

A life put on pause: An exploration of the health-related quality of life issues relevant to adolescents and young adults with cancer

Running head: Health-related Quality of Life in AYAs with cancer

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Abstract

Purpose

In recent years, the assessment of health-related quality of life (HRQoL) has been recognized as particularly informative to health care providers. For adolescents and young adults (AYAs), the impact of a cancer diagnosis and subsequent treatment is likely to be distinct from other age groups given the unique and complex physical and psychosocial challenges of this developmental phase. The objective of this study was to capture the HRQoL issues described by AYAs with cancer using thematic analysis.

Methods

Semi-structured interviews were carried out with 45 AYAs aged 14-25 years from 6 countries.

Results

The most prevalent cancers presented were leukemia (n=12) and lymphoma (n=8). AYAs' descriptive accounts were analysed and 12 categories identified: Symptoms (i.e., pain, nausea, vomiting) (84% AYAs); activity limitations (education, leisure time activities) (87%); disrupted life plans (29%); social (loss of friends, family life) (91%); emotional (depression, anxiety) (64%); body image (conscious of changed appearance) (36%); self-appraisals (greater maturity, braver) (47%); outlook on life (altered priorities, increased motivation to achieve) (33%); lifestyle (restricted diet, avoidance of infections) (18%), treatment-related (absence of age-appropriate information, treatment burden) (31%); fertility (24%); and financial concerns (13%).

Conclusions

A wide spectrum of both negative and positive issues were described. Several of these issues, such as disrupted life plans and difficulty establishing romantic relationships, are likely to be more common to AYAs with cancer and might not be captured by existing HRQoL measures. Recognition of these issues and finding ways of addressing them should be seen as an essential component of AYA-tailored cancer care.

Keywords

Health-related Quality of Life (HRQoL); Psychosocial; Supportive Care

Introduction

Health-related quality of life (HRQoL) is increasingly recognized as integral to health outcome assessment with an increased emphasis on the development and use of patient reported outcome measures (PROMs).¹ According to the World Health Organization (WHO) Quality of Life Group (QLG), HRQoL can be defined as a multi-dimensional construct shaped by physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to important environmental features.² HRQoL assessment can improve routine clinical practice by providing patients with a platform to express concerns which might otherwise remain undetected.³ For Adolescents and Young Adults (AYAs) with cancer, the assessment of HRQoL concerns is particularly pertinent given the complex developmental challenges they face.⁴⁻⁶

Irrespective of a diagnosis of cancer, AYAs find themselves in a period of transition from childhood to adulthood characterized by significant physical and cognitive changes and is heavily laden with critical psychosocial challenges. There is variability in the age definition of AYAs;⁷ and can be as broad as ranging from 15-39 years⁸ although in the the UK, the age range is more conservative with AYA oncology services tailored for 15-25 year olds.⁹

According to Erikson's psychosocial stages of development¹⁰, adolescence is a time when individuals start to develop their own identity and vision of the future and seek the adoption of roles in an attempt to become an adult and fit into society. This phase is characterized by decisions regarding career choices, and challenges relating to peer relationships, as well as establishing autonomy from family members. The development of intimate relationships and questions relating to sexuality are also integral features during adolescence and early adulthood. A diagnosis of cancer during this crucial developmental stage might further complicate the negotiation of these challenges,⁴ for example, young people with cancer might find themselves having to relinquish their newly found independence as they rely on others to care for them.⁴ Relationships with peers and romantic partners might also be negatively impacted by cancer.⁴ Adolescents with cancer interviewed by Stinson et al.¹¹ described feeling less attractive and desirable to others which in turn impacted on their self-esteem and confidence in engaging in romantic relationships. In addition, young people might not be as well-equipped as their older counterparts in coping with the demands of a cancer diagnosis.⁴ Furthermore, for AYAs, the development and realisation of future plans might also have to be put on hold due to cancer. In Chiang et al.'s qualitative study,¹² future life plans were described by adolescents as interrupted due to a lack of participation in activities, which in turn impaired their self-performance and compromised the realisation of talents. It therefore follows that compared with other groups, AYAs are likely to experience more distress and poorer HRQoL following a diagnosis of cancer.^{4; 13}

A number of PROMs have been used to evaluate HRQoL in AYAs with cancer, many of which represent adaptations from pediatric or adult versions of measures.¹⁴ Issues assessed include physical, cognitive, restricted activities, relationships with others, fertility, emotions, body image and spirituality / outlook on life. Choice of measurement tool is often driven by the purpose of the study. The types of HRQoL issues captured from these studies thus reflect the purpose of the study and measure used. Open-ended, interview based studies, however, provide the opportunity for general, less directed, discussions relating to the impact of cancer and its treatment on HRQoL.

As part of our study looking at the feasibility of developing a new European Organization for Research and Treatment of Cancer (EORTC) HRQoL measure specific to AYAs receiving treatment or supportive care for cancer, we carried out a literature review of 69 studies involving AYAs diagnosed and undergoing treatment for cancer.¹⁴ We did not identify any open-ended, interview-based study asking both adolescents and young adults to describe all the ways in which their life has been affected by cancer and its treatment. Some of the interviews involving adolescents or young adults focused solely on a particular domain of interest such as pain,¹⁵ fatigue,^{12;16} body image,¹⁷ romantic relationships and fertility.¹¹ The other, less structured, interviews included adolescents as part of a sample including children¹⁸⁻²⁰ or focused only on adolescents²¹ or young adults.²²

The objective of the current study is to extend previous research by investigating all aspects of HRQoL as described by both adolescents and young adults receiving treatment or palliative care for cancer. The focus is on the diagnosis and treatment period rather than the post-treatment or survivorship phase, which presents its own set of challenges.²³ For the purposes of the current study, and in line with the age range for AYA oncology service provision in the UK, we define AYAs as aged between 14 and 25 years.

Methods

The study protocol was peer reviewed and approved by the EORTC QLG. The format for the study was informed by the EORTC QLG module development guidelines.²⁴

Participants

AYAs aged between 14 and 25 years receiving treatment or supportive palliative care for cancer from 7 research centres across France, Israel, Norway, Poland, the Netherlands and UK were invited to take part in the study. Participants were recruited and interviewed during their clinic visit or hospital stay by the delegated researcher for each site. Those who had completed treatment and attending a clinic for follow-up only were excluded from the study.

Procedure

Ethical and research governance approvals were obtained at each centre in accordance with local requirements. Participants and, where appropriate, parents (of participants aged 14 and 15 years), were given verbal and written information about the study. Interviews were arranged once consent and, where appropriate, assent were given.

Interviews

Interviewers received detailed instructions from the study coordinator (SS) regarding the format of interviews and checks were made to ensure consistency across research sites. All interviewers had previous experience of interviewing (either in a qualitative research or clinical capacity) and were well acquainted with the EORTC module development framework²⁴ as they had been involved in previous EORTC QLG studies. Before the interview started, a case report form was completed together with participants and included details relating to education attainment, employment status and domestic situation.

Participants were also asked to self-report any comorbidities and to complete a measure of

performance status,²⁵ which gave a broad indication of the impact of disease and treatment on daily activities.

The interviews followed a semi-structured format opening with a general question asking participants to describe the different ways in which their life has been affected by cancer and its treatment. Participants were then asked several prompt questions informed by our literature review¹⁴ relating to certain aspects of life that might have been affected by cancer. In addition, the EORTC core questionnaire (EORTC QLQ-C30)²⁶ was shown to participants to encourage further discussion. The interview template is available as supplementary material. Following completion of the interview, the researcher accessed medical notes to record information relating to diagnosis and treatment schedules.

Interviews were audio-recorded and summaries of the content of the interviews were prepared in the form of narratives with quotes and translated where appropriate by each interviewer and sent to the study co-ordinator (SS) for analysis. The content of the interviews was analysed using the principles of thematic analysis.²⁷ A list of preliminary codes or themes was developed inductively by SS with iterations to the master code list carried out by members of the research team (ASD, OH, GR, BV). Each interviewer was also asked to check the application of themes for the interviews they had conducted and any conflicts in interpretation resolved following discussions with the research team. Coding assumptions were continually reviewed and an audit trail of all research team discussions recorded to enhance rigour.

Examples of each theme were extracted from the interviews as direct quotes or summaries of issues raised. Each participant was given a code with their country identifier followed by a number. The following codes were given to each country: France: FR, Israel: IS, Netherlands: NL, Norway: NO, Poland: PO, United Kingdom: UK.

Results

Participants

Collaborators were asked to recruit, where possible, participants with a spread of ages, diagnosis type and treatment/palliative status. Recruitment continued until no new issues were raised with accumulating data reviewed after every fifth interview and recruitment ended after 45 interviews. All participants opted to be interviewed alone. Full details regarding the demographics and clinical characteristics of the sample are presented in Table 1. The sample included an almost even split of males (53%) and females (47%), mean age 20.3 years, 27% had completed compulsory education, i.e. the minimum period of education imposed by law, 20% were either currently enrolled in or not able to complete compulsory education, and 38% had enrolled in or completed college. Only 22% of the sample were currently in full time or part time employment. The majority of the sample lived with a partner (64%) or parents (24%). Participants presented with 12 different cancer types with leukemia (28%) and lymphoma (18%) the most predominant diagnoses. The median time since diagnosis was 9 months and ranged between 1 month and 7 years. The majority of participants were currently on treatment with curative intent (78%), predominantly chemotherapy (53%). Twenty participants had undergone surgery and one was awaiting surgery. The majority (80%) of the sample did not report any co-morbidities. Thirty three percent described themselves on the ECOG performance scale as fully active and 42% as restricted in physically strenuous activity.

Insert Table 1 about here

Themes

HRQoL issues were extracted from the interviews and organized within the following 12 thematic categories: symptoms, activity limitations, disrupted life plans, social, emotional, body image, self-appraisal, outlook on life, lifestyle, treatment-related concerns, fertility and

financial concerns. Table 2 presents these categories along with example quotes from participants.

Insert Table 2 about here

Symptoms

The majority of participants (n=38, 84%) talked about symptom side effects of their cancer and its treatment including pain, nausea, vomiting, fatigue, sleep-related problems, loss of strength and energy, shortness of breath, cognitive issues, difficulty gaining weight and mobility problems. Over half the participants (n=25, 56%) talked about problems relating to fatigue or loss of energy, for example, not being able to resume their education, return to work or go out with friends. Participants talked about a generalized state of feeling unwell and not feeling “normal”, for one 20 year old with acute lymphoblastic leukemia (UK003), feelings of nausea and headaches contributed to not feeling his “usual self”. Some symptoms such as weight changes and hair loss resulted in visible bodily changes and served as constant reminders of the cancer:

“..the hair loss was the most disturbing as it made the cancer visible, a constant reminder”
(NL007, 22 years old with lymphoma)

Activity limitations

Most AYAs (n=39, 87%) reported that their cancer and its treatment restricted their activities. Twenty (44%) participants discussed the impact on leisure activities and hobbies and in particular restricted participation in sporting activities due to lack of strength and tiredness. AYAs also found themselves restricted in being able to go out and pursue activities due to risk of infections and 3 (7%) participants described having to postpone their travel plans. The impact of activity limitations on mood was also described; one 17 year old participant with leukemia (PO009) reported feelings of frustration from not having the energy to carry

out even the most simplest of tasks. A 14 year old with leukemia described the impact of not being able to play soccer:

“Not to be able to play soccer and not to be able to do nearly anything, have to think about the illness all the time; I find it boring” (NO001).

Fourteen (31%) AYAs talked about the impact of being ill on work life, for example in terms of having to take sick leave, reducing the number of hours worked or having to change jobs:

"I had a very promising job, but now I have to stay on sick leave" (PO011, 23 years old diagnosed with breast cancer).

AYAs also talked about worries relating to returning to work and future employment prospects.

Twenty eight (62%) participants talked about interruptions to their studies and, for 7 (16%), disrupted education and physical limitations impacted on their chosen career pathway.

Disrupted life plans

Life plans being put on hold was a recurring theme, the emotional impact of which was exacerbated by comparisons made with achievements realized by their peers. An 18 year old male with acute lymphoblastic leukemia explained:

“I feel like I’m not going anywhere, It’s like my life has been put on pause....I see everyone else getting on with their lives” (UK002).

A 19 year old with gynecological cancer (IS005) recounted that one moment she was on the same path as the rest of her friends and a moment later she had to face a completely different reality involving hospital admissions and tests. Disrupted life plans were also regarded as causing developmental delays as AYAs find themselves in a different developmental phase to their peers.

In addition, a 19 year old a male with leukemia (IS003) talked about difficulties in making plans for the future due to the time “wasted” in hospital.

Social

The social impact of cancer and its treatment was described by 41 (91%) AYAs and included the effects on friendships, family and romantic relationships. An inability to go out and socialize with peers was frequently reported and for some led to feelings of isolation. Several AYAs sensed that their peers found it difficult to relate to what they were going through and this caused difficulties in communicating with them:

“My friends do not understand my situation, it’s difficult for me to explain to them” (NE004, 19 years old with lymphoma)

Friends were described as being in shock that someone of their age could become so seriously ill and potentially die and they could not cope with this thought:

“They consider you dead before you die....“it’s like they put their fingers in their ears and walked away”. (UK005, 21 years old with non Hodgkin lymphoma)

Participants described losing friendships and feeling let down by others as friends were often scared to contact them. One participant aged 23 years with a brain tumour explained that her friends had adapted to her limitations but she felt bad about it (UK009). Other participants also shared the concern of being a burden to others especially to family members. Having to rely on others for help, for example, for self-care was noted as something people of their age do not normally have to do:

“It’s like you’re a kid again” (UK005, 21 years old with non Hodgkin lymphoma)

Participants described difficulties associated with surrendering the independence enjoyed by their peers especially as they often found themselves having to move back in with parents and

for a 23 year old participant (UK009) this meant moving back into her parent's house with her husband at a time when they should have been developing their relationship. While many AYAs talked about having to ask family to help look after them, some also had young families of their own: a 23 year old with gynecological cancer (IS004) had to call upon help from the family to care for her baby. AYAs talked about the impact their diagnosis had on their family and home life both emotionally and practically. Several AYAs were concerned about the worry and stress brought upon their parents as well as the impact on siblings both emotionally and practically in terms of them receiving less attention from parents:

“I feel bad for the time my parents spend taking care of me...my father missed work and mum is with me at hospital instead of taking care of my little brothers” (IS003, 19 year old male with leukemia).

Several AYAs reported that their parents had put their own careers and employment on hold in order to care for them:

“My mum had to change her career path to care for me” (UK003, 20 year old male with acute lymphoblastic leukemia).

For some participants, cancer and its treatment had put the relationship with their partners under strain, for example, a 20 year old male with testicular cancer (PO006) talked about marital difficulties resulting from an inability to communicate feelings to his spouse. Limited opportunities for spending time with partners and for intimacy were also described. A 23 year old diagnosed with breast cancer (PO003) explained that her sex life and plans to start a family had to be put on hold. An 18 year old male with acute lymphoblastic leukemia (UK002) also expressed concern over not being able to have a “usual” relationship and share a bed with his girlfriend. Two of the AYAs went through a relationship break up since their diagnosis.

Difficulties in establishing new romantic relationships due to limited opportunities, body image and self-esteem issues were also described. A 19 year old with leukemia (IS003) expressed concerns over how girls would view him and lacked confidence in dating:

“I used to date a lot before I got sick” (IS003)

For a 22 year old male with testicular cancer (PO005), concerns rested with future “private” relationships due to uncertainty over fertility.

Not all accounts of the social impact of cancer were negative as 4 (9%) AYAs described opportunities to make new friends with fellow patients and 16 (36%) felt that their relationships with family and friends had been strengthened as a result of more time devoted to these relationships.

Emotional

AYAs described the emotional impact of cancer including feelings of sadness and depression often brought about by restrictions to previously enjoyed activities and disrupted life plans. Seventeen (38%) AYAs worried about their diagnosis and the implications for their future.. Two (4%) AYAs described feeling scared about their diagnosis and one talked about feeling afraid of dying:

“I became paralysed by my diagnosis” (PO011, 23 years old with breast cancer)

Several AYAs expressed feelings of disbelief and shock at their diagnosis. Feelings of anger were also described; a 23 year old with gynecological cancer (PO007) was angry with herself for not attending regular screening while a 20 year old male with testicular cancer (PO006) was angry at the surgery he had to have (removal of testicle) which also left him feeling embarrassed. Two (4%) participants felt that they had been let down by their body. A 23 year old participant with gynecological cancer (PO012) described concerns about the long term effects of the disease and life not being able to return to normal:

"I am afraid that once the treatment ends I will not know how to go back to everyday life"

This participant (PO012) also described being consumed by thoughts about the disease while a 21 year old male with a neuroendocrine tumour (NL002) was worried that any physical ailment meant that his disease was progressing.

Four (9%) AYAs described feelings of boredom from the time spent in hospital and restrictions imposed on them, which was in contrast to their more active pre-diagnosis lifestyle:

“time is not spent in a valuable way, time you will never get back again” (UK005, 21 years old, non Hodgkin lymphoma)

Body image

Symptoms presented above such as hair loss, changes to weight and rashes resulted in appearance changes which impacted on self-esteem and had social repercussions as they often felt self-conscious in front of others and even too embarrassed to leave the house:

“I didn’t recognize myself in the mirror” (UK005, 21 years old with non Hodgkin lymphoma)

Participants also referred to the lack of preparation for such significant changes in appearance. Altered appearance also affected feelings of femininity and manliness with accounts of feeling disfigured. Concerns relating to permanent changes due to scars were also voiced and a 23 year old with gynecological cancer (PO007) worried that she would not be attractive following her treatment. By contrast, a 21 year old with bone cancer (NL008) described no longer being worried about his appearance and what others thought.

Self-appraisal

AYAs not only described changes to their physical appearance but also to the way they felt about themselves:

“I can’t be the person I was last year”. “It changes you and you can’t do anything about it” (UK002, 18 years old with acute lymphoblastic leukemia).

AYAs described greater self-awareness and as mentioned earlier within the context of body image and relationships with others, several AYAs described feeling less confident in themselves and their bodies. A 23 year old with breast cancer (PO003) explained how her diagnosis had shattered her perception of herself. There were also accounts of being less tolerant to others who appear to have less to deal with:

“I find it hard to be understanding of others who do not cope well with diseases” (NL010, 22 years old with thyroid cancer)

In contrast, 4 (9%) AYAs talked about feeling more confident and self-assured through their experiences. There were also accounts of feeling braver, stronger, more mature, and positive.

“.....it impacts you as a person, I am now more sympathetic, more sensitive to others and more motivated to help others” (UK001, 17 years old with acute lymphoblastic leukemia)

“I have become more grown up in a way” (NO003, 19 years old with Ewing’s sarcoma)

Changed outlook on life

Ten (22%) AYAs talked about cancer changing their outlook on life, for some this was a more positive outlook on life and the future with different priorities and a desire to live life to its fullest and embrace every opportunity offered. A 21 year old male with non Hodgkin lymphoma described a “greater thirst for life” with life taking on an intensity (UK005) as well as a greater motivation to achieve personal goals and succeed academically:

“...it gives you a pathway, and motivation to do things”

A 22 year old participant with non Hodgkin lymphoma (NL012) explained that cancer had provided him with greater life experience and an awareness of different emotions. The

experience of cancer also brought some AYAs face to face with their own mortality, which also led the realization of the fragility of life and to feelings of gratitude for being alive and not taking things for granted.

Lifestyle

Eight (18%) participants found themselves having to make lifestyle changes in terms of following special diets and minimising risk of infection particularly during treatment. While several participants described feeling motivated to follow a health promoting lifestyle, some described the struggles associated with the restricted food and drink intake, and the avoidance of high-risk situations, which impacted on their ability to go out and enjoy the things their peers take for granted:

“I am not able to meet friends or be part of any social activity due to risk of infection”

(IS005, 19 years old with gynecological cancer)

Treatment-related

AYAs discussed the burden imposed by their treatment and in particular the length of treatment. Dissatisfaction with care was also a common theme and included not being taken seriously because of their age and misdiagnosis when they first presented with symptoms:

“...they made multiple mistakes and did not take me seriously” (NL007, 22 years old with lymphoma)

AYAs also talked about lack of age appropriate care, information on how to lead a healthier lifestyle, what to expect from treatment, in terms of age-specific effects, and adequate psychosocial support. A 25 year old with testicular cancer (NL014) described the frustration felt as the hospital staff expressed little understanding of the strains imposed by treatment on his young family. The lack of a young adult ward was also discussed with one 19 year old

with melanoma (NL006) describing feelings of loneliness from being the youngest patient on the ward.

Fertility

Both male and female participants considered the impact of treatment on their ability to have children:

"What will happen if I will not be able to be a mother?" (PO011, 23 years old with breast cancer).

Some females talked about the impact of becoming pregnant in terms of cancer recurrence and having to alter medication. For a 25 year old male with testicular cancer (NL014), reduced fertility and the desire for a bigger family caused tension and uncertainty for him and his partner. Three (7%) AYAs talked about looking into fertility preservation methods.

Financial impact

Six (13%) of the AYAs interviewed discussed the financial impact of their illness. Although some AYAs received some financial help, financial struggles were discussed within the context of not being able to work and, in some cases, having a young family to support. Financial constraints also forced plans, such as purchasing a house, to be put on hold. In addition, a 19 year old patient with sarcoma (UK010) talked about the significant costs of sperm banking.

Discussion

From our interviews with both adolescents and young adults with cancer, we generated a list of inter-related HRQoL themes reflecting the multi-dimensional nature of HRQoL.² . This

study represents an extension of previous qualitative studies in the literature by employing semi-structured interviews with a larger cohort of AYA patients with different cancer diagnoses representing numerous cultural backgrounds. We have expanded on previous research by providing a detailed overview of a wide range of HRQoL issues in a more culturally diverse sample thus our findings could be argued to be more comprehensive and have greater applicability .

Although our interviews followed a script, the emphasis was on giving AYAs the opportunity to tell their own unique story and this is reflected in the number and diversity of HRQoL themes (both positive and negative) captured in this study. Issues were organized according to the following 12 broad themes: symptoms, activity limitations, disrupted life plans, social, emotional, body image, self-appraisal, outlook on life, lifestyle, treatment burden, fertility and financial. While it could be argued that these issues are familiar concerns for other age groups, they are likely to be more pronounced in AYAs⁴. The impact of symptoms on AYAs' ability to engage in everyday activities, partake in sports, attend school, work and interact with others was frequently reported in the interviews and is consistent with previous research with young people with cancer.^{15;18;21;22} In line with Hinds et al. (2004),²⁰ we found that AYAs often use their peers' position in life as a frame of reference leading them to conclude that they are falling behind where they should be in life. Most AYAs in our study (91%) described the impact of cancer on friendships, family or romantic relationships although not all accounts were negative, for example, strengthening of existing relationships and opportunities to forge new bonds with fellow AYAs with cancer were also described. Our interviews also covered the issue of fertility which is identified as a significant psychosocial concern amongst both male and female AYAs with cancer²⁸ with increasing recognition of the need to allow space in conversations with AYAs to discuss the often uncomfortable topic of fertility as well as sexual concerns.²⁹

AYAs in our study described a range of feelings surrounding their diagnosis with cancer and the effects of its treatment including initial feelings of shock and disbelief, frustration and anger at not being able to follow the pathway of their peers, as well as concerns over the future and mortality.

Body image concerns described by AYAs in our sample have also previously been identified as an important aspect of the AYA's experience of cancer^{17; 21} impacting on self-confidence and self-esteem.^{14; 17; 21} Negative self perceptions did not however feature in the stories of all AYAs we interviewed. AYAs also talked about improved self-appraisals, such as greater maturity and these replicate findings in the literature.^{18; 21} In addition, for some AYAs we interviewed, this positivity extended to changes in life perspective and subsequent priority reorganization which has previously been described in the literature within the context of personal growth^{18; 22} as well as response shift in HRQoL evaluation.³⁰

Financial concerns resulting from the direct and indirect costs of cancer were also raised in the interviews and while they may not be unique to AYAs, they are likely to be more prominent during adolescence and adulthood, a time when AYAs might have only just recently secured employment and therefore might not enjoy the benefits, such as sick pay, accrued by their older counterparts. In addition, AYAs might have limited savings and possibly student debts,³¹ a young family to support or significant financial commitments in the form of mortgage repayments. For an AYA with cancer, it follows that identifying and accessing means of financial support can be a potentially daunting task.

This study provides a detailed insight into the widespread impact of cancer and its treatment on the lives of AYAs by collating all the different HRQoL issues as described by AYAs. Activity limitations, social impact and symptoms were highlighted as the most commonly discussed issues in our sample. However, it could be argued that these issues were more

commonly raised in response to prompts relating to these topics and exposure to the EORTC QLQ-C30 items which measure these issues. Thus, we are not in a position to make claims regarding prevalence and generalize from our sample. In addition, this study did not make formal age comparisons in HRQoL issues therefore we are only able to speculate that issues such as the opportunity for establishing intimate relationships and disrupted career plans might be more familiar to AYAs compared with older adults. We acknowledge that several of the HRQoL issues captured by this study, for example, symptoms and emotions, do not begin and end in the AYA years. In addition, it could be argued that we should not treat AYAs with cancer as a homogeneous entity³² and that a 14 year old will not share the same concerns as a 25 year old. Again, identifying differences within our sample according to age was beyond the scope of our current study. Although our focus was on AYAs receiving treatment or palliative care, the issues raised are likely to be familiar to AYAs living beyond cancer treatment.³³

In this paper, we have provided a comprehensive list of HRQoL issues described by AYAs undergoing treatment for cancer. It is likely that not all of these issues are covered by any one of the existing PROMs used with AYAs,¹⁴ a finding which is consistent with the work of Anthony et al. (2017)³⁴ in the context of pediatric oncology. The findings from this study form part of a larger EORTC QLG study and will inform the development of a new AYA-specific measure that will include all relevant and important issues for AYAs undergoing treatment or receiving palliative care for cancer. Our study also highlights the diverse and potentially unique needs of AYAs with cancer. The use of an AYA-specific HRQoL module could facilitate discussion of such needs that might otherwise be overlooked. In addition, information gathered from HRQoL assessments can be used to tailor treatments and has the potential to support the effective delivery of care and improve clinical outcomes as well as HRQoL beyond cancer.^{3,35}

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Author Disclosure Statement

No competing financial interests exist

Table 1. Demographic and clinical background of the sample

Variable	Total Interviewed (N=45)
	N (%)
Patients recruited per country (country Identifier)	
Netherlands (NL)	13 (28.9%)
Poland (PO)	12 (26.7%)
United Kingdom (UK)	10 (22.2%)
Israel (IS)	6 (13.3%)
Norway (NO)	3 (6.7%)
France (FR)	1 (2.2%)
Gender	
Male	24 (53.3%)
Female	21 (46.7%)
Age (years)	
Mean (standard deviation)	20.3 (2.8)
Range	14-25
Education level	
Currently not able to complete education	5 (11.1%)
Currently in compulsory education	4 (8.9%)
Compulsory school education completed	12 (26.7%)
Post compulsory school education (college)	17 (37.8%)
University	7 (15.5%)
Employment status¹	
Full time	5 (11.1%)
Part time	5 (11.1%)
Sick leave	11 (24.4%)
None	16 (35.6%)
Other	8 (17.8%)
Living situation²	
Alone	2 (4.4%)
Partner	29 (64.4%)
Parents	11 (24.4%)
Living with others	4 (8.9%)
Time since diagnosis (months)	
Median	9
Range	1-87
Disease status	
Localized	16 (35.6%)
Metastatic	9 (20.0%)
Not applicable (Leukemia, lymphoma)	20 (44.4%)
Diagnosis	
Leukemia	12 (26.7%)

Lymphoma	8 (17.8%)
Gynecological	5 (11.1%)
Testicular	4 (8.9%)
Bone	3 (6.7%)
Sarcoma	3 (6.7%)
Head and neck	3 (6.7%)
Brain and central nervous system	2 (4.4%)
Breast	2 (4.4%)
Thyroid	1 (2.2%)
Melanoma	1 (2.2%)
Neuroendocrine	1 (2.2%)
Treatment status	
Currently on treatment	35 (77.8%)
Supportive / palliative care	10 (22.2%)
Treatment type³	
Chemotherapy	24 (53.3%)
Radiotherapy	8 (17.8%)
Hormonal	4 (8.9%)
Targeted therapy	3 (6.7%)
Stem cell transplantation	1 (2.2%)
Psychological	1 (2.2%)
Co-morbidities⁴	
None	36 (80.0%)
Renal	3 (6.7%)
Respiratory	2 (4.4%)
Muscular	2 (4.4%)
Hypertension	1 (2.2%)
Neurofibromatosis type 1	1 (2.2%)
ECOG Performance Status⁵	
0 (Fully active)	15 (33.3%)
1 (Restricted in physical strenuous activity)	19 (42.2%)
2 (Unable to carry out work activities)	9 (20.0%)

¹2 participants within the none category and 2 within the other were students

² 1 participant lived with a partner and parents

³ Several participants were receiving multiple treatments. Details on treatment type were unavailable for one participant

⁴ Several participants indicated more than one co-morbidity. Co-morbidity details were not collected for one patient. One patient had been diagnosed with attention deficit hyperactivity disorder.

⁵ One participant indicated a score of 1.5 (between restricted in physical activity and unable to carry out work activities). Performance status was not indicated for one participant.

Table 2. HRQoL Themes

HRQoL Issue	Extracts from interviews	Number (percentage) of participants referring to the issue
Symptoms		38 (84%)
Pain	“...difficulties controlling pain restrict daily routines” (PO008)	5 (11%)
Nausea & Vomiting	“Feelings of nausea and headaches make me not feel normal” (UK003)	11, 7 (24, 16%)
Lack of appetite	“I have lost my appetite which is a cause for concern for doctors” (PO009)	3 (7%)
Weight gain	“I see myself as fatter” (UK002)	1 (2 %)
Weight loss or difficulty gaining weight	“I have lost weight which is a positive thing (not for the doctors)” (PO009)	3 (7%)
Tiredness or lack of energy	“I am not able to do anything useful because of my tiredness” (PO009)	25 (56%)
Weakness or loss of strength	“I am physically weaker and cannot do things around the house” (PO006)	12 (27%)
Heartburn	“heartburn...problems that in the past I considered to be adult problems” (IS003)	1 (2%)
Bowel (constipation, diarrhoea)	“Constipation imposed the biggest restriction” (UK009)	4 (9%)
Hair loss	“...I consider the hair loss the most disturbing...it makes the cancer visible...a constant	7 (16%)

	reminder...made me feel unfeminine” (NL007)	
Shortness of breath	“...because of my shortness of breath, I cannot do things that are normal” (UK002)	4 (9%)
Trouble sleeping	...work performance is affected due to trouble sleeping” (PO002)	10 (22%)
Mobility problems	“My mum has to take me everywhere....I am afraid that I won’t be able to walk normally after treatment” (PO001)	5 (11%)
Difficulty concentrating	“I find it difficult to concentrate especially when I am pre-occupied with concerns about the future” (PO004)	10 (22%)
Activity limitations		39 (87%)
Impact on hobbies or leisure time activities	“I used to do a lot of things, I played soccer four times a week....”I particularly miss soccer” (NO001)	20 (44%)
Not able to bathe, take showers or dress yourself	“I feel angry about not being able to wash myself and shower with the line in” (UK002)	3 (7%)
Not able to go out	“I do not go out much due to lack of energy” (NL011)	6 (13%)
Restricted daily activities	“I am not able to do everything even though I think I can do it” (NO002)	4 (9%)
Interrupted education	“I am worried about wasting time....instead of promoting myself towards education and	28 (62%)

	future planning, I have to stay in hospital” (IS003)	
Employment	“I had a very promising job, but now I have to stay on sick leave” (PO011)	14 (31%)
Disrupted life and career plans		13 (29%)
	“Currently I feel like everything I did sort of stopped” (PO009)	
Social		41 (91%)
Loss of friends	“...it’s like they put their fingers in their ears and walked away” (UK005)	7 (16%)
Isolation from friends	“I could not be with friends” (NO003)	8 (18%)
Less time to go out with friends	“I have less time to meet up with friends” (IS004)	2 (4%)
Greater dependence on others	“I have had to rely on help from others, for example with medication....things teenagers ordinarily wouldn’t have to worry about” (UK011)	15 (33%)
Greater burden on others	“I feel useless and a burden to others because I am limited in being able to help around the home” (PO006)	2 (4%)
Change in living situation	“We had to move back in with my parents at a time we should have been developing our own relationship” (UK009)	4 (9%)

Impact on family members	“...it was probably mum and dad who were most anxious” (NO003)	14 (31%)
Impact on family life	“...our life together as a young family is put on hold” (IS004) “My dad has had to miss work and my mum should be looking after my brothers instead of me” (IS005)	6 (13%)
Unable to care for others	“...I cannot take care of him and that is what I find difficult to deal with” (IS004)	1 (2%)
Impact on romantic / sexual relationships	“I used to date a lot before I got sick and now I lack confidence in talking to other women” (IS003)	14 (31%)
Strengthening existing relationships	“I became closer to my family and “real” friends” (NL001)	16 (36%)
Opportunity to make new friends	“I made new friends at the hospital...we helped each other feel positive about the future” (PO001)	4 (9%)
Appreciation of the support received from others	“I have supportive friends who try to raise my spirits” (PO004)	7 (16%)
Less tolerant of others	“I am less tolerant and get more annoyed with others” (PO006)	2 (4%)
Emotional		29 (64%)

Feelings of sadness or depression	“I feel miserable when I experience the side effects of treatment” (NO001)	15 (33%)
Anxiety	“When I think about my situation I start to get this rush of thoughts, a lot of things come into my mind at the same time and I feel disorientated and a bit afraid” (PO005)	7 (16%)
Preoccupation with illness and heightened awareness of symptoms	“I find it difficult to concentrate or think constructively because of thoughts of disease” (PO012)	3 (7%)
Embarrassment	“...my face was swollen, I was too embarrassed to leave the house.” (IS003)	1 (2%)
Fear of recurrence	“I worry about recurrence since the cancer already recurred four times” (NL008)	5 (11%)
Worry about what the future holds and life not returning to normal	“Though the doctors say I should be alright once the treatment ends I feel afraid of what is going to happen in a year or more” (PO001)	8 (18%)
Worry about the long term effects of cancer and its treatment	“I worry about the long-term effects of the disease and treatment” (PO004)	1 (2%)
Worry about dying	“I know that I am being treated but I am very afraid of dying (PO011)	1 (2%)

Shock of diagnosis	“I did not expect that such a thing could happen to me” (PO011)	4 (9%)
Anger	“...angry at being disfigured” (PO006)	3 (7%)
Feel let down by your body	“...felt let down by my body, had no control” (NL004)	2 (4%)
Boredom	“frequent visits and stays at hospital bore me” (PO008)	4 (9%)
Body image		16 (36%)
Altered appearance	“when you look in the mirror, you don’t look like yourself, you look dead” (UK005)	14 (31%)
More self-conscious	“...what do they think about my disease, how do they look at me, how do girls look at me?” (IS003)	4 (9%)
Less concerned about appearance	“I am less concerned about appearance and other’s opinions of me” (NL008)	1 (2%)
Self-appraisals		21 (47%)
Lowered self-confidence / self-esteem	“I lost confidence in myself and the world” (PO003)	5 (11%)
Greater self-awareness	“I learned something about myself because of cancer” (NE003)	1 (2%)
Stronger person	“I am mentally stronger” (PO005)	4 (9%)

Better person	“Cancer has made me a better and richer person and therefore I am thankful” (NL009)	1 (2%)
More positive person	“...it impacts you as a person, I am now a more positive person” (UK001)	3 (7%)
Braver	“I feel a lot more braver” (UK007)	1 (2%)
Increased maturity	“Compared to my friends, I feel more grown up” (NO003)	2 (4%)
Greater confidence	“I am proud cancer does not control my life which gives me the feeling I can do and handle everything by my own way of coping” (NL010)	4 (9%)
More sympathetic	“It impacts you as a person, I am sympathetic to others, more sensitive to others, more motivated to help others” (UK001)	1 (2%)
Outlook on life		15 (33%)
More positive outlook on life	“I now have a more positive outlook on life and the future” (UK004)	2 (4%)
Different priorities in life	“I’ve learnt how to prioritize the important things in life and understand what is important in life” (PO010)	5 (11%)
Greater desire to live life to the fullest	“Life takes on an intensity, I realized the importance of making each minute count...it gives you a pathway, and	3 (7%)

	motivation to do things” (UK005)	
Greater life experience	“The disease brought me life experience, medical knowledge and different emotions” (NL012)	1 (2%)
Greater motivation to achieve personal goals	“It gives you a pathway and motivation to achieve things” (UK005)“	2 (4%)
Greater awareness of one’s mortality	“I had to confront my own mortality” (UK005)	2 (4%)
Inability to plan for the future	“I’ve stopped making plans for the future” (IS004) “I cannot think of the future” (FR001)	2 (4%)
Lifestyle		8 (18%)
Motivation to lead a healthier lifestyle	“I no longer participate in “risky” behaviours” (NO002)	4 (9%)
Take greater care to avoid infections	“I have to be a lot more careful to avoid infections, something I took for granted when healthy” (UK001)	5 (11%)
Restricted diet (food and drink)	“I miss takeaway food” (UK001)	4 (9%)
Treatment-related		14 (31%)
Difficulty adjusting to being ill and having to take medication	“...difficulty adjusting to a different path in life imposed by disease” (IS009)	2 (4%)
Dissatisfaction with care	“Doctors didn’t take me seriously and would talk to my parents rather than me, I felt as if I wasn’t treated properly” (UK005)	6 (13%)

Lack of age appropriate care	<p>“I had to ask my doctor about fertility preservation, no good information was given” (NL001)</p> <p>“...no information about age-specific effects” (NL002)</p>	5 (11%)
Treatment burden	“Frequent visits and stays at hospital bore me” (PO008)	2 (4%)
Fertility		11 (24%)
	“I worry that cancer might affect my ability to have children” (PO004)	
Financial		6 (13%)
	“...I look forward to resuming these plans (travel) when I’m in remission but I am worried about expensive travel insurance” (UK005)	

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