

Does Age Matter? A Comparison of Health-Related Quality of Life Issues of Adolescents and Young Adults with Cancer

Running Title: Adolescents and young adults with cancer

Samantha C. Sodergren¹, Olga Husson², Gudrun.E. Rohde^{3,4}, Iwona. M. Tomaszewska⁵, Helen Griffiths⁶, Aya Pessing⁷, Noam Yarom⁸, Louise Hooker⁹, Amy Din¹, Anne Sophie Darlington¹. On behalf of the EORTC Quality of Life Group

Address for Correspondence:

Samantha C Sodergren, School of Health Sciences, University of Southampton, Highfield, Southampton, SO17 1BJ, UK. Email: S.C.Sodergren@soton.ac.uk

¹ School of Health Sciences, University of Southampton, Southampton, UK.

² Institute of Cancer Research, London, UK

³ Faculty of Health and Sport Sciences, University of Agder, Norway

⁴ Department of Clinical Research, Sorlandet Hospital, Norway

⁵ Department of Medical Education, Jagiellonian University Medical College, Krakow, Poland

⁶ Oxford Children's Hospital, Oxford, UK

⁷ Department of Oral & Maxillofacial Surgery, Sheba Medical Center, Tel-Hashomer, Israel

⁸ Department of Oral Pathology and Oral Medicine, Tel-Aviv University, Tel-Aviv, Israel

⁹ Teenage and Young Adult Cancer Service, University Hospital Southampton, Southampton, UK

Acknowledgements

We would like to thank all the people who shared their illness experiences with us. Also, thank you to the following colleagues for their assistance: Joanne Grout and Kim Stevens (University Hospital Southampton NHS Foundation Trust); Chaim Churi (Sheba Medical Center); Karen Scanke and Christop Muller (Sorlandet Hospital). We would also like to thank Sean Ewings for statistical advice.

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved at the lead site (University of Southampton, UK) by the South-Central Oxford C Research Ethics Committee.

Conflict of interests

The authors have no conflict of interest to declare

Funding

This study was funded by the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Group. The grant was awarded to Associate Professor Anne Sophie Darlington.

Abstract

Objective

Health-related quality of life (HRQoL) concerns of adolescents and young adults (AYAs) aged 14-25 years were compared with those of older adults (26-60 years) with cancer.

Methods

AYAs and older adults receiving curative intent treatment or supportive palliative care for cancer were recruited from eight research centres across Europe. Participants used a rating scale to score the relevance and importance of a list of 77 issues covering 10 areas of HRQoL concern: Symptoms; activity restrictions; social; emotional; body image; self-appraisals; outlook on life; lifestyle; treatment-related and life beyond treatment.

Results

HRQoL issues were reviewed by 33 AYAs and 25 older adults. Several issues were recognised as relevant and important across all age groups: symptoms, emotional impact, outlook on life, lifestyle and treatment-related. A number of issues were more relevant or important to AYAs including interrupted education, greater motivation to achieve academic goals, increased maturity, boredom, fertility, and change in living situation.

Conclusion

While there is overlap in several of the HRQoL concerns across the age span, it is important that HRQoL measures used with AYAs capture the diverse and unique psychosocial aspects of this developmental stage.

Keywords

Quality of Life; Adolescent; Young Adult; Psycho-oncology

Introduction

Irrespective of a diagnosis of cancer, adolescents and young adults (AYAs) find themselves in a period of transition from childhood to adulthood characterised by significant physical and cognitive changes as well as critical psychosocial challenges. Developing a sense of identity, decisions regarding career choices, challenges relating to peer relationships, as well as establishing autonomy from family members are hallmarks of this development stage (Erikson, 1963). The development of intimate relationships and questions relating to sexuality are also integral features during adolescence and early or emerging adulthood. A diagnosis of cancer during this crucial developmental stage will further complicate and disrupt the negotiation of these challenges (Sansom-Daly & Wakefield, 2013; Zebrack, 2011).

While cancer in AYAs is relatively rare, its incidence is increasing and the incidence of cancer in AYAs is higher than in children (Bleyer, O'Leary, Barr, & Ries, 2006; Croucher, Whelan, Moller, Davies, 2009; Stiller et al., 2006; van der Horst, Winther, & Olsen, 2006). In Europe, 14,000 new cases of cancer are diagnosed in AYAs annually (Steliarova-Foucher et al., 2015). AYAs are also more likely to be diagnosed with advanced or aggressive cancers (Bleyer et al., 2006). Ten per cent of tumours seen in AYAs are predominantly childhood tumours, while 30% of tumours have a peak in adolescence and include Hodgkin's Lymphoma, Ewing's Sarcoma, osteosarcoma, germ-cell tumours and rare soft-tissue sarcomas. A final 60% are early-onset adult cancers (Eden, 2006; Birch et al., 2002). Furthermore, cancer-specific outcomes in AYAs are significantly worse than in children and older adults (Chen et al., 2018; Keegan et al., 2016; Stiller et al., 2006). There is also evidence to suggest that current services are not meeting the specific needs of this age group with AYAs often finding themselves treated within paediatric or adult settings (Bleyer, 2005; Thomas, Albritton, & Ferrari, 2010; Zebrack et al., 2013).

Irrespective of age, a cancer diagnosis is likely to be met with negative emotions such as anxiety and uncertainty. However, the emotional impact of cancer has been widely reported to be felt more significantly by AYAs with cancer compared with other age groups, especially older adults, with an elevated risk of distress, depression and anxiety (Burgoyne et al., 2015; Lang, David, & Giese-Davis, 2015; Park & Rosenstein, 2015). In addition, symptom side effects such as fatigue, weakness, sickness, pain, and difficulty concentrating are also likely to be recognised by all age groups with specific symptoms linked more closely to tumour site or treatment type rather than age. However, once again, the perception of these might vary according to age with younger adults reporting greater symptom burden and cognitive dysfunction as well as expressing greater concerns about body image, sexuality, and fertility (Avis, Crawford, & Manuel, 2005). An investigation into the

effect of age on HRQoL using a pooled analysis of randomised controlled trials which used the EORTC QLQ-C30 (Aaronson et al., 1993) revealed poorer social functioning and greater financial difficulties amongst younger patients (Quinten et al., 2015) and this has been replicated in lymphoma (Oerlemans, Nijziel, & van de Poll-Franse, 2015) and thyroid patients (Mols et al., 2018). As mentioned above, for AYAs, their diagnosis and treatment is likely to disrupt important personal goals such as forging a career pathway or establishing intimate relationships and thus they are likely to experience cancer differently compared with other age groups as they see themselves lagging behind their peers and where they had hoped to be in life. Snobholm and Heiwe (2013) proposed that younger people's experiences of cancer also differ from those of older cancer patients due to a lack of previous experience of severe illness. Perceptions of HRQoL are shaped by past experience, present circumstances, and expectations for the future (Bowling, 2001) and thus age and developmental stage are likely to play a role. AYAs will not necessarily be aligned to older adults in their appraisals of the HRQoL impact of cancer.

In an outline of research priorities for AYAs with cancer, the AYA Oncology Progress Review Group acknowledged that the research infrastructure for assessing AYA cancer-related issues is inadequate and needs to be supported by the development or modification of existing AYA assessment tools (Adolescent and Young Adult Oncology Progress Review Group, 2006). Our programme of research, carried out on behalf of the EORTC Quality of Life Group (QLG), addresses this key issue by investigating the optimal way of assessing the impact of cancer on the health-related quality of life (HRQoL) of AYAs. Firstly, we investigated the broad spectrum of HRQoL concerns of 45 AYAs aged 14-25 years who were currently on treatment or receiving palliative support for cancer (Sodergren et al., 2018). Our interviews captured numerous concerns relating to symptoms, restrictions to activities, disrupted life plans, body image, self-appraisals, outlook on life, lifestyle, treatment, fertility as well as the social, emotional and financial impact on life. Our current study aims to identify whether there are differences according to age in terms of the impact of cancer on different areas of HRQoL, specifically whether there are particular concerns which are more relevant and important to AYAs. We have also previously acknowledged that amongst AYAs themselves, there might be distinct differences (Sodergren et al., 2018) given that between the ages of 14 and 25, significant life changes occur, for example, leaving compulsory education, starting out on a career and changes to living arrangements supporting a more independent existence.

To our knowledge, this is the first study to make a direct comparison between AYAs and older adults undergoing treatment or supportive care for cancer in terms of the wide spectrum of HRQoL

concerns. Previous research providing age comparisons (Avis et al., 2005; Burgoyne et al., 2015; Lang et al., 2015; Mao et al., 2007) are often limited in their focus to one particular aspect of HRQoL or in terms of age range which is not inclusive of adolescents (Avis et al., 2005; Mao et al., 2007). This study provides insight into whether AYAs are unique in terms of the impact of cancer on different aspects of HRQoL which in turn will have implications for how HRQoL is assessed in this age group. Specifically, if there are age differences in terms of the impact of cancer, HRQoL measures will need to be tailored to the specific concerns of this age group. The current study addresses the following hypotheses:

1. HRQoL issues which are not developmentally related such as symptoms, emotions, and impact on family, will be rated as relevant and important to all cancer patients regardless of age.
2. AYAs will differ from older adults in terms of how they perceive cancer to impact on their life across a number of areas including education and work, socially, fertility.
3. Although AYAs form a distinct group, there will be some differences between younger and older AYAs in their evaluation of how cancer has affected their life.

Method

Study design

The study was designed in accordance with the EORTC QLQ module development guidelines (Johnson et al., 2011) with the protocol peer reviewed and approved by the EORTC QLQ. As mentioned above, the study forms part of a larger study designed to develop a suitable method for assessing HRQoL in AYAs and as part of this, age comparisons were performed in order to justify whether or not an AYA specific measure is required. To identify whether certain HRQoL concerns are more prominent amongst AYAs (14-25 years), we invited AYAs and older adults (26-60 years) to be interviewed. As part of the interview, participants were asked to review the relevance and importance of a list of HRQoL issues generated from AYAs aged 14-25 (Sodergren et al., 2018) as well as issues captured from a systematic review of the literature on AYA oncology (Sodergren et al., 2017). The list included 77 issues organised according to the following categories: Symptoms (physical, cognitive) (n=12 issues); Activity restrictions (including disrupted life plans) (n=7); Social (interactions with family and friends) (n=14); Emotional (n=12); Body image (n=3); Self-appraisals (how one feels about oneself) (n=7); Outlook on life (including priorities) (n=9); Lifestyle (n=5); Treatment-related (including treatment burden) (n=5); and Life beyond treatment (n=5). Participants were encouraged to adopt a “think aloud” approach (Ericsson & Simon, 1980) when rating the issues and the narratives were recorded for the purposes of providing insight into why the

ratings had been assigned and also to help inform the next phase of research involving the selection of issues to be included in an AYA-specific questionnaire.

Participants

AYAs aged between 14 and 25 years receiving treatment or supportive palliative care for cancer were recruited from eight research centres across France, Israel, Norway (two centres), Poland, The Netherlands and UK (two centres). AYAs were recruited and interviewed at hospitals. Those who had completed curative intent treatment and attending a clinic for follow-up only were excluded from the study. Older adults with cancer aged 26-60 years were also recruited and represented our comparison group. We adopted a similar approach to the one used in the development of the EORTC HRQoL questionnaire specific to elderly patients (EORTC QLQ-ELD15; Johnson et al., 2010) which compared ratings of elderly patients to those of younger adults.

In order to capture any potential differences within the AYA group, we formed two sub-groups: younger AYAs (14-18 years) and older AYAs (19-25 years). The older adults were also sub-divided: 26-50 years and 51-60 years. In view of the different distribution of cancer types according to age, groups were not matched according to diagnosis. In line with EORTC QLG guidelines (Johnson et al., 2011), the intention was to recruit 10-15 participants per age sub-group.

Ethical and research governance approvals were obtained at each centre in accordance with local requirements. Participants and, where appropriate (for participants aged 14 and 15 years), parents were given verbal and written information about the study with participation explained as a one off interview whereby a list of issues arising from previous interviews with AYAs would be reviewed for relevance and importance. Parents of adolescents below the age of 16 were shown the interview schedule before making their decision regarding their child's participation and were given the option to accompany their child during the interview. Interviews were arranged once consent and, where appropriate, assent were given.

Interviews

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 helped to complete a measure of performance status (the Eastern Cooperative Oncology Group; ECOG, Oken et al., 1982), which gave a broad indication of the impact of disease and treatment on daily activities. Participants were then invited to review the issue list in terms of relevance (whether or not they recognised or experienced an issue using a yes/no response

option) and importance (extent to which an issue had been troublesome or bothersome to them) on a 4-point Likert scale ranging from 1 “Not at all” to 4 “Very much”. Participants were also asked to talk about why they had assigned a particular score to issues, i.e., why something is relevant or important to them. The interview schedule is available as supplementary material (*Supplementary material 1*). Following completion of the interview, the researcher accessed medical notes to record information relating to diagnosis and treatment schedules.

Data analysis

Ratings for each HRQoL concern were analysed in terms of percentage of participants indicating that an issue was relevant to them and mean importance score (1-4). Ratings were compared across the four age groups. Tests of significance using the chi squared statistic (for relevance) and ANOVA (for importance) were also performed. These tests were treated as indicative rather than confirmatory given the increased Type I error risk due to the number of tests carried out and sub-group sample sizes. The significance level was consequently adjusted using the Bonferonni correction to $p < .0001$. No official post-hoc statistical comparisons were performed and we have exercised caution in our interpretation of the findings given the small sample sizes. Thus, we were largely guided by the EORTC QLQ recommendations for the interpretation of ratings with relevance of $\geq 60\%$ and mean importance of ≥ 1.5 identified as benchmarks. Analyses were carried out using IBM SPSS Statistics 24.

Results

Participant characteristics

A total of 58 patients were involved in the review process and were recruited from 6 countries. Table 1 displays the socio-demographic and clinical characteristics of the participants. Slightly more female patients were interviewed (57%), the sample was predominantly white (88%) with an age range of participants between 14-58 years. The sample included 14 AYAs aged 14-18 years, 19 older AYAs aged 19-25 years, 12 adults aged 26-50 years and 13 older adults aged 51-60 years. Participants presented 12 different tumour types with a distinction in diagnosis type according to age group: 21% of AYAs were diagnosed with leukaemia which was not represented in the other age groups. Lymphoma was the most common diagnosis of 14-18 years, while breast and colorectal cancer were only presented by older adults. Disease status was predominantly localised (48%) with the majority of participants (97%) currently on treatment and for 87.5% of those on treatment, it was delivered with curative intent. Chemotherapy was the most frequently reported (81%) treatment option. The majority of patients did not report any co-morbidities (71%) and this was especially true for younger AYAs. Older adults predominantly (61.5%) rated themselves as unable to carry out work activities. In contrast to the other age groups, the majority of younger AYAs were currently enrolled in compulsory education, were not in employment and lived with their parents.

Insert Table 1 about here.

HRQoL issues ratings

Table 2 displays the individual HRQoL issue ratings across the age groups in terms of percentage participants in each age group marking an issue as relevant and mean importance rating (1-4 with a higher number indicating greater importance). The results of the tests of significance are also presented in Table 2.

Insert Table 2 about here.

Hypothesis 1. Some HRQoL issues will be rated as relevant and important across age groups and are thus not unique to AYAs

Several HRQoL concerns evaluated did not emerge as age-specific in terms of their relevance, with at least 60% of participants in each age group identifying with the concern, and mean importance of ≥ 1.5 for each age group. These generic concerns include symptoms (such as pain, tiredness, energy, loss of strength), impact on hobbies and leisure time activities, interrupted life plans (falling behind in life), emotional impact (worry about the future, recurrence and dying, shock), body image concerns (altered appearance), outlook on life (such as changed priorities), lifestyle and treatment-related factors (such as difficulty adjusting to being ill and treatment burden). Avoidance of infections was also recognised as relevant and important across age groups (mean > 1.5 and relevance $> 60\%$) but particularly high amongst the 14-18 year olds (relevant to all participants of this age group and mean 3.2). A strengthening of relationships with family and friends was recognised as an important issue across age groups (mean > 2) and, with the exception of older adults, was recognised as relevant by at least 60% of participants within each age group (including 93% of 14-18 year olds). The impact on romantic/intimate relationships was relevant to older AYAs (79%) and 26-50 year olds (67%).

In addition, some issues resonated more for older adults (in particular 51-60 years) compared with the AYAs and include restrictions in ability to care for others (mean 3.5 compared to 1.3 for 14-18 year olds) which achieved a significance level of $p < .0001$, and financial difficulties which were relevant to only 36% (mean importance 1.2) of younger AYAs compared with 77% (mean importance 3.0) of older adults.

Hypothesis 2. Some issues will be recognised as more relevant and important to AYAs aged 14-25 years.

A number of issues were rated as more relevant and important to AYAs. Interruption to education was identified as relevant to 86% of 14-18 year olds and 100% of 19-25 year olds compared with 25% of 26-50 year olds and 15% of 51-60 year olds ($p=.001$). AYAs also assigned greater importance to the impact of cancer on education with a mean of 3 for 14-18 year olds compared with 1.3 for 51-60 year olds ($p=.004$). Despite facing disruptions to their education, a greater drive to succeed academically was recognised as an important issue amongst AYAs with a mean importance rating of >2 for both of the AYA age groups compared with 1.3 and 1.2 for 26-50 and 51-60 year olds respectively. This issue was also rated as particularly relevant to the younger AYAs (86% of 14-18 year olds compared with 8% of 51-60 year olds) and both relevance and importance ratings reached the significance threshold ($p<.001$).

Increased maturity was also recognised as more relevant and important for AYA with 86% of 14-25 year olds and 68% 19-25 year olds recognising this issue (mean importance >2 for both groups) compared with 25% of 26-50 years and none of the older adults (mean importance 1.4 and 1.0 respectively). Differences between groups in terms of increased maturity achieved significance at $p<.0001$.

Access to age appropriate information was also more important to AYAs (mean of > 1.5 for both AYA sub-groups compared with 1.3 and 1.2 for the older age groups respectively, these differences did not however reach significance) and was discussed in the context of psychosocial concerns specific to the age group, for example fertility concerns, the long term effects of treatment in particular with respect to future health as well as prospects for future employment and intimate relationships. Fertility concerns were significantly more relevant and important to AYAs (at $p<.0001$) with 71% of 14-18 year olds and 68% of 19-25 year olds identifying these as relevant compared to 50% and 8% of the older age groups (26-50 years and 51-60 years respectively). Mean importance was 3.3 for 19-25 year olds compared to 1.1 for 51-60 year olds.

Hypothesis 3. The two AYA sub-groups will differ in their ratings of some HRQoL issues

For the younger AYAs (14-18 year olds), cancer was more likely to be seen as an opportunity to forge new friendships (relevant to 86%, mean importance of 2.4) compared to 19-25 year olds (relevant to 37% and mean importance of 1.7). A greater motivation to achieve personal goals was also recognised as more relevant to younger AYAs (79%) compared with the other groups. In addition, for this age group, boredom was also more frequently recognised (86%) although there was no significant difference across the age groups for these HRQoL concerns.

A change in living situation (e.g., having to move in with parents) was however recognised as more relevant (63%) to older AYAs (19-25 years) compared to only 8% of younger AYAs (14-18 year olds). Importance ratings also followed a similar pattern with a mean of 2.7 for the older AYAs compared with 1.1 for their younger counterparts. Differences in change in living situation across the age spectrum did not however reach the threshold for significance ($p=.001$ for both relevance and importance).

Discussion

Our study compared HRQoL issues facing AYAs aged 14-25 years with cancer with older adults (26-60 years) with cancer and included evaluations of the extent to which they were troublesome to them. Several of the issues describing symptoms, treatment side effects as well as the emotional impact of cancer were rated as relevant and important irrespective of age group and thus confirm our hypothesis. These issues are generic (non-tumour, treatment or age-specific) and are covered by available HRQoL generic cancer instruments (e.g., EORTC QLQ-C30; Aaronson et al., 1993) and thus we would not necessarily expect significant age differences.

The AYA literature provides numerous reports of disconnected social networks following a cancer diagnosis (Ang et al., 2018; Bansal, Sharma, Vatsa, & Bakhshi, 2013; Momani et al., 2015). The AYAs we previously interviewed (Sodergren et al., 2018) talked about their friends not knowing how to help them and feeling uncomfortable around them as they did not expect someone of their age to become so ill. In the current study, the social impact of cancer was recognised as relevant and important across all age groups including, but not confined to, AYAs. However, the opportunity for new friendships was identified as particularly important and relevant for the younger group of AYAs aged 14-18 years suggesting that, at this age, peer relationships take centre stage. With a larger sample size, the differences between groups might have been more pronounced and reached significance.

Our findings relating to the impact of cancer on education for AYAs replicate what we previously found (Sodergren et al., 2018) as well as other research (Ang, Koh, Lee, Shorey, 2018; Chiang, Yeh, Wang, & Yang, 2009; Sandeberg, Johansson, Björk, & Wettergren, 2008) and features in measures used with young people such as the PedsQL (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). It was also not surprising that the impact on education was more obvious for younger

participants as they were mostly currently enrolled in education or had to suspend their education following their diagnosis.

Boredom was recognised as more common amongst younger AYAs and has been reported in the literature on children with cancer (Moody et al., 2006). It can be speculated that younger people tend to lead more active lives which is brought to a sudden halt by a diagnosis of cancer. In addition, younger people might be more affected by their peers' levels of achievement and therefore their own life involving hospital visits and stays might seem boring in comparison. Hinds et al. (2004) found that when discussing the impact of illness and treatment, adolescents often made reference to milestones reached by their peers such as selecting colleges and learning to drive. Regardless of a cancer diagnosis, boredom is common amongst adolescents and is regarded as functional for psychological growth (Biolcati, Mancini, & Trombini, 2018) therefore expressions of boredom might be viewed as a positive issue and a proxy for feeling better and "normal".

Lack of age appropriate information was a more salient concern for AYAs and related specifically to the psychosocial concerns of this age group which have previously been reported in the context of unmet needs (e.g., Zebrack et al., 2013) and in recognition of the importance of the delivery of age appropriate care to AYAs (e.g., Marris, Morgan & Stark, 2011). Fertility concerns were also more relevant and important to AYAs which echoes previous research with AYAs with calls for fertility to be brought to the forefront of AYA measures (Stinson et al., 2015).

Although the importance of avoiding infections was recognised across age groups, it was more relevant and important to younger AYAs (although not significant) compared with older age groups and this might be explained by the common cancer diagnoses of the younger age group (leukaemia, lymphoma) which are linked to immunosuppression and thus increased risk of infection.

Issues relating to a relinquishing of autonomy in the form of having to move back home to be cared for by parents was more relevant and important to AYAs within the 19-25 year old group. This is the age whereby people are looking to gain independence from parents and having to return to the family home is likely to be seen as a backward step. This issue was not so relevant to the younger AYAs who had not yet left the family home.

Previous research with AYAs has tended to look at the impact of cancer through a more negative lens in terms of the hindrance of goals (Daniel, Barakat, Brumley, & Schwartz, 2014) and lack of motivation (Chiang et al., 2009) although benefit finding amongst adolescents which included increased drive to achieve was reported by Wicks & Mitchell (2010). We found that AYAs

were more likely to identify positive impacts of cancer in the form of increased motivation to achieve academic and personal goals as well as greater maturity through the experience of having cancer, which has been previously reported in the literature (Enskär, Carlsson, Golsäter, & Hamrin, 1997; Wicks & Mitchell, 2010). As mentioned earlier, an additional positive outcome recognised by more younger AYAs (14-18 years) was cancer opening up the opportunity to meet new friends who were going through similar experiences.

Although the younger and older AYAs exhibited some similarities in their HRQoL judgements, there were some differences, as noted above, in terms of change in domestic arrangements and impact of friendships. These differences between younger and older AYAs support previous claims that AYAs with cancer should not be treated as a homogeneous entity (Treadgold & Kuperberg, 2010).

Although our definition of AYA is aligned with the UK AYA oncology service provision, this age range is broad in terms of the different developmental stages it embraces (Erikson, 1963), with a 14 year old likely to live at home with no financial responsibilities and dependent on parents while a 25 year old might be more financially independent with responsibilities and have dependents of their own.

Limitations

We were guided by the EORTC QLG framework when setting our target sample size but the recommendations for this phase of research assume more exploratory work rather than confirmatory statistical enquiry. We conducted statistical analyses to help interpret our findings but we acknowledge that the generalisability of the findings and reliability of our conclusions are restricted by our small sample. In addition, our conclusions might also be compromised by the method in which we performed our comparisons – using relevance and importance ratings. The extent to which the participants understood the task and accurately conveyed their judgements could be questioned. However, the task was completed in the presence of the researcher who was available to answer any questions and clarify the task. Finally, there might have been some bias in terms of how the study was introduced to participants – they were told that the issues had already been recognised by AYAs and that we wanted to check whether or not they are unique to this age group, thus older participants might have had the expectation that several of the issues would not be relevant to them. However, there was notable overlap between the groups in terms of issues which were relevant and important. Researchers across centres received a briefing (interview script) from the coordinator in order to improve rigor and maintain consistency across sites and reduce the potential for bias.

Conclusion

While there is some overlap in the HRQoL impact of cancer on AYAs and older age groups, our study highlights the unique and diverse concerns of AYAs, shaped by their current life situation and developmental stage. Our findings not only have implications for how HRQoL is best assessed with AYAs but also in terms of other aspects of clinical practice. An understanding of the different ways in which a diagnosis and its treatment fits in to a young person's life might help inform the type of conversations clinicians have with them and also in terms of treatment planning in order to minimise disruption to the young person's life.

References

Aaronson, N.K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N.J., Filiberti, A., Flechtner, Fleishman, S.B., de Haes, J.C.J.M., Kaasa, S., Klee, M., Osoba, D., Razavi, D., Rofe, P.B., Schraub, S., Sneeuw, K., Sullivan, M., & Takeda, F. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A quality of life instrument for use in international clinical trials in oncology. *Journal of the National Institute*, 85, 365-376.

Adolescent and Young Adult Oncology Group (2006). Care Imperatives for adolescents and young adults with cancer. Report of the Adolescent and Young Adult Oncology Group.

<https://www.cancer.gov/types/aya/research/ayao-august-2006.pdf>

Ang, S., Koh, S., Lee, X., & Shorey, S. (2018). Experiences of adolescents living with cancer: A descriptive qualitative study. *Journal of Child Health Care*, ss.1-13.

doi: 10.1177/1367493518763109

Avis, N.E., Crawford, S., & Manuel, J. (2005). Quality of life among younger women with breast cancer. *Journal of Clinical Oncology*, 23, 3322-3330.

Biolcati, R., Mancini, G., & Trombini, E. (2018). Proneness to boredom and risk behaviors during adolescents' free time. *Psychological reports*, 121, 303-323. Epub 2017/08/05. PMID:28776483.

Bleyer, A. (2005). The adolescent and young adult gap in cancer care and outcome. *Current Problems in Pediatric and Adolescent Health Care*, 35, 182-217.

Bleyer, A., O'Leary, M., Barr, R., & Ries, L.A.G. (eds) (2006). *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. National Cancer Institute, NIH Pub. No. 06-5767. Bethesda, MD.

Bowling, A. (Ed.) (2001). *Measuring disease: a review of disease-specific quality of life measurement scale (2nd ed.)*, Open University Press, Buckingham, 1-22.

Burgoyne, M.J., Bingen, K., Leuck, J., Dasgupta, M., Ryan, P., & Hoffmann, R.G. (2015). Cancer-related distress in young adults compared to middle-aged and senior adults. *Journal of Adolescent and Young Adult Oncology*, 4, 56-63. <https://doi.org/10.1089/jayao.2014.0005>.

Chen, I., Pasalic, D., Fischer-Valuck, B., Frangoul, H., DeWees, T., Shinohara, E. T., & Perkins, S. M. (2018). Disparity in Outcomes for Adolescent and Young Adult Patients Diagnosed With Pediatric Solid Tumors Across 4 Decades. *American Journal of Clinical Oncology*, 41, 471-475. doi: 10.1097/coc.0000000000000304

Chiang, Y.C., Yeh, C.H., Wang, K.W.K., & Yang, C.P. (2009). The experience of cancer-related fatigue in Taiwanese children. *European Journal of Cancer Care*, 18, 43-49

Croucher, C., Whelan, J.S., Moller, H., & Davies, E.A. (2009). Trends in the incidence and survival of cancer in teenagers and young adults: Regional analysis for South East England 1960 – 2002. *Clinical Oncology*, 21, 417-424.

Daniel, L. C., Barakat, L. P., Brumley, L. D., & Schwartz, L. A. (2014). Health-related hindrance of personal goals of adolescents with cancer: The role of the interaction of race/ethnicity and income. *Journal of Clinical Psychology in Medical Settings*, 21, 155-164.

Enskär, K., Carlsson, M., Golsäter, M., & Hamrin, E. (1997). Symptom distress and life situation in adolescents with cancer. *Cancer Nursing*, 20, 23-33.

Erikson, E.H. (1963). *Childhood and society* (2nd ed.). New York: Norton.

Ericsson, K. A., & Simon, H. A. (1980). Verbal reports as data. *Psychological Review*, *87*(3), 215-251.

Hinds, P. S., Gattuso, J. S., Fletcher, A., Baker, E., Coleman, B., Jackson, T., Jacobs-Levine, A., June, D., Rai, S. N., Lensing, S., & Pui, C. H. (2004). Quality of life as conveyed by pediatric patients with cancer. *Quality of Life Research*, *13*, 761-772.

Johnson, C., Aaronson, N., Blazeby, J., Bottomley, A., Fayers, P., Koller, M., Kuliš, D., Ramage, J., Sprangers, M., Velikova, G., & Young, T. (2011). Guidelines for developing questionnaire modules. Report 4th Ed. Brussels.

Johnson, C., Fitzsimmons, D., Gilbert, J., Arrarras, J.I., Hammerlid, E., Bredart, A., Ozmen, M., Dilektasli, E., Coolbrandt, A., Kenis, C., Young, T., Chow, E., Venkitaraman, R., Howse, F., George, S., O'Connor, S., Yadegarfar, G., & EORTC Quality of Life Group. (2010). Development of the European Organisation for Research and Treatment of Cancer quality of life questionnaire module for older people with cancer: The EORTC QLQ-ELD15. *European Journal of Cancer*, *46*, 2242–2252.

Keegan TH, Ries LA, Barr RD, Geiger AM, Dahlke DV, Pollock BH, & Bleyer WA. (2016). National Cancer Institute Next Steps for Adolescent and Young Adult Oncology Epidemiology Working Group. Comparison of cancer survival trends in the United States of adolescents and young adults with those in children and older adults. *Cancer*, *122*, 1009-1016. doi: 10.1002/cncr.29869.

Lang M.J., David, V., & Giese-Davis, J. (2015). The Age conundrum: A scoping review of younger age or adolescent and young adult as a risk factor for clinical distress, depression, or anxiety in cancer. *Journal of Adolescent and Young Adult Oncology*, *4*, 157-173.

Mao, J.J., Armstrong, K., Bowman, M.A., Xie, S.X., Kadakia, R., & Farrar, J.T. (2007). Symptom burden among cancer survivors: impact of age and comorbidity. *The Journal of the American Board of Family Medicine*, *20*, 434-443.

Marris, S., Morgan, S., & Stark, D. (2011). "Listening to patients": what is the value of age-

appropriate care to teenagers and young adults with cancer? *European Journal of Cancer Care*, 20, 145-51.

Mols, F., Schoormans, D., Smit, J.W.A., Netea-Maier, R.T., Links, T.P., van der Graaf, W.T.A., & Husson, O. (2018). Age-related differences in health-related quality of life among thyroid cancer survivors compared with a normative sample: Results from the PROFILES Registry, Head and Neck, 1-11.

Momani, T.G., Mandrell, B.N., Gattuso, J.S., West, N.K., Taylor, S.L., & Hinds, P.S. (2015). Children's Perspective on Health-Related Quality of Life During Active Treatment for Acute Lymphoblastic Leukemia. *Cancer Nurs.* 2015; 38, 50-59.

Moody, K., Meyer, M., Mancuso, C. A., Charlson, M., & Robbins, L. (2006). Exploring concerns of children with cancer. *Supportive Care in Cancer*, 14, 960-966.

Oerlemans, S., Nijziel, M.R., & van de Poll-Franse, L.V. (2015). Age-related differences in quality of life among patients with diffuse large B-cell lymphoma. *Cancer*, 121, 2857-2858.
doi: 10.1002/cncr.29427. Epub 2015 Apr 29.

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., & Carbone, P.P. (1982). Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. *American Journal of Clinical Oncology*, 5, 649-655.

Park, E.M., & Rosenstein, D.L. (2015). Depression in adolescents and young adults with cancer. *Dialogues in Clinical Neuroscience*, 17, 171-180.

Quinten, C., Coens, C., Ghislain, I., Zikos, E., Sprangers, M. A. G., Ringash, J., . . . Bottomley, A. (2015). The effects of age on health-related quality of life in cancer populations: A pooled analysis of randomized controlled trials using the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 involving 6024 cancer patients. *European Journal of Cancer*, 51, 2808-2819.
doi: <https://doi.org/10.1016/j.ejca.2015.08.027>

Sandeberg, M., Johansson, E., Björk, O., & Wettergren, L. (2008). Health-related quality of life relates to school attendance in children on treatment for cancer. *Journal of Pediatric Oncology Nursing*, 25, 265-274.

Sansom-Daly, U.M., & Wakefield, C. (2013). Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review. *Translational Pediatrics*, 2, 167-197.

Snöbohm, C., & Heiwe, S. (2013). Stressors, coping and coping strategies among young adults, with cancer. *World Journal of Psycho-Social Oncology*, 3, 15-28.

Sodergren SC, Husson, O, Robinson, J., Rohde, G.E., Tomaszewska, I.M., Vivat, B., Dyar, R., & Darlington, AS., EORTC Quality of Life Group. (2017). Systematic review of the health-related quality of life issues facing adolescents and young adults with cancer *Quality of Life Research*, 26, 1659-1672. doi: 10.1007/s11136-017-1520-x. Epub 2017 Mar 1 1659.

Sodergren, S.C., Husson O, Rohde G, Tomasewska I, Vivat B, Yarom N, Griffiths H, & Darlington AS. (2018). A Life Put on Pause: An Exploration of the Health-Related Quality of Life Issues Relevant to Adolescents and Young Adults with Cancer. *Journal of Adolescent and Young Adult Oncology*, 7, 453-464. DOI: 10.1089/jayao.2017.0110

Steliarova-Foucher E., O'Callaghan M., Ferlay J., Masuyer E., Rosso S., Forman, D., Bray F. & Comber, H. (2015) The European cancer observatory: a new data resource. *European Journal of Cancer*, 51, 1131–1143.

Stiller, C.A., Desandes, E., Danon, S.E., Izarzugaza, I., Ratiu, A., Vassileva-Valerianova, Z., & Steliarova-Foucher, E. (2006). Cancer incidence and survival in European adolescents (1978 – 1997). Report from the Automated Childhood Cancer Information System project. *European Journal of Cancer*, 42, 2006 – 2018.

Stinson, J., Jibb, L., Greenberg, M., Barrera, M., Luca, S., White, M., & Gupta, A. (2015). A Qualitative Study of the Impact of Cancer on Romantic Relationships, Sexual Relationships, and Fertility:

Perspectives of Canadian Adolescents and Parents During and After Treatment. *Journal of Adolescent and Young Adult Oncology*, 4, 84-90.

Thomas, D.M., Albritton, K.H., & Ferrari, A. (2010). Adolescent and young adult oncology: an emerging field. *Journal of Clinical Oncology*, 28, 4781-4782.

Treadgold C., & Kuperberg, A. (2010). Been there, done that wrote the blog: The choices and challenges of supporting adolescents and young adults with cancer. *Journal of Clinical Oncology*, 228(32), 4842-4849.

van der Horst, M., Winther, J.F., & Olsen, J.H. (2006). Cancer incidence in the age range 0 – 34 years: Historical and actual status in Denmark. *International Journal of Cancer*, 118, 2816-2826.

Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer*, 94, 2090-2106.

Wicks, L., & Mitchell, A. (2010). The adolescent cancer experience: loss of control and benefit finding. *European Journal of Cancer Care*, 19, 778-785.

Zebrack, B.J. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer*, 117, 2289-2294

Zebrack, B.J., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K.A., Li, Y., Butler, M., & Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer*, 119, 201-214.

Table 1. Socio-demographic and clinical characteristics of participants (AYAs and older adults) N=58

Variable	Total Interviewed (N=58)	14-18 years (n=14)	19-25 years (n=19)	26-50 years (n=12)	51-60 years (n=13)
Patients recruited per country					
France	4 (6.9%)	0 (0)	4 (21.1%)	0	0
Israel	2 (3.4%)	2 (14.3%)	0	0	0
Netherlands	14 (24.1%)	2 (14.3%)	5 (26.3%)	5 (41.7%)	2 (15.4%)
Norway	6 (10.3%)	3 (21.4%)	0	1 (8.3%)	2 (15.4%)
Poland	19 (32.8)	2 (14.3%)	5 (26.3%)	4 (33.3%)	8 (61.5%)
United Kingdom	13 (22.4%)	5 (35.7%)	5 (26.3%)	2 (16.7%)	1 (7.7%)
Gender					
Male	25 (43.1%)	7 (50.0%)	9 (47.4%)	5 (41.7%)	4 (30.8%)
Female	33 (56.9%)	7 (50.0%)	10 (52.6%)	7 (58.3%)	9 (69.2%)
Age (years)					
Mean (standard deviation)	31.5 (15.3)	16.7 (1.4)	21.8 (2.0)	38.4 (7.9)	54.9 (2.5)
Range	14-58	14-18	19-25	26-49	51-58
Ethnicity					
White	51 (87.9%)	13 (92.9%)	15 (78.9%)	10 (83.3%)	13 (100%)
Asian	1 (1.7%)	0	0	1 (8.3%)	0
Mixed	2 (3.4)	1 (7.1%)	0	1 (8.3%)	0
Missing	4 (6.9%)	0	4 (21.1%)	0	0
Education level					
Currently not able to complete education	3 (5.2%)	1 (7.1%)	2 (10.5%)	0	0
Currently in compulsory education	6 (10.3%)	6 (42.9%)	0	0	0
Compulsory school education completed	15 (25.9%)	4 (28.6%)	4 (21.1%)	3 (25.0%)	4 (30.8%)
Post compulsory school	21 (36.2%)	3 (21.4%)	8 (42.1%)	4 (33.3%)	6 (46.2%)

education (college)					
University	13 (22.4%)	0	5 (26.3%)	5 (41.7%)	3 (23.1%)
Employment status					
Full time	6 (10.3%)	0	3 (15.8%)	2 (16.7%)	1 (7.7%)
Part time	9 (15.5%)	0	4 (21.1%)	4 (33.3%)	1 (7.7%)
Homemaker	3 (5.2%)	0	0	1 (8.3%)	2 (15.4%)
Sick leave	13 (22.4%)	1 (7.1%)	2 (10.5%)	3 (25.0%)	7 (53.8%)
Disability	2 (3.4%)	0	0	1 (8.3%)	1 (7.7%)
None	22 (37.9%)	11 (78.6%)	9 (47.4%)	1 (8.3%)	1 (7.7%)
Other	2 (3.4%)	1 (7.1%)	1 (5.3%)	0	0
Missing	1 (1.7%)	1 (7.1%)	0	0	0
Living situation					
Alone	8 (13.8%)	0	4 (21.1%)	2 (16.7%)	2 (15.4%)
Parents	27 (46.6%)	14 (100%)	10 (52.6%)	2 (16.7%)	1 (7.7%)
Partner	18 (31.0%)	0	3 (15.8%)	6 (50.0%)	9 (69.2%)
Living with others	4 (6.9%)	0	1 (5.3%)	2 (16.7%)	1 (7.7%)
Missing	1 (1.7%)	0	1 (5.3%)	0	0
Time since diagnosis (months)					
Median	4	4	2.5	4	5
Range	0-48	0-37	0-29	1-32	1-48
Disease status					
Localised	28 (48.3%)	6 (42.9%)	10 (52.6%)	8 (66.7%)	8 (61.5%)
Metastatic	17 (29.3%)	2 (14.3%)	3 (15.8%)	4 (33.3%)	4 (30.8%)
Not applicable (Leukaemia, lymphoma)	10 (17.2%)	6 (42.9%)	4 (21.1%)	0	0
Missing	3 (5.2%)	0	2 (10.5%)	0	1 (7.7%)
Diagnosis ¹					
Leukaemia	7 (12.1%)	3 (21.4%)	4 (21.1%)	0	0
Lymphoma	7 (12.1%)	6 (42.9%)	1 (5.3%)	0	0
Gynaecological	12 (20.7%)	0	4 (21.1%)	5 (41.7%)	3 (23.1%)
Testicular	5 (8.6%)	2 (14.3%)	3 (15.8%)	0	0
Bone	5 (8.6%)	3 (21.4%)	2 (10.5%)	0	0

Sarcoma	4 (6.9%)	0	3 (15.8%)	1 (8.3%)	0
Head and neck	2 (3.4%)	0	0	1 (8.3%)	1 (7.7%)
Breast	8 (13.8%)	0	0	3 (25.0%)	5 (38.5%)
Melanoma	2 (3.4%)	1 (7.1%)	1 (5.3%)	0	0
Lung	1 (1.7%)	0	0	1 (8.3%)	0
Colorectal	4 (6.9%)	0	0	0	4 (30.8%)
Oesophagus	1 (1.7%)	0	0	1 (8.3)	0
Missing	1 (1.7%)	0	1 (5.3%)	0	0
Treatment status					
Currently on treatment	56 (96.6%)	13 (92.9%)	18 (94.7%)	12 (100%)	12 (92.3%)
Supportive / palliative care	2 (3.4%)	1 (7.1%)	0	0	1 (7.7%)
Missing	0	0	1 (5.3%)	0	0
Treatment intent					
Curative	49 (84.5%)	14 (100%)	16 (84.2%)	10 (83.3%)	9 (69.2%)
Palliative	7 (12.1%)	0	2 (10.5%)	1 (8.3%)	4 (30.8%)
Missing	2 (3.4%)	0	1 (5.3%)	1 (8.3%)	0
Treatment type²					
Chemotherapy	47 (81.0%)	11 (78.6%)	15 (78.9%)	10 (83.3%)	11 (84.6%)
Radiotherapy	10 (17.2%)	2 (14.3%)	2 (10.5%)	3 (25%)	3 (23.1%)
Hormonal	2 (3.4%)	0	0	0	2 (15.4%)
Targeted therapy	3 (5.2%)	0	2 (10.5%)	1 (8.3%)	0
Steroid	2 (3.4%)	1 (7.1%)	1 (5.3%)	0	0
Other (not specified)	3 (5.2%)	0		2 (16.7%)	1 (7.7%)
Missing	2 (3.4%)	0	1 (5.3%)	0	1 (7.7%)
Co-morbidities³					
None	41 (70.7%)	14 (100%)	13 (68.4%)	7 (58.3%)	7 (53.8%)
Renal	1 (1.7%)	0	1 (5.3%)	0	0
Cardiac	4 (6.9%)	0	1 (5.3%)	0	3 (23.1%)
Respiratory	4 (6.9%)	0	1 (5.3%)	1 (8.3%)	2 (15.4%)
Rheumatic	3 (5.2%)	0	1 (5.3%)	2 (16.7%)	0
Diabetes	1 (1.7%)	0	0	0	1 (7.7%)

Thyroid	1 (1.7%)	0	0	0	1 (7.7%)
Obesity	1 (1.7%)	0	1 (5.3%)		
Skin problems (e.g., psoriasis)	1 (1.7%)	0	0	0	1 (7.7%)
Missing	3 (5.2%)	0	2 (10.5%)	1 (8.3%)	0
ECOG Performance Status ⁴					
0 (Fully active)	16 (27.6%)	7 (50%)	4 (21.1%)	3 (25%)	2 (15.4%)
1 (Restricted in physical strenuous activity)	17 (29.3%)	2 (14.3%)	9 (47.4%)	3 (25%)	3 (23.1%)
2 (Unable to carry out work activities)	18 (31.0%)	4 (28.6%)	4 (21.1%)	2 (16.7%)	8 (61.5%)
3 (Limited self-care)	1 (1.7%)	0	0	1 (8.3%)	0
Missing	5 (8.6%)	1 (7.1%)	2 (10.5%)	2 (16.7%)	0

¹One participant had more than one diagnosis

²Patients indicated all current treatment types

³Several patients presented more than one co-morbidity

⁴One participant indicated 0.5 (between fully active and restricted) on the ECOG Performance Status

Table 2. HRQoL Issues according to age group

HRQoL Issues		14-18 years		19-25 years		26-50 years		51-60 years		Tests of significant differences according to Age	
		% Relevance	Mean (SD) Importance	% Relevance	Mean (SD) Importance	% Relevance	Mean (SD) Importance	% Relevance	Mean (SD) Importance	Relevance	Importance
Symptoms	Greater awareness of physical symptoms	79	2.2 (1.1)	74	2.8 (1.03)	92	2.2 (1.9)	77	2.4 (1.3)	$\chi^2 (3, N = 54) = 2.38, p = .498$	$F (3,54) = 1.02, p = .393$
	Pain	71	2.2 (1.5)	74	3.2 (0.8)	75	2.5 (1.2)	85	3.2 (1.2)	$\chi^2 (3, N = 54) = 2.75, p = .431$	$F (3,54) = 2.67, p = .056$
	Nausea	71	2.2 (1.3)	79	3.3 (0.8)	92	3.2 (1.0)	92	3.5 (0.5)	$\chi^2 (3, N = 54) = 6.44, p = .092$	$F (3,52) = 5.22, p = .003$
	Vomiting	64	1.8 (1.3)	74	2.9 (0.8)	63	2.5 (1.4)	85	3.1 (0.6)	$\chi^2 (3, N = 54) = 6.09, p = .107$	$F (3,53) = 4.58, p = .006$
	Tiredness	100	3.0 (1.0)	79	3.3 (0.7)	100	3.4 (1.0)	100	3.5 (0.5)	NA	$F (3,54) = 0.93, p = .431,$
	Lack of energy	86	2.9 (1.1)	79	3.3 (0.6)	100	3.5 (0.7)	100	3.6 (0.5)	$\chi^2 (3, N = 54) = 5.93, p = .115$	$F (3,53) = 2.13, p = .107,$
	Loss of	86	2.6 (1.0)	74	2.9 (1.0)	83	2.7 (1.2)	100	3.3 (0.5)	$\chi^2 (3, N = 54)$	$F (3,54) = 1.33,$

	strength									= 2.65, p=.449	p=.274
	Shortness of breath	57	1.5 (1.1)	53	2.2 (0.8)	58	2.3 (1.3)	85	2.2 (0.9)	χ^2 (3, N = 54) = 2.83, p=.418	F (3,54) = 1.76, p=.166
	Trouble sleeping	64	1.7 (1.4)	68	2.6 (0.7)	100	2.8 (1.3)	92	2.7 (0.9)	χ^2 (3, N = 54) = 7.48, p=.058	F (3,54) = 2.80, p=.049
	Difficulty gaining weight	29	1.2 (1.2)	47	2.2 (1.3)	58	1.8 (1.4)	46	1.9 (1.3)	χ^2 (3, N = 53) = 3.49, p=.322	F (3,53) = 1.49, p=.227
	Mobility problems	57	1.5 (1.3)	63	2.6 (1.2)	58	1.7 (1.4)	77	2.7 (1.1)	χ^2 (3, N = 54) = 2.76, p=.430	F (3,53) = 3.55, p=.020
	Difficulty concentrating	71	1.9 (0.9)	74	2.5 (0.8)	67	2.4 (1.2)	92	3.0 (0.9)	χ^2 (3, N = 54) = 5.09, p=.165	F (3,54) = 3.15, p=.032
Activity Restrictions	Impact on hobbies/ leisure time activities	93	3.2 (1.1)	74	3.2 (1.1)	83	2.8 (1.3)	92	2.9 (0.8)	χ^2 (3, N = 54) = 1.02, p=.797	F (3,53) = 0.50, p=.684
	Not able to bathe, take showers or dress yourself	64	1.8 (1.3)	58	2.4 (1.0)	42	1.6 (1.2)	77	2.8 (1.2)	χ^2 (3, N = 54) = 4.13, p=.247	F (3,53) = 2.98, p=.040
	Not able to go out	71	2.5 (1.6)	74	3.1 (0.7)	58	2.2 (1.5)	69	2.3 (1.2)	χ^2 (3, N = 54) = 4.66, p=.233	F (3,52) = 1.47, p=.233

									$p=.199$		
	Education has been interrupted	86	3.0 (1.4)	100	2.6 (1.6)	25	1.5 (1.3)	15	1.2 (1.1)	$\chi^2 (3, N = 54) = 16.92, p=.001$	$F (3,53) = 5.02, p=.004$
	Changed career plans	57	1.8 (1.6)	58	2.5 (1.2)	58	2.3 (1.6)	62	2.5 (1.5)	$\chi^2 (3, N = 54) = 1.02, p=.797$	$F (3,53) = 0.71, p=.548$
	Not able to work	71	2.2 (1.4)	68	2.9 (1.1)	83	2.6 (1.4)	92	3.9 (0.3)	$\chi^2 (3, N = 54) = 2.30, p=.512$	$F (3,52) = 5.59, p=.002$
	Fallen behind where you want to be in life	64	1.9 (1.4)	68	2.9 (1.6)	67	2.0 (1.4)	62	2.5 (1.3)	$\chi^2 (3, N = 54) = 2.72, p=.436$	$F (3,53) = 2.25, p=.093$
Social	Loss of friends	57	1.6 (1.5)	37	2.0 (1.4)	33	1.7 (1.4)	15	1.7 (1.3)	$\chi^2 (3, N = 54) = 5.52, p=.137$	$F (3,53) = 0.23, p=.878$
	Isolation from friends	64	2.1 (1.4)	68	2.5 (1.2)	58	2.7 (1.5)	69	2.6 (1.2)	$\chi^2 (3, N = 54) = 3.00, p=.391$	$F (3,53) = 0.49, p=.689$
	Less time to go out with friends	86	2.6 (1.2)	58	2.5 (1.0)	75	2.5 (1.3)	54	1.8 (0.8)	$\chi^2 (3, N = 53) = 3.86, p=.277$	$F (3,52) = 1.62, p=.195$
	Impact on romantic/sexual relationships	50	1.6 (1.5)	79	2.8 (0.9)	67	2.6 (1.4)	54	2.8 (1.4)	$\chi^2 (3, N = 54) = 10.43, p=.015$	$F (3,51) = 2.83, p=.048$

Strengthening existing relationships with friends and family	93	2.8 (0.8)	63	2.7 (1.1)	75	2.3 (1.3)	46	2.3 (1.4)	$\chi^2 (3, N = 54) = 8.13$ $p = .043$	$F (3,51) = 0.75,$ $p = .527$
Opportunity to make new friends	86	2.4 (1.1)	37	1.7 (0.9)	17	1.2 (1.1)	46	1.6 (0.7)	$\chi^2 (3, N = 54) = 12.62,$ $p = .006$	$F (3,52) = 3.31,$ $p = .027$
Greater dependence on others	71	1.9 (1.3)	74	3.0 (0.7)	50	2.3 (1.5)	85	3.2 (0.8)	$\chi^2 (3, N = 54) = 7.59,$ $p = .055$	$F (3,52) = 4.23,$ $p = .009$
Greater burden on others	71	2.4 (1.1)	74	3.0 (0.9)	75	2.5 (1.1)	85	3.5 (0.9)	$\chi^2 (3, N = 54) = 2.75,$ $p = .431$	$F (3,52) = 3.37,$ $p = .025$
Change in living situation	21	1.1 (1.3)	63	2.7 (1.4)	42	1.8 (1.4)	8	0.9 (0.3)	$\chi^2 (3, N = 53) = 17.09,$ $p = .001$	$F (3,52) = 6.93,$ $p = .001$
Impact on family and friends	93	2.6 (1.1)	74	3.2 (0.8)	83	3.2 (1.1)	85	3.8 (0.4)	$\chi^2 (3, N = 53) = 9.72,$ $p = .808$	$F (3,51) = 3.58,$ $p = .020$
Impact on family life	93	2.7 (1.1)	68	3.1 (0.7)	75	3.0 (1.1)	92	3.9 (0.3)	$\chi^2 (3, N = 53) = 4.07,$ $p = .254$	$F (3,52) = 4.21,$ $p = .010$
Unable to care for others	50	1.3 (1.1)	42	2.2 (1.1)	50	1.9 (1.3)	77	3.5 (0.7)	$\chi^2 (3, N = 53) = 3.99,$ $p = .263$	$F (3,52) = 9.15,$ $p = < .001$

	Less tolerant of others	57	1.6 (1.3)	53	2.1 (1.0)	33	1.5 (1.2)	54	2.1 (1.0)	$\chi^2 (3, N = 53) = 3.18, p = .365$	$F (3,52) = 0.91, p = .441$
	More sympathetic to others	79	2.1 (1.2)	42	2.2 (1.1)	17	1.3 (1.0)	62	2.4 (1.1)	$\chi^2 (3, N = 53) = 10.93, p = .012$	$F (3,52) = 2.06, p = .117$
Emotional	Boredom	86	2.2 (0.9)	58	2.3 (0.9)	50	1.6 (1.2)	31	1.4 (0.7)	$\chi^2 (3, N = 53) = 9.10, p = .028$	$F (3,52) = 3.52, p = .021$
	Depression	86	2.3 (1.2)	79	2.7 (0.7)	54	2.1 (1.2)	92	3.2 (0.8)	$\chi^2 (3, N = 53) = 16.80, p = .010$	$F (3,52) = 2.80, p = .049$
	Anxiety	64	1.7 (1.1)	68	2.6 (0.9)	83	2.6 (1.2)	92	3.1 (0.7)	$\chi^2 (3, N = 53) = 6.08, p = .108$	$F (3,52) = 4.26, p = .009$
	Preoccupation with illness	71	1.7 (1.1)	74	2.9 (1.2)	83	2.3 (1.4)	92	2.9 (0.8)	$\chi^2 (3, N = 53) = 5.39, p = .145$	$F (3,52) = 3.34, p = .026$
	Embarrassment	50	1.5 (1.3)	58	2.2 (0.9)	42	1.5 (1.2)	62	2.6 (1.2)	$\chi^2 (3, N = 53) = 3.51, p = .320$	$F (3,51) = 2.91, p = .043$
	Fear of recurrence	79	2.4 (1.2)	79	3.3 (0.8)	92	2.8 (1.3)	85	3.4 (0.7)	$\chi^2 (3, N = 52) = 5.89, p = .117$	$F (3,52) = 2.40, p = .078$

	Worry about what the future holds	86	2.3 (1.1)	68	2.8 (0.9)	83	2.8 (1.2)	92	3.3 (0.9)	$\chi^2 (3, N = 53) = 2.06, p=.561$	$F (3,52) = 2.02, p=.123$
	Worry about dying	64	2.1 (1.6)	63	2.7 (1.2)	75	2.3 (1.2)	92	3.3 (0.8)	$\chi^2 (3, N = 52) = 5.78, p=.123$	$F (3,51) = 1.94, p=.135$
	Shock of diagnosis	86	3.0 (1.5)	68	3.4 (0.5)	83	3.2 (0.9)	92	3.8 (0.4)	$\chi^2 (3, N = 52) = 2.41, p=.491$	$F (3,50) = 1.82, p=.155$
	Anger	64	1.9 (1.5)	74	2.7 (1.1)	58	2.2 (1.2)	69	2.4 (1.0)	$\chi^2 (3, N = 53) = 5.08, p=.166$	$F (3,52) = 1.32, p=.277$
	Question why is this happening to me?	79	2.6 (1.3)	68	2.9 (1.1)	58	1.8 (1.0)	85	3.2 (0.8)	$\chi^2 (3, N = 52) = 6.17, p=.104$	$F (3,51) = 3.32, p=.027$
	Feel let down by your body	64	2.0 (1.3)	37	2.1 (1.3)	42	1.8 (1.3)	62	2.5 (1.3)	$\chi^2 (3, N = 51) = 1.96, p=.580$	$F (3,50) = 0.47, p=.706$
Body image	Altered appearance	79	2.9 (1.4)	68	2.7 (1.2)	75	2.4 (1.3)	69	3.1 (0.8)	$\chi^2 (3, N = 53) = 7.69, p=.857$	$F (3,52) = 0.64, p=.590$
	More self-conscious and concern about one's appearance	79	2.6 (1.4)	68	2.2 (0.9)	67	2.1 (1.2)	46	2.0 (1.1)	$\chi^2 (3, N = 53) = 4.92, p=.178$	$F (3,52) = 0.62, p=.606$

	Less concerned about one's appearance	50	1.4 (1.2)	53	1.8 (1.1)	25	1.3 (0.9)	62	1.64 (0.8)	$\chi^2 (3, N = 52) = 6.64, p=.084$	$F (3,52) = 0.87, p=.464$
Self-appraisals	Greater self-awareness	86	2.3 (1.4)	47	2.2 (1.7)	75	2.5 (1.0)	54	2.0 (0.8)	$\chi^2 (3, N = 51) = 2.17, p=.537$	$F (3,51) = 0.42, p=.739$
	Stronger person	93	2.6 (0.9)	53	2.4 (1.0)	75	2.2 (1.1)	62	2.4 (0.8)	$\chi^2 (3, N = 51) = 2.42, p=.489$	$F (3,51) = 0.53, p=.661$
	Better person	71	2.0 (1.1)	42	2.1 (1.0)	33	1.4 (1.1)	15	1.4 (0.7)	$\chi^2 (3, N = 51) = 8.45, p=.037$	$F (3,50) = 1.84, p=.151$
	Braver	64	2.2 (1.4)	53	2.2 (0.9)	42	1.8 (1.1)	54	2.0 (1.1)	$\chi^2 (3, N = 51) = 2.62, p=.455$	$F (3,50) = 0.48, p=.700$
	Increased maturity	86	3.2 (1.0)	68	2.8 (0.7)	25	1.4 (1.2)	0	1.0 (0.0)	$\chi^2 (3, N = 51) = 31.24, p < .001$	$F (3,49) = 17.13, p < .001$
	Greater confidence	50	1.7 (1.4)	37	1.7 (1.0)	42	1.5 (1.3)	23	1.3 (0.5)	$\chi^2 (3, N = 50) = 1.99, p=.574$	$F (3,49) = 0.36, p=.784$

	Lowered self-confidence / self-esteem	71	1.9 (1.1)	58	2.1 (1.2)	58	1.9 (1.2)	69	2.5 (1.0)	$\chi^2 (3, N = 51) = 1.96, p=.582$	$F (3,51) = 0.65, p=.587$
Outlook on life	Changed outlook on life	86	2.5 (1.2)	74	3.2 (0.6)	75	2.4 (1.0)	77	2.9 (1.0)	$\chi^2 (3, N = 51) = 4.05, p=.256$	$F (3,51) = 2.42, p=.077$
	More positive outlook on life	71	2.5 (1.3)	47	2.1 (1.1)	46	1.8 (1.3)	31	1.8 (1.2)	$\chi^2 (3, N = 51) = 7.31, p=.293$	$F (3,50) = 0.79, p=.506$
	Different priorities in life	100	3.1 (0.9)	79	3.1 (0.9)	88	2.3 (1.4)	85	3.3 (0.7)	$\chi^2 (3, N = 52) = 6.93, p=.327$	$F (3,50) = 2.36, p=.082$
	Greater desire to live life to the fullest	93	3.0 (1.0)	68	2.9 (1.0)	83	2.5 (1.4)	62	2.4 (1.0)	$\chi^2 (3, N = 51) = 2.82, p=.421$	$F (3,50) = 0.87, p=.463$
	Greater life experience	79	2.8 (1.2)	63	2.1 (0.8)	67	2.3 (1.2)	62	2.3 (1.0)	$\chi^2 (3, N = 51) = 1.43, p=.699$	$F (3,50) = 1.18, p=.325$
	Greater awareness of one's mortality	71	2.5 (1.3)	47	2.1 (1.3)	75	2.5 (1.2)	62	2.7 (1.3)	$\chi^2 (3, N = 51) = 1.43, p=.699$	$F (3,50) = 0.59, p=.623$
	Inability to plan for the future	57	2.2 (1.3)	63	2.3 (1.1)	50	2.1 (1.4)	85	3.3 (0.8)	$\chi^2 (3, N = 51) = 10.11, p=.066$	$F (3,50) = 2.56, p=.066$

										$p = .018$	
	Greater motivation to succeed academically	86	2.8 (1.2)	42	2.0 (1.1)	25	1.3 (1.1)	8	1.2 (0.6)	$\chi^2 (3, N = 51) = 17.68, p < .001$	$F (3, 49) = 6.18, p < .001$
	Greater motivation to achieve personal goals	79	2.6 (1.4)	53	2.4 (1.2)	42	1.8 (1.4)	38	1.7 (0.8)	$\chi^2 (3, N = 52) = 2.43, p = .142$	$F (3, 51) = 1.87, p = .146$
Lifestyle	Motivation to lead a healthier lifestyle	79	2.3 (1.2)	68	2.6 (1.1)	75	2.4 (1.0)	85	2.5 (1.1)	$\chi^2 (3, N = 52) = 2.43, p = .049$	$F (3, 52) = 0.30, p = .824$
	Take greater care to avoid infections	100	3.2 (0.8)	63	2.7 (0.9)	67	1.8 (1.2)	69	2.2 (1.1)	$\chi^2 (3, N = 53) = 5.20, p = .157$	$F (3, 52) = 4.89, p = .005$
	Difficulty adjusting to being ill and having to take medication	64	2.0 (1.5)	68	2.6 (1.2)	75	2.3 (1.2)	69	2.5 (0.9)	$\chi^2 (3, N = 51) = 2.54, p = .468$	$F (3, 52) = 0.78, p = .513$
	Restricted food choice	79	2.6 (1.2)	42	2.1 (1.2)	58	1.8 (1.4)	62	2.5 (1.4)	$\chi^2 (3, N = 53) = 2.24, p = .524$	$F (3, 52) = 0.97, p = .415$
	Restricted choice of drinks	64	2.2 (1.3)	42	2.2 (1.3)	58	1.7 (1.2)	62	2.4 (1.2)	$\chi^2 (3, N = 53) = 0.62, p = .892$	$F (3, 52) = 0.69, p = .563$

Treatment-related	Dissatisfaction with care	43	1.3 (1.2)	63	2.3 (1.2)	58	1.8 (1.3)	77	2.5 (1.1)	$\chi^2 (3, N = 53) = 6.58, p=.087$	$F (3,51) = 2.76, p=.052$
	Lack of age appropriate information	50	1.6 (1.4)	42	1.9 (1.3)	33	1.3 (0.8)	8	1.2 (0.4)	$\chi^2 (3, N = 52) = 6.81, p=.078$	$F (3,52) = 1.50, p=.224$
	Treatment burden	79	2.5 (0.9)	68	3.0 (1.2)	67	2.9 (1.0)	85	3.3 (0.9)	$\chi^2 (3, N = 50) = 0.65, p=.886$	$F (3,51) = 1.37, p=.263$
Life beyond treatment	Difficulty readjusting to life after treatment is over	71	2.3 (1.3)	53	2.4 (1.4)	50	2.1 (1.3)	69	2.6 (1.1)	$\chi^2 (3, N = 49) = 2.31, p=.511$	$F (3,51) = 0.28, p=.841$
	Concern over long-term effects of disease or treatment	79	2.3 (1.1)	74	3.2 (0.9)	75	2.6 (1.4)	92	3.7 (0.5)	$\chi^2 (3, N = 52) = 6.86, p=.076$	$F (3,50) = 4.86, p=.005$
	Concerns over fertility	71	2.1 (1.4)	68	3.3 (0.9)	50	1.9 (1.6)	8	1.1 (0.3)	$\chi^2 (3, N = 52) = 20.44, p < .001$	$F (3,49) = 8.62, p < .001$
	Desire for life to return to "normal"	93	3.6 (0.9)	63	3.2 (1.4)	100	3.3 (1.1)	92	3.6 (0.7)	$\chi^2 (3, N = 52) = 3.39, p=.336$	$F (3,50) = 0.61, p=.613$
	Financial difficulties	36	1.2 (1.1)	58	2.7 (1.2)	75	2.3 (1.4)	77	3.0 (1.4)	$\chi^2 (3, N = 52) = 8.88, p=.031$	$F (3,49) = 5.08, p=.004$

