement als gevolg van de door de overheid opgelegde COVID-19-lockdown op het welzijn in AYA’s van 16 tot 39 jaar met sarcoom in een secundaire analyse van een cross-sectionele studie in sarcoom patienten.. We ondervroegen 350 patiënten met een sarcoom uit twee Londense ziekenhuizen tijdens de eerste twee maanden van de lockdown (23 maart-23 mei 2020). Zestig van deze deelnemers waren AYA’s (52% mannelijk). AYA’s rapporteerden vaker dan volwassenen dat de pandemie een impact had op hun emotionele welzijn (60% versus 38%; P=.002), en ze hadden ook een significant en klinisch relevant lager emotioneel functioneren t.o.v. oudere volwassenen (gemiddelde score, 63,1 vs 74,6; P=.001). Eenzaamheid was ook hoger bij AYA’s (33%) dan bij volwassenen (22%). AYA’s die aangaven zich eenzaam te voelen, hadden een significant lager emotioneel functioneren dan degenen die geen eenzaamheid rapporteerden, wat suggereert dat dit een sterke relatie kan hebben met verminderd welzijn (gemiddelde score, 52,9 versus 68,1; P=.048). Omdat de gegevens echter cross-sectioneel gemeten zijn, kan de causaliteit niet worden vastgesteld. Hoewel kleine aantallen ons verhinderden om het YA-cohort binnen deze groep te analyseren, onderbouwen deze bevindingen de behoefte van YAs aan ondersteuning bij het onderhouden van relaties met gezonde leeftijdsgenoten tijdens een lock-down.

APPENDIX 1

PhD Portfolio

PHD PORTFOLIO

PhD training

Category	Year	Activity	Workload (Hours / ECTS)
Courses, workshops, seminars, lectures	Year 1 Oct 2017-Sep 2018	• Royal Marsden Hospital Good Clinical Practice Course	7.5 / 0.30
		• Royal Marsden Hospital Mendeley Workshop	1.0 / 0.04
		• Institute of Cancer Research Survival Analysis (link)	4.0 / 0.16
		• Institute of Cancer Research Introduction to R (link)	4.0 / 0.16
		• London School of Hygiene and Tropical Medicine Mixed Method Modelling	1.0 / 0.04
		• Royal Marsden Hospital Applied Health Research Seminar	1.0 / 0.04
		• Institute of Cancer Research Meet the Editors	1.0 / 0.04
		• Royal Marsden Hospital Schwartz Round	1.5 / 0.06
	Year 2 Oct 2018-Sep 2019	• Introduction day Radboudumc (link)	7.5 / 0.30
		• Graduate School specific introductory course (RIHS, link)$^{\#}$	12.0 / 0.48
		• Institute of Cancer Research Scientific Integrity course (link)	5.0 / 0.20
		• Royal Marsden Hospital Budget Holder Skills	2.0 / 0.08
		• EORTC Clinical Trials Course	15.0 / 0.60
		• NIHR Research for Patient Benefit Grant Meeting Royal Marsden Hospital	2.0 / 0.08
		• Royal Marsden Hospital SoECAT research costing seminar	1.5 / 0.06
		• Royal Marsden Hospital Clinical Trials Contracts Seminar	1.5 / 0.06
		• Standard evaluation of patient reported outcomes	1.5 / 0.06
	Year 3 Oct 2019-Sep 2020	• Patient and Public Involvement and Engagement – An introduction session	3.0 / 0.12
		• Kings College London Contemporary Applied Psychometrics Course (link)	43.0 / 1.72
		• Psycho-social Impact Course (Royal Marsden School)	2.5 / 0.10
		• Open Access at Radboudumc	1.0 / 0.04
		• TYA Care Virtual Day	4.0 / 0.16
		• Impactful Presentations (Institute of Cancer Research)	1.0 / 0.04
		• Influencing Skills (Institute of Cancer Research)	4.0 / 0.16
		• Making an Impact at Meetings (Institute of Cancer Research)	2.0 / 0.08
	Year 4 / 4.5 Oct 2020-Mar 2022	• Managing your research project (Institute of Cancer Research)	3.0 / 0.30
		• Institute of Cancer Research – Advanced R (link)	7.5 / 0.30

PhD training

Category	Year	Activity	Workload (Hours / ECTS)
		Royal Marsden Hospital Good Clinical Practice Update	4.0 / 0.16
		CATO Masterclass Intermediate Fellowships (Imperial College London Clinical Academic Training Office)	1.5 / 0.06
		Data cleaning (Royal Marsden Clinical Trials Unit)	2.0 / 0.08
Conferences, symposia & congresses	Year 1 Oct 2017-Sep 2018	Survivorship Summit: Improving Outcomes for People Living with and Beyond Cancer (Birmingham, UK)	7.5 / 0.30
		EORTC Quality of Life Group Meeting (Paris, France)	15.0 / 0.60
		Patient Reported Outcome Measures conference (Birmingham, UK; poster)	15.0 / 0.60
		EORTC Quality of Life Group Meeting (Opatija, Croatia)	15.0 / 0.60
	Year 2 Oct 2018-Sep 2019	Radboud Frontiers – Big Data in Healthcare	15.0 / 0.60
		International Society for Quality of Life Research Conference (Dublin, Ireland)	22.5 / 0.90
		Keystone Symposia – Digital Health: From Science to Application (Keystone, Colorado USA; poster + presentation)	44.0 / 1.76
		EORTC Quality of Life Group Meeting (Brussels, Belgium)	15.0 / 0.60
		SHINE Cancer Patient Event (London, UK; Poster)	15.0 / 0.60
		Patient Reported Outcome Measures conference (Leeds, UK; presentation)	15.0 / 0.60
		Royal Society of Medicine – Young Women with Breast Cancer Symposium (London, UK; poster)	15.0 / 0.60
		EORTC Quality of Life Group Meeting (Naples, Italy)	15.0 / 0.60
		International Society for Quality of Life Research Conference (San Diego, US; poster)	32.0 / 1.28
	Year 3 Oct 2019-Sep 2020	UK Interdisciplinary Breast Cancer Symposium (Birmingham, UK; poster)	22.0 / 0.88
		Cancer Survivorship Summit (Virtual, UK)	7.5 / 0.03
		EORTC Quality of Life Group Meeting (Virtual; presentation)	22.0 / 0.88
		International Society for Quality of Life Research Conference (Virtual)	30.0 / 1.20
	Year 4 / 4.5 Oct 2020-Mar 2022	NCRI Virtual Showcase (Poster)	2.0 / 0.08
		EORTC Quality of Life Group Meeting (Virtual; presentation)	22.0 / 0.88
		EORTC Quality of Life Group Meeting (Virtual; presentation)	22.0 / 0.88
		4th AYA Global Congress (Virtual; Presentation)	22.0 / 0.88

PhD training

Category	Year	Activity	Workload (Hours / ECTS)
Committees and other academic activities	Year 1 Oct 2017-Sep 2018	• Peer-review article (Progress in Community Health Partnerships: Research, Education and Action)	3.0 / 0.12
		• Royal Marsden Hospital PROFILES Review and Management Group Committee Member	24.0 / 0.96
		• Peer-review article (Journal of Supportive Care in Cancer)	3.0 / 0.12
		• Royal Marsden Patient & Public Involvement Steering Committee member	1.5 / 0.06
	Year 2 Oct 2018-Sep 2019	• Royal Marsden Hospital PROFILES Review and Management Group Committee Member	24.0 / 0.96
		• Royal Marsden Patient & Public Involvement Steering Committee member	12.0 / 0.48
		• National BRC Qualitative Network Member	10.0 / 0.40
		• Peer-review article (Psycho-Oncology)	3.0 / 0.12
		• Peer-review article (Eur. J. Cancer Care)	3.0 / 0.12
		• Peer-review abstracts (International Society of Quality of Life Conference)	3.0 / 0.12
		• Peer-review article (Progress in Community Health Partnerships: Research, Education and Action)	3.0 / 0.12
	Year 3 Oct 2019-Sep 2020	• Royal Marsden Hospital PROFILES Review and Management Group Committee Member	24.0 / 0.96
		• National BRC Qualitative Network Member	10.0 / 0.40
		• Royal Marsden Patient & Public Involvement Steering Committee member	12.0 / 0.48
		• Peer review article (Quality of Life Research)	3.0 / 0.12
		• Peer review article (Journal of Supportive Care in Cancer)	3.0 / 0.12
		• Peer review article (Eur. J. Cancer Care)	3.0 / 0.12
		• Peer review conference abstracts (International Society for Quality of Life Research)	3.0 / 0.12
		• Chair of EORTC Quality of Life Group Early Career Investigator Group	16.0 / 0.64
		• Peer review article (Journal of Supportive Care in Cancer)	3.0 / 0.12
	Year 4 / 4.5 Oct 2020-Mar 2022	• Royal Marsden Hospital PROFILES Review and Management Group Committee Member	36.0 / 1.44
		• National BRC Qualitative Network Member	15.0 / 0.60
		• Royal Marsden Patient & Public Involvement Steering Committee member	18.0 / 0.72
		• Chair of EORTC Quality of Life Group Early Career Investigator Group	16.0 / 0.64
		• Blog on patient involvement in analysis of PhD paper	3.0 / 0.12
		• Peer review article (Trials)	3.0 / 0.12
		• Publications Editor EORTC Quality of Life Group	15.0 / 0.60
		• Peer review article (BMC Public Health)	3.0 / 0.12

PhD training			
Category	**Year**	**Activity**	**Workload (Hours / ECTS)**
Teaching and supervision	Year 1 Oct 2017-Sep 2018	- Supervise clinical research fellow in patient-reported outcome research	5.0 / 0.20
	Year 2 Oct 2018-Sep 2019	- Imperial College Emergency Medicine Centre Lecture on Unmet Needs of Young Adult Cancer Patients	8.0 / 0.32
	Year 3 Oct 2019-Sep 2020	- Supervision of MD student qualitative project with geriatric gynaecological patients	10.0 / 0.40
	Year 4 / 4.5 Oct 2020-Mar 2022	- Supervision of data manager with systematic review methodology	10.0 / 0.40
Total Hours / ECTS			**846.5 hours / 33.86**

APPENDIX 2

List of publications

LIST OF PUBLICATIONS

Lidington, E., Younger, E., Husson, O. & Kaal, S. E. J. Psychosocial Support of Adolescents and Young Adults with Cancer: Focus on Professional and Social Reintegration. in ESMO Handbook of Cancer in Adolescents and Young Adults (eds. Mountzios, G., Bielack, S. S. & Mehra N.) 227-237 (ESMO Press, 2022).

Darlington, A. S., Sodergren, S. C., **Lidington, E.**, van der Meer, D. J. & Husson, O. Quality of Life in Adolescents and Young Adults with Cancer. in *Handbook of Quality of Life in Cancer* (eds. Kassianos, A. P.) 265-287 (Springer Cham, 2022).

Schut, A. R. W., **Lidington, E.**, Timbergen, M. J. M. *et al*. Unravelling desmoid-type fibromatosis-specific health-related quality of life: Who is at risk for poor outcomes. *Cancers*. **14**, 2979 (2022)

Lidington, E., Giesinger, J. M., Janssen, S. H. M. *et al*. Identifying health-related quality of life cut-off scores that indicate the need for supportive care in young adults with cancer. *Qual. Life Res.* **31**, 2717-2727 (2022).

den Hollander, D., **Lidington, E.**, Singer, S. *et al*. 'I thought I had fibroids, and now I don't': A mixed method study on health-related quality of life in uterine sarcoma patients. *Health Qual. Life Outcomes*. **20**, 65 (2022).

Casillas, J. N., Bolano, C., Schwartz, L. F. *et al*. A survivorship educational tool for Latino adolescent and young adult cancer survivors. *Health Prom. Pract*. **23**, 861-873 (2022).

Schut, A. R. W., **Lidington, E.**, Timbergen, M. J. M. *et al*. Development of a disease-specific health-related quality of life questionnaire (DTF-QoL) for patients with desmoid-type fibromatosis. *Cancers*. **14**, 709 (2022).

van Leeuwen, M., Kieffer, J. M., Young, T. E. *et al*. Phase III study of the European Organisation for Research and Treatment of Cancer Quality of Life cancer survivorship core questionnaire. *J. Cancer Surviv.* (2022).

Casillas, J. N., Ganz, P. A., Kahn, K. *et al*. Improving cancer survivorship care for Latino adolescent, young adult survivors through community-partnered participatory research. *J. Part. Res. Methods* **2** (2021).

van Eck, I., den Hollander, D., **Lidington, E.** *et al*. Health-Related Quality of Life Issues Experienced by Thoracic and Breast Sarcoma Patients: A Rare and Understudied Group. *J. Clin. Med.* **10**, 5534 (2021).

Soomers, V. L. M. N., **Lidington, E.**, Sirohi, B. *et al*. The prolonged diagnostic pathway of young adults (aged 25-39) with cancer in the United Kingdom: results from the Young Adult Cancer Patient Journey Study. *J. Clin. Med*. **10**, 4646 (2021).

Lidington, E., Darlington, A. S., Din, A. *et al*. Describing unmet supportive care needs among young adults with cancer (25-39 years) and the relationship with health-related quality of life, psychological distress and illness cognitions. *J. Clin. Med*. **10**, 4449 (2021).

Schut, A. R. W., Timbergen, M. J. M., **Lidington, E.** *et al*. The evaluation of health-related quality of life issues experienced by patients with desmoid-type fibromatosis (The QUALIFIED Study) – A protocol for an international cohort study. *Cancers*. **13**, 3068 (2021).

Kaal, S., **Lidington, E.**, Prins, J. B. *et al*. Health-related quality of life issues in adolescents and young adults with cancer: discrepancies with the perceptions of health care professionals. *J. Clin. Med*. **10**, 1833 (2021).

Dumas, L.,* **Lidington, E.,*** Appadu, L. *et al*. Exploring older women's attitudes to and experience of treatment for advanced ovarian cancer: a qualitative phenomenological study. *Cancers*. **13**, 1207 (2021). *Joint first authors

Lidington, E., Vlooswijk, C., Stallard, K. *et al*. 'This is not part of my life plan': a qualitative study on the psychosocial experiences and practical challenges in young adults with cancer age 25 to 39 years at diagnosis. *Eur. J. Cancer Care*. **30**, e13458 (2021).

Lidington, E., Darlington, A. S., Vlooswijk, C. *et al*. Beyond teenage and young adult cancer care: Care experiences of patients ages 25 to 39 years old in the United Kingdom National Health Service. *Clin. Onc*. **33**, 494-506 (2021).

Lidington, E., Ingley, K. M., Smrke, A. *et al*. Cancer care and wellbeing in adolescents and young adults during the COVID-19 pandemic: a UK sarcoma perspective [Correspondence]. *Cancer*. **126**, 5185-5373 (2020).

Younger, E., Smrke, A., **Lidington, E.** *et al*. Health-related quality of life and experiences of sarcoma patients during the COVID-19 pandemic. *Cancers*. **12**, 1-27 (2020).

Staal, D. P., Vlooswijk, C., Mols, F. *et al*. Diagnosed with a common cancer at an unusual age: causal attributions of survivors of adolescent and young adult colorectal cancer. *Support. Care Cancer*. **29**, 409-416 (2020).

Lidington, E., McGrath, S., Noble, J. *et al*. Evaluating a digital tool for supporting breast cancer patients: a randomised controlled trial protocol (ADAPT). *Trials*. **21**, 86 (2020).

Husson, O., **Lidington, E.**, Younger, E. & van der Graaf, W. T. A. Young Adults: A unique group in cancer epidemiological research [Correspondence]. *Lancet Oncol*. **19**, e72 (2018).

Casillas, J. N., Kao, R. L., Macadangdang, J. *et al*. Improving fertility preservation discussions for adolescent & young male oncology patients. *Oncol. Issues J*. **33**, 16-26 (2018).

Casillas, J., Goyal, A., Bryman, J. *et al*. Development of a text messaging system to improve receipt of survivorship care in adolescent and young adult survivors of childhood cancer. *J. Cancer Surviv*. **11** 505-516 (2017).