

Health and Disability

“It’s been a life-changing experience!” A qualitative study of young adult cancer survivors’ experiences of the coexistence of negative and positive outcomes after cancer treatment

MAY A. HAUKEN,  MARTHE GRUE and ATLE DYREGROV 

Center for Crisis Psychology, Faculty of Psychology, University of Bergen, Norway

Hauken, M. A., Grue, M. & Dyregrov, A. (2019). “It’s been a life-changing experience!” A qualitative study of young adult cancer survivors’ experiences of the coexistence of negative and positive outcomes after cancer treatment. *Scandinavian Journal of Psychology*, 60, 577–584.

The aim of this study was to illuminate the coexistence of negative and positive experiences of young adult cancer survivors after cancer treatment. Using an interpretive descriptive design, 20 young adult cancer survivors were interviewed. The participants stated that the cancer was a life-changing experience followed by both negative and positive outcomes. The range of negative outcomes was identified in the main theme “the cancer still hampers me,” subdivided into three subthemes “impaired function and changed body,” “intrusion of thoughts and feelings” and “negative impact on relationships.” Simultaneously, the informants experienced positive outcomes identified in the main theme “I have acknowledged what’s important in life,” where “a changed perspective,” “personal growth” and “the significance of close relationships” were important facets. The findings indicate that young adult cancer survivors need close and sustained follow up with screening and tailored interventions to minimize negative physical, emotional and social outcomes. In addition, actions that promote positive outcomes such as increasing social support, prioritizing close relationships and facilitating positive changes in values and life goals should be fostered during the entire cancer trajectory.

Key words: Positive and negative outcomes, young adult cancer survivors, coexistence of positive and negative outcomes, personal growth, distress.

May A. Hauken, Center for Crisis Psychology, University of Bergen, Møllendalsbakken 9, 5009 Bergen, Norway. Tel: +47 415 49 612; e-mail: may.hauken@uib.no

INTRODUCTION

Stressful life events, such as receiving a cancer diagnosis with its subsequent treatments, can lead to both negative and positive outcomes (Ramos & Leal, 2013; Regel & Joseph, 2017). However, the coexistence of these issues has received little attention, especially in young adult cancer survivors (YACS), defined to be between 18 and 35 years of age (Miedema, Hamilton & Easley, 2007).

Previous research on YACS has mainly focused on negative outcomes, showing that they are at an increased risk of physical and psychosocial late-effects, where fatigue, fear of recurrence, distress, fertility issues and financial challenges seem to be especially predominant (Fisher, Fortmann, Pugh, Hough & Gregory, 2018; Graugaard, Sperling, Hølge-Hazelton, Boisen & Petersen, 2018; Hølge-Hazelton, Timm, Graugaard, Boisen & Sperling, 2016; Nass, Beaupin, Demark-Wahnefried *et al.*, 2015; Sansom-Daly *et al.*, 2018; Stone, Ganz, Pavlish & Robbins, 2017). In contrast, few studies have focused on positive outcomes in YACS. Vetsch, Wakefield, McGill *et al.* (2018) found a positive shift in YACS’ life goals and priorities post treatment and two studies showed that positive outcomes seemed to depend on social support and close relationships, completed education, using appropriate coping strategies and regular physical activity (Love & Sabiston, 2011; Zebrack & Butler, 2012).

Despite an increased focus on the coexistence of both negative and positive outcomes in adult cancer survivors (Shand, Cowlishaw, Brooker, Burney & Ricciardelli, 2015), this has hardly been studied in YACS. Bellizzi, Smith, Schmidt *et al.*

(2012) identified that negative outcomes in YACS such as financial difficulties, negative body image, poor social relationships and infertility coexisted with positive outcomes such as developing close relationships, having clear plans and goals. Park, Chmielewski and Blank (2010) found that personal growth moderated intrusive thoughts and protected against PTS in YACS, while Cho and Park (2017) identified that the fear of recurrence’s negative impact on quality of life (QOL) was moderated by perceived growth. In contrast, other studies have found no, or only a modest relationship between negative and positive outcomes (Husson, Zebrack, Block *et al.*, 2017; McDonnell, Pope, Schuler & Ford, 2018; Zebrack, Kwak, Salsman *et al.*, 2015).

The outlined research indicates an evident research gap related to the coexistence of negative and positive outcomes in YACS post treatment. In particular, there seems to be a need to explore the individuals’ own expressed experiences of these issues. This knowledge will help us understand YACS’ complex situations in terms of survivorship and potentially inform interventions to ameliorate risk factors and promote positive outcomes.

AIM AND RESEARCH QUESTION

The aim of this study was to increase the knowledge of YACS’ experience of the coexistence of negative and positive outcomes after cancer treatment, addressing the research question: How do young cancer survivors perceive negative and positive outcomes after finishing cancer treatment?

METHODS

This study used a qualitative research method with an interpretive descriptive design (IDD) (Hunt, 2009). This design builds on a constructivist approach, whereby new understanding is created in an interaction (co-constructed) between the researcher and the informants. Interpretive descriptive design is particularly suited to addressing complex issues that unfold over time (Creswell, 2007; Hunt, 2009).

Eligibility criteria and recruitment

Participants were recruited by using purposive sampling from a larger study on cancer rehabilitation (Hauken, Larsen & Holsen, 2017). The eligibility criteria were: (1) being between 18–35 years of age; (2) being treated for any cancer; and (3) having finished cancer treatment within the last 5 years. Of the 20 eligible and invited participants, all agreed to participate (Table 1).

Data collection

Data were collected by interviews conducted by the first author in a quiet office before the participants started their rehabilitation programme. The interviews were based on a semi-structured interview guide with open-ended questions. The main question was: “Can you please describe your perceived negative and positive outcomes after finishing cancer treatment?” Additional questions were asked to encourage elaboration on the YACS’

Table 1. Demographic and medical variables of the sample ($N = 20$)

	n (%)	M/SD (Range)
Gender		
Age (years)		31.1/3.9 (24–35)
Male	5 (25%)	
Female	15 (75%)	
Highest fulfilled education		
Senior high school	6 (30%)	
University/university college	14 (70%)	
Work status		
Permanent employment	9 (45%)	
Short-time employment	5 (25%)	
Student	6 (30%)	
Civil status		
Married/cohabiting	11 (55%)	
Single/divorced	9 (45%)	
Medical characteristics		
Cancer diagnosis		
Gynecological	5 (25%)	
Lymphoma	5 (25%)	
Breast	4 (20%)	
Colon	2 (10%)	
Testes	2 (10%)	
Head & neck	1 (5%)	
Sarcoma	1 (5%)	
Types of cancer treatment		
Single treatment	8 (40%)	
Multimodal treatment	12 (60%)	
Months since		
Diagnosis		24.6/16.0 (4–71)
Treatment		16/15.8 (1–66)
Months of treatment		7.8/6.8 (1–30)

Table 2. The Semi-structured interview guide

Main question	Period	Follow up questions if necessary
Can you please describe how you experience your present situation after finishing your cancer treatment?	After cancer treatment	<p>Can you please describe if you have experienced any negative outcomes from your cancer experience?</p> <ul style="list-style-type: none"> Negative physical outcomes – which? Negative emotional/cognitive outcomes – which? Negative social outcomes (private) – which? Negative work/study outcomes – which? <p>Can you please describe if you have experienced any positive outcomes from your cancer experience?</p> <ul style="list-style-type: none"> Aspects of learning? Aspects of maturing? Mentally/emotionally? Social aspects

experience. The interview guide is outlined in Table 2. The interviews usually lasted 45–70 minutes and were audiotaped and transcribed verbatim. The identity of all participants was masked.

Ethics

The Western Norway Regional Committee of Research approved the study (registration number 2010/1936a). The participants received verbal and written information and all gave written consent.

Analysis

Systematic Text Condensation (STC; Malterud, 2012) was used to analyze data and NVivo 9 software was used to code and sort them. Following the STC’s four steps, we first read the interviews to obtain a general impression of the data. The interviews were then re-read, and codes of meaning were extracted. The extracted codes were condensed into groups and subgroups. The two first authors analyzed and coded the transcribed data separately to enhance validity. They then engaged in an analytical circle, discussing the identified codes, the transcribed interviews and the researchers’ pre-understanding and context. This process included several facets of analyzes and continued until consensus was reached (Creswell, 2007). The analysis concluded with an overarching or bridging theme. It also included one main theme for negative outcomes and one for positive outcomes with each including several subthemes. In the fourth step, the findings were compared against the interviews to ensure that we had captured the informants’ expressed and intended meanings and illustrating quotes were extracted. The analysis process is outlined in Table 3.

FINDINGS

The analysis showed that informants simultaneously experienced both positive and negative outcomes in the aftermath of their

Table 3. Overview of the STC analyzing process in the study

STEP 1: Getting an overall impression	STEP 2: Identifying meaning units			STEP 3: Abstracting the contents of individual meaning units	STEP 4: Summarizing the findings																							
<i>Process:</i> a) The authors read the transcribed interviews separately b) Discussed the total impression to reach consensus	<i>Process:</i> a) The authors coded the data separately b) Discussed the codes to reach consensus within the codes			<i>Process:</i> a) The authors analysed the contents separately b) Several discussions to reach consensus	<i>Process:</i> b) The authors discussed the findings against the transcribed interviews c) Each author found direct statements to elucidate units of meaning and discussed to reach consensus																							
Identified total impression:	Identified meaning units:			Abstracted contents/themes:	Summarizing:																							
Negative outcomes: A range of physical late effects Lack of understanding and network withdrawal Psychological late-effects, e.g., depression, anxiety – related to period of treatment, but also future, e.g., cancer recurrence, economy, family Positive outcomes: More mature Changed perspective Focusing on close relationships Appreciate everyday life	<table border="1"> <thead> <tr> <th><i>Code^a</i></th> <th><i>Source^b</i></th> <th><i>References^c</i></th> </tr> </thead> <tbody> <tr> <td>Physical impairments</td> <td>20</td> <td>70</td> </tr> <tr> <td>Psychological impairments</td> <td>20</td> <td>160</td> </tr> <tr> <td>Worries about future</td> <td>20</td> <td>54</td> </tr> <tr> <td>Social impairments</td> <td>13</td> <td>46</td> </tr> <tr> <td>Changed perspective</td> <td>20</td> <td>57</td> </tr> <tr> <td>Importance of social relationships</td> <td>14</td> <td>14</td> </tr> <tr> <td>Personal growth</td> <td>18</td> <td>36</td> </tr> </tbody> </table>	<i>Code^a</i>	<i>Source^b</i>	<i>References^c</i>	Physical impairments	20	70	Psychological impairments	20	160	Worries about future	20	54	Social impairments	13	46	Changed perspective	20	57	Importance of social relationships	14	14	Personal growth	18	36		Theme 1: "The cancer still hampers me" elaborated by the subthemes: - 1a: "Impaired functions and changed body" - 1b: "Intrusion of thoughts and feelings" - 1c: "Negative impact on relationships" Theme 2: "I have acknowledged what's important in life" elaborated by the subthemes: - 2a: "A changed perspective" - 2b: "Personal growth". - 2c: "The significance of close relationships"	Summarized findings and presenting direct statements within the abstracted contents The findings were discussed and unanimously validated by four YACS who had not participated in the study.
<i>Code^a</i>	<i>Source^b</i>	<i>References^c</i>																										
Physical impairments	20	70																										
Psychological impairments	20	160																										
Worries about future	20	54																										
Social impairments	13	46																										
Changed perspective	20	57																										
Importance of social relationships	14	14																										
Personal growth	18	36																										

^aCode: identified meaning units.

^bSource: number of informants talking about the code (N = 20).

^cReferences: number of quotes related to the code.

cancer treatment. Overall, they described that the cancer experience had been a life-changing experience. They outlined a range of negative physical, psychological and social outcomes but also positive ones. The experienced negative outcomes were captured in the main theme: "The cancer still hampers me," while the positive ones were identified in main theme: "I know what's important in life." Both the negative and positive outcomes were elaborated by three subthemes, showing the complexity of YACS'

survivorship experience. The main findings are illustrated in Fig. 1 and described as follows.

Theme 1: "The cancer still hampers me"

The analysis showed that all participants experienced a range of negative physical, psychological and social outcomes. Consequently, all participants expressed that the cancer still

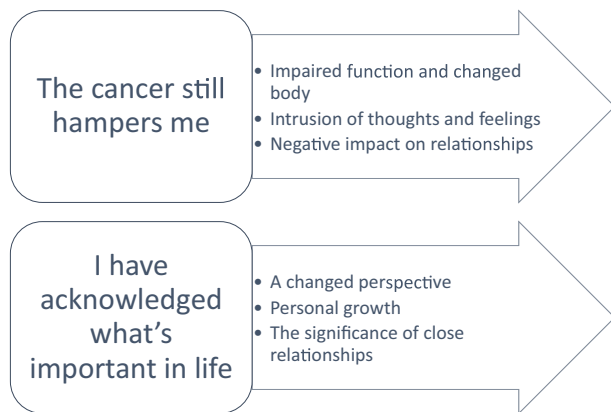


Fig. 1. The study's main findings.

hampered them in negative ways affecting most areas of their everyday life. This is elaborated in the three subthemes: (1a) "Impaired function and changed body"; (1b) "Intrusion of thoughts and feelings"; and (1c) "Negative impact on relationships."

Subtheme 1a: "Impaired function and changed body". All participants described impaired physical function and that their body had changed significantly due to the cancer treatment. These changes especially included losing a breast, scars, impaired mobility and a range of physical late-effects, concentration and memory problems, pain, hormone and infertility problems, gastrointestinal problems and other physical conditions like neuropathies, fistulas or lymphedema. Still, all participants stated that fatigue was the most significant impairment: "It's both physical and psychological. Yet, I have not figured out how my body works (...) why I am so fatigued (...) It takes too much from me" (Eva, lymphoma survivor).

Thus, these late-effects, especially the fatigue, affected the participants' ability to manage the same things as they had before the cancer appeared concerning physical activities, work and social situations. Most informants were not prepared for these impairments, and they felt highly unfamiliar with their body post treatment: "I don't recognize my body anymore... I don't know what it tolerates... I just [want to] be as I was before. Normal" (Pia, breast cancer survivor).

Subtheme 1b: "Intrusion of thoughts and feelings". The second subtheme that gave important clues as to why the cancer still hampered them, were related to psychological impairments and distress. On the one hand, such psychological distress was related to cancer treatment, and on the other hand to worries about the future.

The participants described a range of negative thoughts and feelings after cancer treatment, such as feelings of being alone, sadness, and emptiness, anxiousness that bad things would happen to themselves or their loved ones, as well as triggered memories. Furthermore, they described memories of painful treatment procedures and side effects, often portrayed as traumatic. A common way they coped with these issues was avoidance: "I've put a lid on a lot of it. I am not sure if it is safe to open it again" (Iren, lymphoma survivor).

Most participants also revealed specific future worries. First, the fear of death was still present and closely linked to a significant fear of relapse, whereby they acknowledged a new fragility of life where they could never feel safe: "The worst thing is the anxiety for relapse (...) I don't trust the check-ups because they are done in a rush (...) I cannot reconcile with me being healthy now" (Morten, head and neck cancer survivor).

Furthermore, the participants expressed future concerns related to work or study and, consequently, their future financial situation. These concerns were especially predominant for those informants that were students or only in temporary positions, worrying whether they would be able to fulfill their education, get a permanent position and be economically independent.

Another predominant future concern was related to the establishment of close relationships, and worries about infertility: "That [being able to get pregnant] bothers me most now ... That is nearly the worst. Of course, it was important for me to be cured, but" (Mary, gynaecological cancer survivor).

Subtheme 1c: "Negative impact on relationships". Yet another facet of how the cancer still hampered the participants' life was that the majority experienced a negative impact on relationships. In particular, they reported a widespread lack of understanding of their current situation from their social network who expected them to be cured and healthy. Several participants stated that both friends and colleagues either became more distant or disappeared completely during the treatment stage. Some participants also felt that the relationships with their partners and parents were affected: "I am not done with the cancer. He is done with it. And I feel that it is ... I feel that is a burden in the relationship" (Ann, breast cancer survivor). However, most participants were afraid to put more strain on their family and friends and found it difficult to put their current distress into words. Consequently, they reported that they rarely discussed their current situation with others.

Theme 2: "I have acknowledged what's important in life"

Even though all informants felt that the cancer still hampered them, all participants also expressed positive outcomes, identified as "I have acknowledged what's important in life." The facets of this theme were elaborated in the three subthemes: (2a) "A changed perspective"; (2b) "Personal growth"; and (2c) "The significance of close relationships."

Subtheme 2a: "A changed perspective". Being confronted with their own mortality through their cancer treatment; all participants expressed a changed perspective as a significant positive outcome post treatment: "It is the perspective. To me, to appreciate the smaller things and ... I might be a bit more satisfied than I was before. I appreciate things that my friends maybe do not appreciate" (Mathilda, gynaecological cancer survivor). They appreciated "small things" such as everyday routines, nature or bodily functions more than before. This changed perspective also made most participants less likely to become irritated by minor matters and they took nothing for granted: "You get another perspective of life. What's important and what's less important. (...) not complaining as much about trifles" (Christian, colon cancer survivor).

Based on their cancer experience, the participants were eager to use their time wisely and build good memories or follow certain dreams, for example to travel more, plan a wedding, initiate a new direction in education. etc.:

I got myself a tattoo of faith, hope and love and bought myself a brand-new motorbike. You feel that you only live once. It's nothing to wait for. In that way, it's a positive experience (Peter, testis cancer survivor).

Subtheme 2b: "Personal growth". Another important facet of the positive outcomes was that most participants experienced personal growth in different life arenas following their cancer experience. This personal growth was especially related to being more aware of their strengths and weaknesses. They stated that they had become better at setting limits and knew that they were able to cope with a very challenging life situation:

I have CHANGED. I've seen sides of myself that I didn't think I had. Both positive and negative. (...) I had never thought that I would manage. (...) but I did (...) A bit impressed by myself (...) by how strong one can be, and that one can handle a great deal. In fact, you feel invincible at times (Ellen, colon cancer survivor).

Several participants expressed that they now were more respectful and empathetic towards the feelings of other people and more willing to help. Furthermore, participants also felt become more mature. However, this maturity also meant that they could feel more separate from and reflective than their peers:

We have matured in different ways. (...) I don't feel superior for that reason (...) but I guess that I have had a "near death" experience that creates a lot of thoughts and feelings... (Stephen, lymphoma cancer survivor).

Subtheme 2c: "The significance of close relationships". A third nuance of YACS' positive outcomes was the participants' re-evaluation of their relations to others leading to a higher appreciation of close relationships. This appreciation of close relationships seemed especially related to family and friends who managed to stand by them during their treatment trajectory. Consequently, most participants had become more selective post treatment concerning who they spent time with:

At least, I have become very selective regarding WHO I spend time with (...). I cannot bear to be with people who are superficial. So, I have become very selective (...) You SAW who your friends were. You did (Yvonne, lymphoma survivor).

DISCUSSION

This study's most important finding is that the cancer experience led to a significant life transition for the participants; characterized by an amount of negative and positive outcomes. The coexistence of negative and positive outcomes resembles results from studies of older cancer survivors (Jim & Jacobsen, 2008; Schroevers, Kraaij & Garnefski, 2011; Shand *et al.*, 2015). In contrast to older adults, the literature has identified that cancer in young

adulthood is linked to a larger and more negative life disruption or transition. This occurs because of the transitional period of life they were in, the cancer itself, the applied therapy and their limited life experience (Arnett, 2000; Nass *et al.*, 2015; Patterson, McDonald, Zebrack & Medlow, 2015).

Our findings indicate a surprisingly high occurrence of physical, psychological and socially negative outcomes, where fatigue, the intrusion of negative thoughts and feelings from the cancer treatment and anxiety about the future, as well as social impairments, are the most prevalent negative factors. An explanation for this high level of negative outcome may be that the participants were recruited from a cancer rehabilitation program where most had gone through multimodal treatment, were in mean nearly one-and-a-half-year post treatment and had not recovered. Still, YACS are considered a higher risk population for negative outcomes than both younger and older cancer survivors (Baker, Toogood, Hawkins & Nathan, 2017; Nass *et al.*, 2015).

Primarily, our participants stated that fatigue was the worst negative outcome as it impaired all areas of their everyday life. These findings align with previous research of cancer survivors across gender, age and diagnosis (Campos, Hassan, Riechelmann & Del Giglio, 2011). However, YACS have a higher prevalence of fatigue than older survivors (Levkovich, Cohen, Alon *et al.*, 2018). Our informants also reported body image issues, challenges with initiating close relationships and fertility problems, areas that are documented as specific challenges for YACS (Nass *et al.*, 2015; Olsson, 2018; Zebrack & Isaacson, 2012).

The second main finding of negative outcomes was psychological distress related to both the past and the future. Research indicates that 40–50% of YACS experience psychological distress such as anxiety and depression post treatment (McCarthy *et al.*, 2016; Nass *et al.*, 2015), which are higher levels than those of older cancer survivors (Hoffman, McCarthy, Recklitis & Ng, 2009; Jim & Jacobsen, 2008). However, an important finding less elaborated in previous research of YACS, is their experience of intrusive thoughts and memories, nightmares and reminders of traumatic events. The participants struggled with future-oriented concerns, especially related to fear of cancer recurrence and death, being able to provide for themselves and starting their own family. These are highly realistic concerns, as YACS are at higher risk of recurrence, the development of new cancers and serious illnesses (Bhuller, Zhang, Li *et al.*, 2016), self-image, sexual and fertility problems (Benedict, McLeggon, Thom *et al.*, 2018; Graugaard *et al.*, 2018; Olsson, 2018), as well as financial and career challenges than older cancer survivors are (Nass *et al.*, 2015; Parsons, Harlan, Lynch *et al.*, 2012; Vetsch *et al.*, 2018). Here, a highly concerning finding is that the participants tended to keep these concerns to themselves. This aligns to Hølge-Hazelton *et al.* (2016) showing that one third of 822 YACS had not talked to anybody about their worries and that the fear of disease and death influenced everyday life in various ways.

The third main finding of negative outcomes was related to a perceived lack of understanding and support from their social surroundings as well as network withdrawal. Lack of social support is critical in times of crisis (Cohen, 2004) and in young

adulthood (Arnett, 2000) as it may hamper coping and adjustment to survivorship and put YACS at a higher risk of isolation and marginalization than older survivors (Decker, 2007; Hammer & Hyggen, 2013).

As discussed above, the informants experienced a high coexistence of negative outcomes in all dimensions or areas of their lives. This pinpoints the importance of having a biopsychosocial or holistic view of YACS during cancer treatment and survivorship. In line with this, newer research stresses the importance of viewing all these negative outcomes as being connected and be seen more as symptom clusters and predictors for impaired function and QOL than single negative outcomes (Abrahams, Gielissen, Verhagen and Knoop (2018); Fisher *et al.*, 2018; Abrahams, Gielissen, Verhagen & Knoop, 2018).

Literature involving YACS has had a marginal focus on the positive, or the coexistence of negative and positive outcomes in the aftermath of disease. Previous research states that positive and negative outcomes are independent constructs rather than ends of a single dimension (Shand *et al.*, 2015). Our findings indicate that the positive outcomes may be more the results of a developing or adaptive process.

Having faced a potentially life-threatening disease, the participants experienced a “wake-up call” and thereby acknowledged what was important in life. Thus, it seems that the participants adapted to their current situation as time went by and acknowledged both the negative and positive outcomes. They experienced a changed perspective including appreciating everyday life more, taking nothing for granted and using their time wisely to follow their dreams. Vetsch *et al.* (2018) and Bellizzi *et al.* (2012) found similar positive shifts in life goals and priorities after cancer treatment for YACS, while Park and Blank (2012) found no such changes.

The participants’ perceived personal growth related particularly to self-confidence and strength and maturity, as well as a willingness to be more respectful of other people’s feelings. Such psychological maturity and empathy is also described in older cancer survivors, but the magnitude seems to be greater for YACS (Shand *et al.*, 2015). However, the participants’ increased maturity also made them feel more distant from their friends, indicating a potential negative side that could add to a feeling of social isolation (Arnett, 2000; Hammer & Hyggen, 2013). The participants’ perceived negative social outcomes seemed to make them re-evaluate their social network and adapt to survivorship, where they appreciated and focused more on those who stood by them in difficult times and lost appreciation for those who did not. Both Love and Sabiston (2011) and Zebrack and Butler (2012) found that positive outcomes for YACS are particularly dependent on close relationships. Overall, the participants’ experience of positive outcomes echoes the positive outcomes and personal growth described in the literature concerning older cancer survivors (Jim & Jacobsen, 2008; Regel & Joseph, 2017; Shand *et al.*, 2015). In contrast to this literature, however, our participants did not mention increased spirituality. This may be because spirituality is a very private phenomenon and the participants did not want to talk about it without being asked to, or that young adults living in a secularized society such as that of Norway do not focus on spirituality and religion. The fact that Park and Cho (2017)

found that spirituality was an important factor in YACS’ adjustment after cancer treatment lends support to there being a cultural explanation for these differences.

Previous studies of negative and positive outcomes in the aftermath of cancer most often refer to PTS and post-traumatic growth (PTG). We have consciously refrained from this labelling as cancer is more often viewed as a chronic condition where the adjustment to survivorship may be a lifelong process involving the individual’s personal characteristics, context and appraisal of goals and world assumptions (Naus, Ishler, Parrott & Kovacs, 2009). Positive changes that result from negative life experiences such as cancer do not have to be traumatic to involve a changed outlook on life. Although our results indicated that YACS struggle with traumatic experiences and reminders, we also found that the cancer experience elicited deep changes in their daily functions, their relationships and their future orientation. This was accompanied by a deeper appreciation for and a changed perspective on life, personal growth and close relationships. To label such changes as PTS and PTG seems to pull these profound life changes into the field of trauma, while they represent changes posed by a very stressful but not necessarily traumatic experience.

Study strength and limitations

A strength of this study is the novel and dual focus on YACS’ own perspectives of negative and positive outcomes. Furthermore, the participants represented various sociodemographic and medical variables, underpinning the heterogeneity of this population. A study limitation may be that only five men were included, so aspects of the male perspective may not have been thoroughly uncovered. We did not reach the youngest YACS, between 18 and 24 years, and do not know whether younger YACS may have other experiences and difficulties compared to older YACS. Another limitation may be that the time from when the participants were diagnosed and finished their treatment varied and we do not know how this time aspect may have influenced the findings. As this is a qualitative study, the findings cannot be generalized. However, findings were consistent, suggesting that we captured a valid sample of the negative and positive experiences following cancer treatment.

Implications for clinical practice and recommendations for future research

Our findings indicate that young cancer survivors face complex issues after treatment, including a range of negative but also positive outcomes. These findings could be useful for providing patients with information about what to expect regarding the coexistence of both negative and positive outcomes following their treatment. Healthcare professionals should be sensitive to YACS’ needs and validate the different experiences of both negative and positive outcomes post treatment. In preventing negative outcomes, cancer survivors should receive close follow up and screening. Healthcare professionals should be upskilled with specific competence in caring for and communicating with young adults, providing them with individual and age-customized information and interventions, for example, cognitive behavioral

methods and tools for coping with complex stressors and optimizing social support. We would especially recommend teaching YACS effective strategies to counteract their fear of cancer recurrence. Patients and survivors should also be made aware of positive outcomes and measures that can be taken to promote them, such as increasing social support, prioritizing close relationships and facilitating positive changes in values and life goals.

Future research is highly warranted. Larger quantitative studies are needed to assess the content of negative and positive outcomes in this patient group. Such studies can determine the frequency of each type of experience and longitudinal studies can highlight how themes from each interact and change in relative importance over time. Furthermore, there seems to be a need to explore the concepts related to negative and positive outcomes contra PTS and PTG.

CONCLUSION

The findings from this study show that participants experienced a coexistence of both negative and positive outcomes, portraying a challenging, multi-faceted and complex picture of YACS' post-treatment situation. They experienced a major and lasting negative impact on their lives, but at the same time felt that the cancer had made them re-evaluate in a positive way. Our findings indicate how gravely YACS' lives are changed, not only while they are undergoing treatment but over time. They struggled with late-effects from impaired bodily function, relationship issues and psychological late-effects from their cancer treatment, as well as future concerns. While the positive outcomes did not outweigh the negative ones, changed values, personal growth and closer relationships led to the fostering of a different and more meaningful existence. To prevent negative outcomes and promote positive ones, the findings indicate that YACS need close follow up, screening and intervention throughout the entire cancer trajectory. As professionals, we may not be able to alleviate all negative outcomes and increase positive ones, but we should be there to assist and guide YACS in this process.

ACKNOWLEDGEMENTS AND DISCLOSURE OF FUNDING

The authors thank the participants for participating in this study and sharing their profound experiences of positive and negative outcomes after cancer treatment. We are grateful for the funding from the Norwegian Cancer Society (Mrs. Hauken, Grant number 6795357) and University of Bergen for student grant (Mrs. Grue).

CONFLICT OF INTEREST

The authors have no funding or conflicts of interest to disclose.

REFERENCES

- Abrahams, H. J. G., Gielissen, M. F. M., Verhagen, C. A. H. H. V. M. & Knoop, H. (2018). The relationship of fatigue in breast cancer survivors with quality of life and factors to address in psychological interventions: A systematic review. *Clinical Psychology Review, 63*, 1–11.
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469–480.
- Baker, K. S., Toogood, A. A., Hawkins, M. & Nathan, P. C. (2017). Adolescent and young adult cancer survivors: late effects of treatment. In A. Bleyer, R. Barr, L. Ries, J. Whelan & A. Ferrari (Eds.), *Cancer in adolescents and young adults* (pp. 687–710). Cham: Springer International Publishing.
- Bellizzi, K. M., Smith, A., Schmidt, S., Keegan, T. H., Zebrack, B., Lynch, C. F. *et al.* (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer, 118*, 5155–5162.
- Benedict, C., McLeggon, J. A., Thom, B., Kelvin, J. F., Landwehr, M., Watson, S. & Ford, J. S. (2018). "Creating a family after battling cancer is exhausting and maddening": Exploring real-world experiences of young adult cancer survivors seeking financial assistance for family building after treatment. *Psychooncology, 27*, 2829–2839.
- Bhuller, K. S., Zhang, Y., Li, D., Sehn, L. H., Goddard, K., McBride, M. L. & Rogers, P. C. (2016). Late mortality, secondary malignancy and hospitalisation in teenage and young adult survivors of Hodgkin lymphoma: Report of the Childhood/Adolescent/Young Adult Cancer Survivors Research Program and the BC Cancer Agency Centre for Lymphoid Cancer. *British Journal of Haematology, 172*, 757–768. <https://doi.org/10.1111/bjh.13903>.
- Campos, M. P., Hassan, B. J., Riechelmann, R. & Del Giglio, A. (2011). Cancer-related fatigue: A practical review. *Annals of Oncology, 22*, 1273–1279.
- Cho, D. & Park, C. L. (2017). Moderating effects of perceived growth on the association between fear of cancer recurrence and health-related quality of life among adolescent and young adult cancer survivors. *Journal of Psychosocial Oncology, 35*, 148–165.
- Cohen, S. (2004). Social relationships and health. *American Psychologist, 59*, 676–684.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd edn). London: Sage.
- Decker, C. L. (2007). Social support and adolescent cancer survivors: A review of the literature. *Psychooncology, 16*, 1–11.
- Fisher, A., Fortmann, J., Pugh, G., Hough, R. & Gregory, A. (2018). Sleep, fatigue and quality of life among teenage and young adult cancer survivors. *International Journal of Behavioral Medicine, 25*, S23–S23.
- Graugaard, C., Sperling, C. D., Hølge-Hazelton, B., Boisen, K. A. & Petersen, G. S. (2018). Sexual and romantic challenges among young Danes diagnosed with cancer: Results from a cross-sectional nationwide questionnaire study. *Psychooncology, 27*, 1608–1614.
- Hammer, T. & Hyggen, C. (2013). Ung voksen-risiko for marginalisering [Young adults in risk of marginalization]. In T. Hammer, & C. Hyggen (Eds.), *Ung voksen og utenfor. Mestring og marginalitet på vei til voksenlivet* (pp. 13–25). Oslo: Gyldendal Norsk Forlag.
- Hauken, M. A., Larsen, T. M. B. & Holsen, I. (2017). "Back on track": A longitudinal mixed methods study on the rehabilitation of young adult cancer survivors. *Journal of Mixed Methods Research, 13*, 339–360. <https://doi.org/10.1177/1558689817698553>.
- Hoffman, K. E., McCarthy, E. P., Recklitis, C. J. & Ng, A. K. (2009). Psychological distress in long-term survivors of adult-onset cancer results from a national survey. *Archives of Internal Medicine, 169*, 1274–1281.
- Hølge-Hazelton, B., Timm, H. U., Graugaard, C., Boisen, K. A. & Sperling, C. D. (2016). "Perhaps I will die young." Fears and worries regarding disease and death among Danish adolescents and young adults with cancer. A mixed method study. *Supportive Care in Cancer, 24*, 4727–4737.
- Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research, 19*, 1284–1292.
- Husson, O., Zebrack, B., Block, R., Embry, L., Aguilar, C., Hayes-Lattin, B. & Cole, S. (2017). Posttraumatic growth and well-being among adolescents and young adults (AYAs) with cancer: A longitudinal study. *Supportive Care in Cancer, 25*, 2881–2890.

- Jim, H. S. L. & Jacobsen, P. B. (2008). Posttraumatic stress and posttraumatic growth in cancer survivorship: A review. *Cancer Journal*, 14, 414–419.
- Levkovich, I., Cohen, M., Alon, S., Kuchuk, I., Nissenbaum, B., et al. (2018). Symptom cluster of emotional distress, fatigue and cognitive difficulties among young and older breast cancer survivors: The mediating role of subjective stress. *Journal of Geriatric Oncology*, 9, 469–475.
- Love, C. & Sabiston, C. M. (2011). Exploring the links between physical activity and posttraumatic growth in young adult cancer survivors. *Psychooncology*, 20, 278–286.
- Malterud, K. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, 40, 795–805.
- McCarthy, M. C., McNeil, R., Drew, S., Dunt, D., Kosola, S., Orme, L. & Sawyer, S. M. (2016). Psychological distress and posttraumatic stress symptoms in adolescents and young adults with cancer and their parents. *Journal of Adolescent and Young Adult Oncology*, 5, 322–329.
- McDonnell, G. A., Pope, A. W., Schuler, T. A. & Ford, J. S. (2018). The relationship between cancer-related worry and posttraumatic growth in adolescent and young adult cancer survivors. *Psychooncology*, 27, 2155–2164. <https://doi.org/10.1002/pon.4785>.
- Miedema, B., Hamilton, R. & Easley, J. (2007). From “invincibility” to “normalcy”: Coping strategies of young adults during the cancer journey. *Palliat Support Care*, 5, 41–49.
- Nass, S. J., Beaupin, L. K., Demark-Wahnefried, W., Fasciano, K., Ganz, P. A., Hayes-Lattin, B. et al. (2015). Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine workshop. *Oncologist*, 20, 186–195.
- Naus, M. J., Ishler, M. D., Parrott, C. E. & Kovacs, S. A. (2009). Cancer survivor adaptation model: Conceptualizing cancer as a chronic illness. *Journal of Clinical Psychology*, 65, 1350–1359. <https://doi.org/10.1002/Jclp.20622>.
- Olsson, M. (2018). *Adolescent and young adult cancer survivors – body image and sexual health*. Gothenburg, Sweden: Sahlgrenska Academy, University of Gothenburg.
- Park, C. L. & Blank, T. O. (2012). Associations of positive and negative life changes with well-being in young and middle-aged adult cancer survivors. *Psychology & Health*, 27, 412–429.
- Park, C. L., Chmielewski, J. & Blank, T. O. (2010). Post-traumatic growth: Finding positive meaning in cancer survivorship moderates the impact of intrusive thoughts on adjustment in younger adults. *Psychooncology*, 19, 1139–1147.
- Park, C. L. & Cho, D. (2017). Spiritual well-being and spiritual distress predict adjustment in adolescent and young adult cancer survivors. *Psycho-Oncology*, 26, 1293–1300. <https://doi.org/10.1002/pon.4145>.
- Parsons, H. M., Harlan, L. C., Lynch, C. F., Hamilton, A. S., Wu, X. C., Kato, I. et al. (2012). Impact of cancer on work and education among adolescent and young adult cancer survivors. *Journal of Clinical Oncology*, 30, 2393–2400.
- Patterson, P., McDonald, F. E. J., Zebrack, B. & Medlow, S. (2015). Emerging issues among adolescent and young adult cancer survivors. *Seminars in Oncology Nursing*, 31, 53–59.
- Ramos, C. & Leal, I. (2013). Posttraumatic growth in the aftermath of trauma: A literature review about related factors and application contexts. *Psychology, Community & Health*, 2, 12.
- Regel, S. & Joseph, S. (2017). *Post-traumatic stress* (2nd edn). Oxford: Oxford University Press.
- Sansom-Daly, U. M., Wakefield, C. E., Robertson, E. G., McGill, B. C., Wilson, H. L. & Bryant, R. A. (2018). Adolescent and young adult cancer survivors’ memory and future thinking processes place them at risk for poor mental health. *Psychooncology*, 27, 2709–2716.
- Schroevers, M. J., Kraaij, V. & Garnefski, N. (2011). Cancer patients’ experience of positive and negative changes due to the illness: Relationships with psychological well-being, coping, and goal reengagement. *Psychooncology*, 20, 165–172.
- Shand, L. K., Cowlshaw, S., Brooker, J. E., Burney, S. & Ricciardelli, L. A. (2015). Correlates of post-traumatic stress symptoms and growth in cancer patients: A systematic review and meta-analysis. *Psychooncology*, 24, 624–634. .
- Stone, D. S., Ganz, P. A., Pavlish, C. & Robbins, W. A. (2017). Young adult cancer survivors and work: A systematic review. *Journal of Cancer Survivorship*, 11, 765–781.
- Vetsch, J., Wakefield, C. E., McGill, B. C., Cohn, R. J., Ellis, S. J., Stefanic, N. et al. (2018). Educational and vocational goal disruption in adolescent and young adult cancer survivors. *Psychooncology*, 27, 532–538. .
- Zebrack, B. & Butler, M. (2012). Context for understanding psychosocial outcomes and behavior among adolescents and young adults with cancer. *Journal of the National Comprehensive Cancer Network*, 10, 1151–1156.
- Zebrack, B. & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, 30, 1221–1226.
- Zebrack, B., Kwak, M., Salsman, J., Cousino, M., Meeske, K., Aguilar, C. et al. (2015). The relationship between posttraumatic stress and posttraumatic growth among adolescent and young adult (AYA) cancer patients. *Psychooncology*, 24, 162–168.

Received 11 January 2019, accepted 9 July 2019