Journal of Pediatric Nursing 49 (2019) e29–e35

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Living as a Cancer Survivor: A Qualitative Study on the Experiences of Belgian Adolescents and Young Adults (AYAs) after Childhood Cancer

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ARTICLE INFO

Article history:
Received 21 March 2019
Revised 29 July 2019
Accepted 29 July 2019

Keywords:
Qualitative research
Cancer survivors
Childhood cancer
Adolescent health
Nursing

ABSTRACT

Purpose: Insight was sought in how a childhood cancer experience plays a role in daily life of adolescents and young adults (AYA) survivors.
Design and methods: A qualitative research in which semi-structured interviews were held with 21 AYA survivors of childhood cancer between the ages of 14 and 25. The AYA survivors were recruited from two pediatric oncology departments of two university hospitals in Belgium.
Results: The current situation and behavior of AYA-survivors who have been treated for childhood cancer are covered in 5 categories: The Feeling of Being Different while Aiming for Normalcy in Relationships, Living with Existential Uncertainty, The Conscious Protection of Health, The Attachment to the Parent(s) with Whom the Cancer Experience was Shared, and The Desire to Be Meaningful to Others.
Conclusions: The AYA survivors did not feel that their cancer experience dominated their current daily life, yet, the cancer experience had an important impact on their functioning.
Practice implications: The findings of the study can be used to optimize holistic psychosocial care of AYA survivors. By starting from the key elements in their current functioning, health care professionals can tailor their support to the way in which AYA survivors have integrated their cancer experience into their everyday lives.

Introduction

A large number of adolescents and young adults who have survived childhood cancer (referred to herein as: AYA survivors), experience, in one or more areas, late effects of their cancer and the related treatment (Kahalley et al., 2013; Shad, Myers, & Hennessy, 2012). These long-term consequences are often chronic in nature, causing the consequences of their survival to be ingrained into the entire course of their lives (Robison & Hudson, 2014).

Earlier studies show that AYA survivors experience neuro-cognitive problems (Barakat et al., 2014; Turner, Rey-Casserly, Liptak, & Chordas, 2009; Zeltzer et al., 2009), behavioral problems (Kahalley et al., 2013; Van Dijk et al., 2009), growth disorders (Wheeler, Thompson, Samers, & Seymour, 2009), and/or a loss of mobility (Hoffman et al., 2013) as a result of their cancer and/or their treatment. At the same time, studies reveal that AYA survivors, in comparison to their healthy peers, more frequently suffer from post-traumatic stress symptoms (Kamibeppu et al., 2010; Ozono et al., 2007). In addition to such psychopathological conditions, AYA survivors can also experience psychosocial late effects, for instance in the areas of education (Holmqvist et al., 2010), social behavior (Jóhannsdóttir et al., 2010), or sexuality (Zebrack, Foley, Wittmann, & Leonard, 2010), which are sometimes less clear to define but, nevertheless, quite disruptive (Jóhannsdóttir et al., 2010). Besides negative consequences, a childhood cancer experience may also foster positive changes, as described in studies concerning post-traumatic growth, resilience or thriving (Kazak et al., 2010; Menna & Turner-Sack, 2016; Zebrack et al., 2012).

While studies often focus on separate parts of the impact of cancer by studying the existence and significance of specific health problems, the reality is that its impact is very much interrelated in nature and that it can be felt on all life domains at the same time (Kim, White, & Patterson, 2016). Physical long-term consequences for example always come along with a psychologic, social and emotional impact, which makes it more complex to fully understand how these consequences affect the survivors' wellbeing or suffering. Especially, as it has been

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https://doi.org/10.1016/j.pedn.2019.07.015
0882-5963/

addressed before that the impact of cancer can be more determined by the survivors' subjective appraisal or individual perception of the cancer experience, than objective factors such as cancer characteristics or tumor biology (Zebrack & Landier, 2011). Therefore, a more holistic view on how different mechanisms in a cancer experience impact the way survivors live their life, is needed. Yet, current literature seldom provides knowledge on the extent of the entire cancer experience (Brown, Pearce, Bailey, & Skinner, 2016; Wong et al., 2017).

Besides the challenges of cancer survivors in general, childhood cancer survivors have to cope with their cancer experience in a distinctive stage of development, namely adolescence. Certain psychosocial topics which can be rather latently subjected to the influence of cancer and its treatment during childhood, such as education orientation, physical appearance, starting a relationship, fertility etc. come explicitly to the foreground when transitioning into adulthood. For instance, the significance of having undergone fertility preservation can be primarily felt when AYAs start to explore their desire to have children (Nilsson et al., 2014). At that point, some survivors realize that they don't have any recollection or much knowledge about the procedures they underwent as a child or are even unaware of their fertility status (Lehmann et al., 2017). Dealing with this new perception of things can cause additional stressors in the AYA survivors' pursuit towards normalcy (Taylor, Pearce, Gibson, Fern, & Whelan, 2013; Wong et al., 2017; Zebrack et al., 2012) and their attempts to reach full potential in life (Holmqvist et al., 2010; Kirchhoff, Yi, Wright, Warner, & Smith, 2012).

Even though long-term follow-up care is recommended for children with a cancer history, few attend regular follow-up (Lown, Phillips, Schwartz, Rosenberg, & Jones, 2015; Rebholz et al., 2011). The current conventional psychosocial care for children with cancer is frequently halted upon termination of the curative treatment, and only responds sporadically to the psychosocial needs of AYA survivors, or often in an insufficiently structured manner (Fernandez et al., 2011; Kahalley et al., 2013). Many AYA survivors experience barriers to engage in survivorship care, such as practical or financial issues, reluctance for help or difficulty in transitioning from pediatrics to adult care (Berg, Stratton, Esiashvili, & Mertens, 2016; Michel & Vetsch, 2015; Szalda et al., 2017).

Therefore, among policy makers and healthcare professionals, a strong call for appropriate and integrated psychosocial support remains highlighted (Fernandez et al., 2011; Shad et al., 2012). An important first step in the determination of the different areas that need to be addressed in, for instance, survivorship care plans, screening tools or specific interventions for AYA survivors, is a thorough exploration of their perspective with a view on gaining insight into the influence of childhood cancer experience in daily life (Taylor et al., 2013; Wong et al., 2017; R.L. Woodgate, Tailor, Yanofsky, & Vanan, 2016). However, there is scant literature on how AYA survivors experience their life to be affected by their childhood cancer (Brown et al., 2016; Lahaye, Aujoulat, Vermylen, & Brichard, 2017; Phillips & Jones, 2014).

The aim of this study is to gain insight in the holistic impact of a childhood cancer experience by examining the perspective of AYA survivors firsthand, exploring in what way a childhood cancer experience plays a role in their current daily life and identifying their needs and resources.

Method

Design

A qualitative research design was chosen since this allows for the in-depth exploration of participants' perspectives, and facilitates the detailed description and understanding of experiences in terms of the meaning people bring to them (Boeije, 2009). As we intended to develop insight in the multiple layers of the experiences of AYA-survivors, semi-structured interviews with AYA-survivors were performed and thematically analysed (Braun & Clarke, 2006).

Sample and recruitment

AYA survivors were recruited from pediatric oncology departments of two university hospitals in Flanders, Belgium. In each setting, one member of the pediatric multidisciplinary team acted as reference persons and identified eligible participants from the electronic patient file from the first cancer episode. AYA survivors who had been between the ages of 0 and 14 when they started their first cancer treatment, who were between the ages of 14 and 25 when participating in the study, and who had terminated their curative treatment at least two years prior to inclusion in the study were purposefully selected. Participants who had a relapse after the age of 14 were excluded from the study. Participants who lacked sufficient proficiency in the Dutch language, and those whose contact details were no longer available, were excluded too.

To achieve diversity in the study population variation was sought with regard to age, sex, diagnosis, treatment, age at the time of diagnosis, level of education, marital status, and the amount of time that has passed since their treatment was completed. As data collection and analysis alternated, new participants were purposefully selected to pursue more comprehensively information regarding their experiences and to study if certain themes were shared. At a given moment, for instance, AYA survivors were selected who had become ill at an early stage in their childhood. In that way, we could study if the AYAs' recollections of their illness and treatment influenced the way they experienced their survivorship.

Of all selected AYA survivors ($n = 23$), two refused to participate, one due to lack of energy ($n = 1$) and one due to too many physical complaints ($n = 1$). The reference persons, acted as “gatekeepers” (Kars et al., 2015): they deterred 4 eligible AYA survivors from participating because they considered recruitment as inappropriate because of severe mental disability, too limited interviewing capacity (autism spectrum disorder) and an emotional crisis situation (a problematic parental divorce and a recent parental cancer diagnosis).

Data collection

One-time individual face-to-face interviews, with an average duration of 70 min (range 31–178 min) were conducted by two researchers (NB and ED). All interviews were audio recorded and transcribed verbatim.

An interview guide was used. Open-ended questions were posed, aiming to elicit extensive answers and expand on key components of the experiences under study (Charmaz, 2006). The interview started with an open question to introduce the focus of the interview without stearing it towards a specific theme. The opening question was: “What does having experienced childhood cancer means to you?”. The following questions were based on what the participant talked about. If it was necessary to give extra input, themes derived from literature review were introduced? Each interview started open but in further interviews themes that came to the fore in the analysis of earlier interviews were also introduced. Topics addressed included confrontation with the disease, experiences with the consequences of the disease and its treatment, and the requirements and needs experienced. Throughout the cyclic process of data collection and analysis, the interview guide was adapted to allow further exploration of specific themes that emerged during the analysis (Holloway & Wheeler, 2013; Kvale & Brinkman, 2009).

Data analysis

The research group was composed of the two researchers charged with interviewing (NB and ED) and four researchers (MK, PR, AVH and SV), all of whom had different content-related and/or methodological expertise which gave breadth to the analysis (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014; Holloway & Wheeler, 2013). Investigator triangulation was applied throughout the entire research process (Holloway, 2008) and an audit trail was set up (Lincoln & Guba, 1985). Data analysis was performed according to an inductive thematic analysis approach with an aim to identify data-driven themes (Braun & Clarke, 2006).

All six researchers independently read and re-read the first four interviews. This enabled them to immerse themselves in the data and to identify patterns and meanings in the data. Supported by NVivo 10 software (QSR International Pty Ltd, 2012), manageable segments of text with similar meanings were given data-driven codes and integrated in a first code tree. New raw data were handled similarly. The open coding of the first eight interviews was followed by axial coding as codes in the code tree were carefully organized into (sub)categories, based on relationships within. Data were compared and reassembled which enabled the identification of patterns of meaning or themes (Braun & Clarke, 2006). All interviews went through this process of data analysis. The research group together worked out a framework of themes that with every new data, was adapted and thoroughly refined. Memoing helped in describing in detail interpretations, ideas, potential directions and conceptual thoughts (Boeije, 2009; Charmaz, 2006). Themes were theorized at a latent level, identifying underlying assumptions and meanings within the AYA survivors' experiences. Data saturation was reached, meaning that gathering new data no longer gave rise to new theoretical insights regarding our overarching themes (Charmaz, 2006).

Ethical review

The study was approved by the Ethics Committees of The Ghent University Hospital and The Leuven University Hospital.

All participants signed an Informed Consent Form. The written permission of parents of AYA survivors under the age of 18 was also obtained.

Findings

A total of 21 semi-structured interviews were conducted, with 8 male and 13 female AYA survivors. The average duration between the end of the curative treatment and participation in the study was 11 years (range: 4–25 years). The analysis indicated that the AYA survivors could be divided into two analytically different groups. Those who received their diagnosis prior to attaining the age of 7 comprised the group of participants diagnosed in "early childhood" ($n = 8$). The remaining AYA survivors diagnosed in "late childhood", namely between the ages of 7 and 14, comprised the second group ($n = 13$) (see Table 1). The decision to use the age of 7 as a delineating factor was supported by theories taken from developmental psychology. Piaget, for example, describes how a person's thought processes are more logical, more flexible and better organized in the concrete operational stage than in early childhood (Piaget & Inhelder, 2013). Erikson describes how social interaction becomes more important for primary school children (Erikson, 1993). Additionally, the manner in which children understand disease can be linked to a change in development from the age of 7 onwards (Bibace & Walsh, 1980; Koopman, Baars, Chaplin, & Zwinderman, 2004).

If a demonstrable difference in findings was found between both groups, this difference is made explicit. If not, the subjects are referred to more generally as "the AYA survivors". The "cancer experience" refers to the AYA survivors' experiences in their trajectory from diagnosis up to and including the follow-up phase.

In the following presentation of the findings, it is first explained in what way the AYA survivors reflected on the childhood cancer experience in their past and how they did not perceive it as a "halt" in their development. This is followed by what was learned, from the data, about the influence of the cancer experience on the AYA survivors' existence and actions. Five categories were identified that demonstrate the role the childhood cancer experience still played in the current daily life of AYA survivors.

Table 1
Demographic characteristics of the participants ($n = 21$).

Time of the cancer diagnosis		Early childhood (0–6 yrs)	Late childhood (7–14 yrs)	Total
Age at diagnosis (yrs)	0–3	4		4
	4–6	4		4
	7–10		3	3
	11–14		10	10
Type of cancer	Bone tumor		5	5
	Leukemia	2	6	8
	Lymphoma		1	1
	Soft tissue sarcoma	2		2
	Hepatic tumor	1		1
	Brain tumor	2	1	3
	Spinal tumor	1		1
Time since the end of the treatment (yrs)	2–5		5	5
	6–9	1	7	8
	10–13	4		4
	14–17	2	1	3
	18–21			
	22–25	1		1
Sex	Female	5	8	13
	Male	3	5	8
In a romantic relationship	Yes	2	8	10
	No	6	5	11
Currently in school or (un) employed	Vocational school	2	5	7
	High school	2	2	4
	University		2	2
	Employed	2	1	3
	Unemployed	2	3	5

The cancer experience: part of a personal life history

To the interviewed AYA survivors, cancer was something that just happened to them during their childhood. They had no other alternative than to deal with it (Table 2, Q1); one AYA survivor described it as a twist of fate.

Similar to other significant events in their lives, such as a parental divorce, all AYA survivors considered their cancer experience as a crucial event in their life course. Those diagnosed in 'late childhood' created a

Table 2
The cancer experience: part of a personal life history: illustrative quotes.

Quotations in the text	Illustrative quote
Q1	"It was something that had to have happened"
Q2	"The way I am today, I have always lived with it, so this is normal, it's a normal thing"
Q3	"It is not something that has dominated my life. Rather, I have the idea that all the choices I have made were not connected to this experience (…) I have simply led my life. I simply went on."
Q4	"You learn to deal with it, and after a while you are used to it (…) it is most difficult at first, but… the better your progress and the more frequently you have to do the same thing each day, over and over again, the more normal it becomes."
Q5	"Because you have fewer muscles, your movements are restricted. And, at certain times, it becomes important to you to not always lose [at sports]. You want to join in with the rest, at their level. This just wasn't possible at a certain point in time, and with this my understanding grew. […] Of course, I knew that something had happened to me but the concrete understanding that what had happened to me was something very serious only came to me in the second or third year [of primary school]."

clear demarcation between life before and after cancer. They had memories of life before as well as after cancer. Those who became ill in early childhood had no awareness of a life without the experience of having cancer (Table 2, Q2).

Although described as an important life event, most AYA survivors did not give their cancer experience a prominent position in their present lives. The interviews revealed that AYA survivors saw the cancer experience above all as something that was past. They described their present lives to be active, full and the cancer experience was never construed as a "halt" in their development. Regardless of whether they were affected by cancer at an early or later stage in their lives, all said that they had learned, over time, to deal with the impact of the cancer experience on their lives (Table 2, Q3). After their cancer experience, all AYA survivors built up a new, normal life, in which they became used to dealing with the consequences of the cancer experience and the medical follow-up (Table 2, Q4).

Several AYA survivors, including the ones diagnosed in 'late childhood', explained that when they were children, they did not fully understand the significance of their cancer experience and had little understanding of the life-threatening nature of the disease or the seriousness of the situation. The full impact of the cancer experience was frequently only understood retrospectively, at a later age (e.g. when certain late effects became clear or when the survivors gained more insight into the full course of the treatment) (Table 2, Q5).

The impact of the cancer experience on existence and actions

Both the past cancer experience and its consequences over time influenced the AYA survivors' identity. Some survivors wondered which aspects of their personality could be attributed to their cancer experience, and which to their own character or disposition (Table 3, Q6). These were considered rhetorical questions (Table 3, Q7).

In all cases, the cancer experience had an impact on the current functioning of the AYA survivors and their existence. From the analysis, the following elements that typified their current lives were identified.

The feeling of being different while aiming for normalcy in relationships

Regardless of whether AYA survivors became ill in early or late childhood, all AYA survivors said that their background gave them the feeling of being different compared to their peers. The AYA survivors distinguished themselves from the rest due to their experience with having had cancer, having undergone treatment and their current experience of the associated consequences. At the same time, it was crucial for them that others did not perceive them as different (Table 3, Q8 and Q9). Still, some AYA survivors expressed a need for recognition of who they were and acceptance of their 'differentness' by others and/or their environment. They expected people to treat them as normal while taking their special situation into account (Table 3, Q10). A distinctive example illustrating AYA survivors' desire not to be different from others was the well-considered disclosure of the past cancer experience.

The announcement of the cancer experience, or "disclosure", to people who had not been informed previously appeared to be a prominent detail in the social relationships and activities of AYA survivors. Firstly, several considered disclosure to be inevitable, as the consequences of the disease were often apparent; e.g., for those with a prominent physical disability. Secondly, some AYA survivors also experienced a need to inform other people of their past, considering that it was a significant part of their life and a formative element in their personality. Whenever avoidable, people who knew nothing about the cancer experience were not informed "*casually*"; disclosure was prompted more frequently than not by a particular situation or certain point in time. To many AYA survivors, this depended on the moment which prompted disclosure to occur "*automatically*" or not. They explained that disclosure never occurred "*out of the blue*": they needed a reason to talk about their experiences; e.g. when they needed to clarify why there were certain things

Table 3
The impact of the cancer experience on existence and actions: illustrative quotes.

Quotations in the text	Illustrative quote
Q6	"I think that it changed me and I would like to know how things would have been if I had not had cancer. What would I be like then? (…) What would my personality be like, would I have been more sociable or… I don't know, more confident in life?"
Q7	"I don't know what was there before the cancer (…) I don't know how it could have been different".
1. The feeling of being different	
Q8	"I want to be just like everyone else and not that person with her leg and scars. That person who was ill, and so on."
Q9	"You are different any way you look at it, but you don't want other people to see you as different. You want simply to be the person that you want to be, just like any other person."
Q10	"They have to simply take me as I am, with my pain, with my background. Interviewer: And if they can't? AYA: Then I don't need them to be a part of my life."
Q11	"…if they ask 'why don't you want to eat that?'. I liked it before, but I don't anymore because of the cancer."
Q12	"I would never tell people immediately (…) When I start trusting a person more and think that this person is not likely to tell everyone else, I might".
Q13	"They say things like 'You can always get it again'."
2. Living with existential uncertainty	
Q14	"It's like they [*the questionnaires*, e.g. *regarding insurance*] create the image that your health is more at stake"
Q15	"I have an uncertain feeling about the effects. What are the effects of the medication I took, and so on, and the treatment truly? Those were extremely toxic substances."
Q16	"Not long ago in school, the teacher was telling the students that it is difficult for people who are very old or who have poor health to get a loan and I was thinking: 'O, will that be a problem for me then?'. Normally, I shouldn't have a problem with that 'cause it [*the cancer*] is gone completely. Yeah, normally. I don't know how it will be for me exactly."
Q17	"If it happens, it will happen"
Q18	"I don't think about the fact of dying; that you can die. Because, yes, you can always die and tomorrow, it's true, I could walk out the door and get run over by a car. So, that's not really what it's about. What's worse is that you would have to experience all of that once again, including the consequences (…). It genuinely is a coping process, and the period afterwards is the part I actually find hardest."
3. The conscious protection of health and avoidance of risks	
Q19	"I have this list that they check every time: blood, kidneys, heart… I'm not scared of a relapse. It's rather the consequences of the chemo on my general health which can worry me sometimes"
Q20	"I have to drink a lot for my kidneys, and in the second year of secondary education I had a teacher who did not permit this. Well, I take my health seriously, so I drank during my classes. Then he said: 'If you take one more sip, I will pour that bottle over your head!' I became very angry, seriously, and the matter was brought to the attention of the school's directors. I mean, it wasn't a soft drink, you know, and it's for my health! I even had a note from my physician."
4. The attachment to the parent(s) with whom the cancer experience was shared	
Q21	An AYA survivor about his absent father: "Now, I can reasonably deal with it, but I will never forget who was there for me during that time and who was not."
Q22	"My mother herself says that there are few people who are as supportive and concerned about her as I am."
5. The desire to be meaningful to others	
Q23	"I try to be there for everyone, always, seven days a week."
Q24	An AYA survivor, called by her friends the "mother of the group", explained: "You are aware of the problems and you want to prevent others from having them."
Q25	"I always have to think of myself first, before thinking of other people, but then I think: you know, in other ways I do think of other people. It's just that now my own needs have to take center stage. So, I need to be egoistical because otherwise I will not be able to make it through the week."

they could no longer do, or when they needed to explain their behavior (Table 3, Q11). The presence of security and trust in the already existing relationship was believed to be essential.

The majority of AYA survivors limited the information they shared with others in order to draw as little attention as possible to their cancer experience and to their "*differentness*". Their focus remained always on safeguarding their normalcy. Some of them had experienced that people, once informed about their history of being a cancer survivor, distanced themselves from them or suddenly started treating them "*differently*"; e.g. with pity. To prevent these kinds of responses, AYA survivors often shared only factual information about concrete matters, rather than their thoughts and emotions. One AYA survivor explained that she had a long and a short explanation, one more detailed than the other, but both a factual representation of occurrences, without further details about how she had felt.

Several AYA survivors made clear that when they talked about their cancer experience, their choice of words was well-considered, and that they often avoided the word "cancer". For example, an AYA survivor with a visual impairment often told people that he had "*something*" as a child, without providing any further details. The interviews demonstrated that he was not the only AYA survivor to hardly ever mention the word 'cancer'. The AYA survivors experienced that cancer has a specific connotation and emotional charge, with the implication that a generalized idea about cancer did not do justice to their individual and personal experience. Several AYA survivors pointed out in the interviews how they were confronted with prejudices and general preconceptions. One AYA survivor was told that he "*didn't look like someone who had had cancer*". Another experienced that people had doubts about his survivorship (Table 3, Q13).

Living with existential uncertainty

In the interviews, all AYA survivors expressed that their past cancer experience had confronted them with their own vulnerability. Once they had understood the seriousness of their experience, a significant time afterwards, an existential uncertainty arose. This became a permanent factor, forever ingrained in their lives. One AYA survivor said in the interview that every time he had to fill out a questionnaire, for instance regarding insurance, he felt the uncertainty of his health status (Table 3, Q14). Other AYA survivors mentioned this uncertainty in reflecting on the impact of the medication (Table 3, Q15) or in thinking about getting a loan (Table 3, Q16). The AYA survivors mentioned that dealing with the consequences and impairments arising from their cancer experience was an everyday reality. They considered impairments as something that "*they will have to deal with throughout their entire lives*". Most AYA survivors had learned over time that when growing older or entering a new phase in their lives, they continuously encountered situations which confronted them anew with the consequences of their cancer experience.

Digging deeper into the possibility of a future relapse, many AYA survivors mentioned that they had clearly been alerted to the possibility of a relapse in the early years following their cancer experience, but that their concern and fear of this had diminished with the passage of time. Although the uncertainty remained and although all assumed that a relapse could never be excluded, they experienced a certain degree of resignation; (Table 3, Q17). Furthermore, data revealed that a lot of survivors did not particularly consider a relapse as a risk, or renewed risk, of death. Rather, a relapse meant having to repeat the entire cancer experience again: the intensive treatment, the pain and discomfort (Table 3, Q18).

The conscious protection of health

The interviews showed how the cancer experience also had an impact on the AYA survivors' attitude towards health. The cancer experience had made all AYA survivors more conscious of their own health and vulnerability. Rather than ruling out or identifying a possible relapse, the check-ups for most AYA survivors every two years were particularly important with a view to assessing their health (Table 3, Q19). Furthermore, several AYA survivors currently appeared to feel a great responsibility to protect their health and were careful to avoid any unnecessary health risks. The AYA survivors often emphasized that they would never smoke, drink or use drugs, and they often described themselves as not being hesitant to speak up when it came to their health. After all, their cancer experience had taught them that health was a priority issue, and that they had to act assertively if this was threatened (Table 3, Q20).

The attachment to parent(s) with whom the cancer experience was shared

None of the AYA survivors interviewed had to undergo his or her illness trajectory and course of treatment alone. In all cases they had received support from one or both parent(s). The interviews revealed how the experienced togetherness in fighting the disease resulted in a strong sense of connection or attachment and loyalty towards the involved caregiving parent(s). These emotions appeared to be anchored in such a way that they would be felt by the AYA survivors throughout their lives. It also worked the other way around. When a parent, for example due to a divorce, was barely involved in the cancer experience, this also had left an indelible impression resulting in the AYA survivors feeling disconnected (Table 3, Q21). Additionally, sharing the cancer experience had led to a reciprocity in which AYA survivors took care of the people who had taken care of them (Table 3, Q22).

Our data indicated that the close ties with the caregiving parent(s) did not stand in the way of the AYA survivors attaining independence as adults. While, for example, many of the AYA survivors interviewed did not feel any need to leave the parental home yet, others had already started taking steps towards adult independence. Based on our data, it seemed that the extent of independence mainly depended on the age of the AYA survivors. It appeared to be unrelated to the sense of connection the AYA survivors experienced with their parent(s). For example, an AYA survivor who currently had two children and had not lived with her mother for quite some time stated that she experienced her ties to her mother as more "*crucial*" to her than her relationship with her partner (who is also the father of her children).

The desire to be meaningful to others

As they were given so much care and attention because of their cancer experience, most AYA survivors tended to consider themselves as being able to demonstrate a lot of empathy and having a great desire to help others, which an AYA survivor illustrated in relation to his fellow cancer survivors (Table 3, Q23 and Q24). Their commitment towards others was also reflected in their academic choices. Many of the interviewed AYA survivors appeared to be interested in a career in healthcare. Nevertheless, as their own health had to always take precedence, some AYA survivors experienced feelings of guilt because they had not always been able to give priority to caring for somebody else (Table 3, Q25).

Discussion

To gain understanding in the perspective of AYA survivors, research based on their self-reported findings is essential (Bitsko et al., 2016; Doukkali et al., 2013). This study showed, that although the cancer experience is relegated to the background in their current lives, it exerts a significant impact on the AYA survivors' functioning in daily life. A weighty issue is the importance the AYA survivors give to being normal. Their childhood cancer experience is a part of who they are and has been integrated in their daily life. Yet, it makes the AYA survivors feel different compared to their peers. In line with previous research (Boydell, Stasiulis, Greenberg, Greenberg, & Spiegler, 2008; Tsangaris et al., 2014; R. L. Woodgate, 2005), maintaining normalcy in social relationships can be a struggle. The interviewed AYA survivors appeared to sometimes communicate a contradictory message to the people surrounding them. Those who were closest to them were supposed to respond normally to them, while respecting their differentness at the same time. As such, this study uncovered a crucial balancing exercise for both AYA survivors and the people surrounding them, namely not feeling perceived (or perceiving) as different, while at the same time feeling acknowledged for (or acknowledging) what the AYA survivors had gone through.

For AYA survivors, finding this balance can also complicate the amount and manner of disclosure to people who are not yet informed about the AYA survivors' illness history. Literature confirms how self-disclosure is deemed necessary for building up an intimate relationship (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011) or obtaining social support (Chaudoir & Fisher, 2010), yet it is hindered by difficulties such as uncertainty with regard to the way in which others might respond to the disclosure (Thompson, Long, & Marsland, 2013).

Consistent with other research (Bitsko et al., 2016; Castellano-Tejedor et al., 2015), the AYA survivors in this study expressed that many years after their cancer experience they were doing fine from a psychosocial point of view. Even though they experienced adverse late effects, they felt that their past cancer experience did not necessarily interfere with their feeling of progression in life or their sense of normalcy. This should not be understood as a contradiction. Merely, it underlines that a childhood cancer experience can represent aspects both of burden and of benefit (Currier, Hermes, & Phipps, 2009; Sundberg, Lampic, Björk, Arvidson, & Wettergren, 2009). Moreover, despite the potential of a cancer experience to have a severe impact on future life, the cancer experience does not necessarily have to be regarded as overpowering, considering that in adolescence many different life events are experienced that lead to important changes in the lives of AYA survivors (R. L. Woodgate, 2005). In a number of ways, the developmental milestones and expectations of AYA survivors in this study were similar to those of their peers (who have not had cancer), such as the search for a specific identity, the desire to be normal and to be accepted by others (Schwartz, Donnellan, Ravert, Luyckx, & Zamboanga, 2013).

Implications for nursing

Health care professionals could optimize psychosocial care by taking the experiences of childhood cancer survivors as a point of departure. It is important that individual support is tailored to the way in which AYA survivors have integrated their cancer experience into their everyday lives, and that support addresses the requirements and needs AYAs have in dealing with their survivorship issues. Although the AYA survivors in the interviews often indicated that their cancer experience was behind them, the analysis revealed that this life event had an existential significance to them which they will carry with them throughout their lives. An essential point for attention for health care professionals is that traces of this survival can often be read between the lines, so that it is recommended to be vigilant in this respect. Special attention could be given to the way AYA survivors communicate about their cancer experience. What do they share about their experiences? Concrete tension can arise between someone's desire to share an experience and his/her willingness to experience again the suffering in that experience by talking about it (Charmaz, 2002). As shown in this study, some AYA survivors don't use the term 'cancer', when talking about their experiences. Health care professionals can try to reveal the meaning of the used terminology. For instance, avoiding the word 'cancer' could be a sign that the AYA survivor is worried of a possible negative attribution towards the disease (Willig, 2011). It could also demonstrate AYA survivor's struggle with identity of being a cancer survivor, his/her sensitivity to social rejection or level of self-esteem (Enskär & Berterö, 2010). It may reflect feelings of uncertainty regarding the seriousness of the past experience, its impact or possible future consequences. Yet, AYA survivors could just as well avoid the term 'cancer' because they do not want to be labeled, for instance because they do not want to dwell on the past and are focusing on the future (Cheung & Delfabbro, 2016). Various explanations could be considered thus health care professionals should take the necessary time to gain understanding in the meaning that AYAs address to their survivorship.

Limitations

The study was marked by a number of limitations. The reference persons who selected the participants acted as gatekeepers. As a result, the participants in this study consisted primarily of AYA survivors who are doing relatively well in life and are not involved in an emotional crisis situation. It is possible that our sample therefore underrepresented AYA survivors who experienced more difficulty with their cancer experience or had other needs and requirements. As attendance of follow-up care was not an inclusion criterion, we have no information on the proportion of participants who are receiving regular follow-up care.

Despite the positive fact that so many AYA survivors could be recruited to participate in this study, AYA survivors with whom all contact was lost, could not be reached. Further research could explore if the AYA survivors who are lost to follow-up give other meaning to their experiences.

Conclusions

This study provided insight into what it means to be an AYA survivor of childhood cancer. The AYA survivors' concerns and how they integrated the consequences of their cancer experience in their current functioning, was explained. The AYA survivors did not feel that their past cancer experience predominated in their current normal life. Nevertheless, it was not possible for them to imagine a life without it; the cancer experience made them the way they are now and impacted their existence and actions. Psychosocial requirements and needs can be drawn from the experiences of AYA survivors which comprise the priority areas around which psychosocial support should be built up.

Author statement

All authors have made a substantial contribution to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting or revising of the manuscript, and (3) final approval of the manuscript.

Declaration of competing interest

The authors have no conflicts of interest to disclose.

Acknowledgements

The researchers wish to thank all participants who were prepared to provide insight into the world as it is perceived by them.

This research was financed by the Flemish League Against Cancer (KOTK), which had no influence in the design or output of this research.

The authors would like to thank and acknowledge the contribution of Veronique Van De Velde and Gertrui Vercruysse in recruiting participants.

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