UNIVERSITAT ROVIRA I VIRGILI

PSYCHOSOCIAL SUPPORT FOR YOUNG CANCER SURVIVORS

Santiago J Galán Ortega

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Psychosocial support for young cancer survivors

Santiago Galán

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I STATE that the present study, entitled “PSYCHOSOCIAL SUPPORT FOR YOUNG CANCER SURVIVORS”, presented by Santiago Galán Ortega for the award of the degree of Doctor, has been carried out under my supervision at the Department of Psychology of this university.

October 23 2017, Tarragona

Doctoral Thesis Supervisor/s

Jordi Miró, PhD

"Nunca te rindas y siempre fuerte"

Pablo Ráez

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Abstract

The number of cancer survivors is growing. However, the side and late effects caused by cancer itself or by the cancer treatment may result in additional needs. Identifying what these needs are and developing specific guidelines about how they can be satisfied is important in order to guarantee a satisfactory quality of life in this population. This Thesis is related to this area of knowledge, and has three studies: a systematic review of the needs of AYAs (Study I), a Delphi study about the importance of these needs (Study II) and a validation of the Centrality of Event Scale (CES) for its use with Spanish-speaking youths (Study III). The main conclusions are the following:

1. AYA cancer survivors have specific needs such as receiving information and individualized counselling, tailored care in the post-treatment phase, and psychological help and social support.
2. Several of these needs are seldom met, mostly related to: fertility and sexual health, healthy lifestyle maintenance, social and family support, and peer relationships.

3. The CES is a reliable and valid assessment tool to be used with young people, which can help determine the importance of centrality to adjustment to cancer events.

1. Introduction

This doctoral dissertation is part of the work that I have been undertaking since 2014 at the Unit for the Study and Treatment of Pain - ALGOS and the Chair in Pediatric Pain, Universitat Rovira i Virgili. The dissertation is related to the study of the needs of adolescents and young adults (AYA) after finishing a cancer treatment. It is divided into six parts. First, in the Introduction section, we deal with the concept of cancer survivorship among adolescents and young adults and report its prevalence. We also explain the importance of studying their difficulties and needs, and the attempts that have been made to identify them. The introduction ends with the description of the interventions that have shown some efficacy in addressing these needs. Second, we describe the objectives of the three studies that we have carried out to advance in this area of knowledge. The aim of the first study was to map out the state of the art of this topic, therefore a systematic review was done. As none of the studies we found in the review was carried out in Spain, we decided to conduct a Delphi study to understand the specific needs of Spanish youths after finishing a cancer treatment. On the basis of the results of these two studies we realized that one of the most important needs of AYA cancer survivors is related to cancer as a central issue in their lives, but there is no scale that could be used with Spanish speaking samples to measure the centrality of an event, such as cancer, in someone's life. Thus, a third study was conducted to validate the *Centrality of Event Scale*, and it is included here. In the third part of the thesis we describe the methodology for the different studies. The fourth part provides the results, that is, the studies are reported in full, in the form in which they have been published. Next, in the fifth part, we discuss the results and explore future lines of research, and describe the contents of a treatment we are developed to improve the quality of life of this population. Finally, in the Conclusions section, we summarize the main results of the dissertation.

1.1 On the concept of cancer survivorship

There are different definitions of "cancer survivor" or "cancer survivorship". For example, a cancer survivor has been seen as a person who has had a cancer diagnosis in the past, but he or she has successfully completed treatment (Doyle, 2008). It has also been conceptualized as a "time of life" that goes from a phase of acute survivorship (period after diagnosis and during primary treatments) to a phase of permanent survivorship (when patients are living with cancer as a chronic disease or when individuals are in remission thanks to ongoing treatment) (Mullan, 1985). In our studies, the following definition is used: people who have finished a cancer treatment (Doyle, 2008).

1.2 The increase of adolescents and young adults (AYA) cancer survivors

The number of cancer survivors continues to grow due to the increase of early detection of cancer and treatment improvements. For example, the 5-year relative survival (that is, the percentage of people with cancer who will be alive 5 years after diagnosis) has increased steadily over time for all European regions for patients age ≥15 years diagnosed in Europe during 2000–2007 (De Angelis et al., 2014). The 5-year survival for all cancers was 87% (Gatta et al., 2009). Moreover, almost 80% of children and adolescents who receive a diagnosis of cancer become long-term survivors (National Cancer Institute, 2005). The study of AYAs, as a group, is vital because they have the more years ahead to live with the consequences of cancer and its treatment.

1.3 Difficulties of AYA cancer survivors

AYA cancer survivors have more disability problems, chronic diseases, and poorer mental and physical health than AYAs with no history of cancer (Tai et al., 2012). Sixty-two percent of adults that are childhood cancer survivors report to have, at least, one chronic condition, and 27% of them a severe or life-threatening condition (Oeffinger et al., 2006). These health problems are also called side effects, but when they are developed years later are known as late effects. Side and late effects may be caused by cancer itself or by the cancer treatment and they can include physical and psychosocial problems.

Among the *physical problems*, there are some specific risks related to heart disease (cardiac toxicity), high blood pressure, diabetes, pulmonary complications (asthma) endocrine dysfunction, osteoporosis, stroke, kidney failure and second malignancies, depending on the type of cancer and treatment (Robison & Hudson, 2013; Slater et al., 2015; Tai et al., 2012; Woodward, Jessop, Glaser, & Stark, 2011). Thirty percent of long-term survivors of childhood leukemia report significant fatigue (Meeske, 2005) and, in the longer term, approximately 5% to 10% of cancer survivors have chronic severe pain that interferes with function (Glare et al., 2014).

AYA cancer survivors are also at a higher risk of developing *psychosocial problems*, particularly anxiety and depression, and lower self-esteem when compared to their peers without cancer (Abrams, Hazen, & Penson, 2007). More than 50% of AYA cancer survivors report problems with memory and attention (Warner et al., 2016). Furthermore, AYA cancer patients report an altered sense of identity, changes in social relationships, challenges in body image and sexuality, impacts on education and employment with financial consequences, preoccupation about cancer recurrence or with death and dying, and generally a less positive outlook on life (Bellizzi et al., 2012). Similarly, post-traumatic stress symptoms have been reported in 40% of adolescent cancer survivors (Schwartz & Drotar, 2005). Posttraumatic stress disorder (PTSD) is associated with a poorer quality of life (physical and mental) and an increase in psychological distress. Data also suggest that survivors with PTSD have significant functional limitations and psychological comorbidity (Meeske, Ruccione, Globe, & Stuber, 2001). Furthermore PTSD influence families' functioning in many different areas like problem-solving, affective responsiveness and affective involvement (Alderfer, Navsaria, & Kazak, 2009).

1.3.1 Centrality of cancer as a traumatic event

Traumatic experiences, as it is the case of having had cancer, can change the view of oneself, especially if the person experiences persistent traumatic psychological effects (Sutherland & Bryant, 2008). In such instances, the trauma may come to play a central role in that person's individual identity. The perceived centrality of the event is related to how central the event is, cancer in this case, to a person's identity and life story (Berntsen & Rubin, 2006).

As described above, one of the consequences of having cancer has to do with the self-concept and the sense of identity. Many people who have been diagnosed with cancer identify themselves as cancer survivors and this is part of their identities (Little, Paul, Jordens, & Sayers, 2002; Prouty, Ward-Smith, & Hutto, 2006). The diagnosis and treatment for cancer also produces changes in their social role and that role can persist for the rest of their lives (Zebrack, 2000). A factor associated with this role may be the development of social stigma (Knapp, Marziliano, & Moyer, 2014). People who have not had cancer usually have a more negative perception of the disease than people who have gone through it (Anagnostopoulos & Spanea, 2005; Chapple, 2004).

However, having cancer is not necessary a traumatic experience for everyone. In fact, many survivors see cancer as a growth opportunity and they report an enhanced appreciation of life, closer relationships, increased spirituality, a shift in priorities, and increased personal strength and seeing themselves as stronger and fighters (Kayser & Sormanti, 2002; Stanton, 2006). The way in which cancer is perceived may play a role in psychological wellbeing. For example, in a study with 240 female breast cancer survivors, higher centrality was related to a poorer mental functioning, besides, for those who viewed the illness in less positive terms, higher scores in centrality were associated with negative affect and psychological distress (Helgeson, 2011). Therefore, the way in which people think about cancer and the extent to which people define themselves in terms of illness survivorship is important to guarantee a good adjustment to the disease. In order to understand the role of the centrality of event in the adjustment to stress and trauma, reliable and valid assessment measures are needed.

1.4 Needs of AYA cancer survivors

There is not enough research about the impact of cancer in the developmental trajectory of AYA cancer survivors (Haase & Phillips, 2004; Soliman & Agresta, 2008). Nevertheless, there are some studies with adults that can shed some light on important issues related to the needs of cancer survivors. For example, in a recent systematic review conducted by Hoekstra et al. (2014), the results showed that the most important needs are psychosocial, particularly, the support provided by general practitioners, followed by the need for help with medical issues, and the need for information on cancer, recovery, late treatment effects and on adjusting to life after treatment. However, AYA have specific problems. Therefore, it is expected that their needs would also be different. In fact, studies conducted with samples of AYAs show that they have certain needs that are not satisfied by the healthcare system (Keegan et al., 2012; Miedema, Easley, & Robinson, 2013; B. Zebrack, 2009b). As shown in a study with a sample of 484 cancer survivors (aged between 15 and 39), those with unmet needs (i.e., financial support, mental health, support groups) reported significantly poorer Health-Related Quality of Life (HRQOL) and social functioning than those without unmet needs (Smith, 2013). Therefore, identifying what these needs are and developing specific guidelines about how they can be satisfied is important in order to guarantee a satisfactory HRQOL in this population.

1.5 Improving the quality of life of AYA cancer survivors: available treatments

Interventions in this population have been focused on two areas: (1) maintaining or developing a healthy lifestyle and (2) addressing psychological issues such as emotional distress, depression or posttraumatic stress symptoms.

The first group has mainly focused on physical activity. For example, a 16-week home-based exercise program has shown to be effective in improving cardio metabolic risk factor status and fitness in a sample of 17 young adult survivors (16 to 30 years old) of childhood acute lymphoblastic leukemia (Järvelä et al., 2012). The program consisted in a muscle training of eight exercises at least three times per week plus aerobic exercise such as walking, jogging or aerobics. Another example is the integrated adventure-based training and health education program developed by Li et al. (2013). Seventy-one childhood cancer survivors (9 to 16 years old) participated in a randomized controlled trial.

Those assigned to the experimental group reported statistically significant differences in physical activity stages of change, higher levels of physical activity and self-efficacy than those in the control group. Interventions to improve nutrition of AYAs have been also studied. Seventy-five post-treatment survivors (11 to 21 years old) participated in a health-promoting multiple behavior change counseling intervention (Mays et al., 2011). The intervention consisted on a half-day interactive behavioral workshop focus on nutrition and bone health behaviors. Results showed the intervention to be efficacious in improving self-reported milk consumption frequency, calcium supplementation, and dietary calcium intake at 1-month follow-up. Finally, a psychoeducational intervention has been also tested in a sample of 21 survivors aged 15 to 25 with the aim of enhancing psychosexual development (Canada, Schover, & Li, 2007). This intervention consisted in two individual counseling sessions lasting approximately 90-min each. The intervention group achieved significant improvements in all the targeted domains (fertility, body image, sexual function and impact of cancer therapy on sexual development).

Regarding the second area of intervention, this has been mainly focused on psychological issues, and using metacognitive therapy, cognitive and behavioral therapy (CBT), coping skills training, psychoeducational or social skills interventions. For example, metacognitive therapy has been used with a group of 12 AYA survivors aged 18-23 to alleviate emotional distress (Fisher, McNicol, Young, Smith, & Salmon, 2015), and results showed large and statistically significant reductions in anxiety, depression, trauma symptoms, and metacognitive beliefs and processes. CBT has also been used to manage cancer-related limitations in a study with a sample of 40 brain tumor survivors aged 4-18 years. Treatment lasted from 4 to 8 months with 2/3 weekly individual sessions lasting 45– 60 min, and results showed that the treatment group (N=17) showed a significant reduction on the withdrawn, somatic complaints and social and attention problems (Poggi et al., 2009). Kazak et al. (2004) implemented a CBT program for the treatment of posttraumatic stress symptoms. The study consisted in a randomized wait-list control trial with a sample of 150 survivors, 146 mothers, and 106 fathers. The age of survivors ranged from 10 to 19 years. The four-session intervention integrated CBT and family therapy approaches. The results showed significant reductions in intrusive thoughts among fathers and in arousal among survivors. Social skills interventions have also been studied with this group of patients. For example, Barrera and Schulte (2009), tested the effects of an intervention including eight 2-hr weekly sessions focusing on social skills -including friendship making and assertion- in 32 survivors aged 8–18 years, resulting in significant improvements from baseline to follow-up in self-control, social skills, and quality of life.

1.5.1 e-Health and AYA cancer survivors

e-Health is the use of electronic communication-based technologies to aid or provide healthcare in some form (Keogh, Rosser, & Eccleston, 2010). The type of interventions that are used with these technological alternatives is similar to the ones administered using the conventional (face-to-face) treatment modalities. Following with the classification used in the previous heading, in the category of interventions addressed to maintain or develop a healthy lifestyle, which are the more studied, we could include a study that used Facebook to increase moderate-to-vigorous intensity physical activity in AYA cancer survivors. The 12-week cognitive theory-based intervention with 86 participants (mean age 30 years) demonstrated its effectiveness significantly increasing the self-reported weekly minutes of moderate-to-vigorous physical activity (Valle, Tate, Mayer, Allicock, & Cai, 2013). Another example is a randomized control trial with follow-up at eight and 12 months with 796 smokers (mean age 31 years). Those assigned to a peer-counseling program that included up to six telephone calls from a trained childhood cancer survivor, tailored and targeted materials, and free nicotine replacement therapy were twice as likely to quit smoking, compared with those assigned to the control group. Results also showed that the more number of counseling calls they did, the more the smoking cessation rate increased (Emmons et al., 2005).

In the category of psychosocial interventions, an internet-based CBT, consisting in delivering 10 written messages thought a secure Internet platform, was used in a study with 20 survivors (Seitz et al., 2014). The aim of the treatment was to reprocess the traumatic cancer-related experiences and to build strategies to cope with current cancer- related fears. Results shown a significant reduction in anxiety. Those clinical improvements were sustained in those who completed the treatment. Helping survivors manage uncertainty about late effects, reducing related health risks and maximizing their health was the aim of a seven, 30-minute sessions of telephone-delivered coping skills training intervention with 20 AYA (ages between 15 and 25 years) and 16 parents. Despite the fact that sample size did not allow for the use of inferential statistics, the program showed feasibility and the authors concluded that in-person long-term follow-up plus telephone-delivered psychosocial care is a practical way to deliver integrated care to AYA and their parents (Judge Santacroce, Asmus, Kadan-Lottick, & Grey, 2010).

An increase in the number of participants and in their ages can be seen in studies that use information and communication technologies to deliver their treatments, compared to studies using conventional treatments. Both, conventional and e-Health treatments, started to be implemented and evaluated during the last decade (except for Emmons, 2005). Only three studies included family members (Judge Santacroce et al., 2010; Kazak et al., 2004; Poggi et al., 2009). Recently, different systematic reviews about health promotion in cancer survivors (Bradford & Chan, 2017; Kopp et al., 2017; Pugh et al., 2016; Wurz & Brunet, 2016) and psychological interventions (Bradford & Chan, 2017; Walker, Martins, Aldiss, Gibson, & Taylor, 2016) about both e-Health and conventional treatment, have been carried out; all of them highlight the lack of high-quality studies. Besides, Bradford & Chan (2017) showed that the interventions delivered face-to-face and those that facilitate peer-to-peer support are promising and anticipate the increase of the use of social media and technology to deliver interventions.

2. Objectives

2.1 Objective 1

To report on the needs of AYA cancer survivors after finishing a cancer treatment. To do so, a systematic review of the literature was conducted and is presented in Study I.

2.2 Objective 2

The aims of Study 2 were to: (1) better understand the needs and importance of these needs of AYAs after a cancer treatment, including their point of view as well as their caregivers' and the cancer health professionals and (2) indicate which of those needs are not currently adequately addressed. This is described in Study II.

2.3 Objective 3

The objective of this study was to evaluate the factor structure, internal consistency and convergent validity of the full- and short-forms of the Centrality of Event Scale (CES) when used with young people. This work is described in Study III.

3. Methods

Three studies are presented in this dissertation: a systematic review of the needs of AYAs (Study I), a Delphi study about the needs of AYAs survivors (Study II) and the validation of the Centrality of Event Scale (CES) for its use with Spanish-speaking youths (Study III). The methods of the studies are briefly described in this section, but they are provided in full in each of the articles (see the Results section of this dissertation).

3.1 Participants

The first study (Galán, de la Vega, & Miró, 2016) is a systematic review of the literature, for which the following combinations of keywords were used: (adolescent* OR young adult* OR childhood OR children OR teenager OR AYA) AND (cancer OR oncolog*) AND (survivor* OR post- treatment OR disease- free OR off- treatment) AND (need*). The following electronic databases were searched: ERIC, MEDLINE, EMBASE, PILOTS, ProQuest, PsycARTICLES, PsycBOOKS, psycCRITIQUES, PsycINFO, Social Services Abstracts, and Sociological Abstracts. Fourteen studies were included in the review.

For the second study (Galán et al., 2017a), three expert groups participated: (1) AYAs between 14 and 24 years old who had undergone a cancer treatment and were free of disease for at least 1 year, (2) immediate relatives of AYAs (including parents, guardians, siblings, or grandparents) or an non-relative caregiver of the patient participants (i.e. nanny, baby-sitter) and (3) physicians, nurses, physiotherapists, social worker or psychologists. All of them with clinical experience in oncology. A total of 17 AYA survivors, 12 relatives or caregivers of AYA survivors and 29 cancer experienced professionals participated in the Delphi study.

For the third study (Galán et al., 2017b) a convenience sample of 262 undergraduate students from the Universitat Rovira i Virgili (Catalonia, Spain) were invited to participate in a study about stressful events. Potential participants had to: (1) be able to speak and read Spanish and (2) be between 18 and 24 years old.

3.2 Procedure and measures

For the systematic review (Study I) PRISMA recommendations for systematic reviews were followed (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009), and the quality of the studies reviewed was assessed with a specific checklist (Hoekstra, Heins, & Korevaar, 2014).

The needs reported in the selected articles were classified according to their theme. In order to assess the quality of the reviewed studies, for each study we analyzed whether: (1) the research question was relevant; (2) a qualitative approach was chosen; (3) the recruitment process and the characteristics of the participants were reported; (4) the process of data collection was described; (5) the authors had obtained informed consent and the approval of an ethics committee; (6) there was an analysis section and (7) the conclusions were supported by the evidence and the limitations of the study discussed.

A Delphi methodology was used in Study II to address the study aims. This consisted of two rounds of an online survey that participants were invited to respond to, which included questions about socio-demographic information (age, sex, education, etc.) and open-ended questions about the needs of AYAs cancer survivors.

For the validation of the Centrality of Events Scale to Spanish population (Study III), we first translated the CES questionnaire into Spanish using a back-translation procedure (Miró, 1997) and then, we administered it to a group of students from the Universitat Rovira i Virgili.

A more detailed explanation of the procedures implemented can be found within each paper.

4. Results

The three studies included in the dissertation are provided in this section:

- Study I: Galán, S., de la Vega, R. & Miró, J. (2016). Needs of adolescents and young adults after cancer treatment: a systematic review. *European Journal of Cancer Care*, 00: 1–14. doi: 10.1111/ecc.12558

- Study II: Galán, S., de la Vega, R., Tomé Pires, C., Racine, M., Solé, E., Jensen, M., & Miró, J. (2017). What are the needs of adolescents and young adults after a cancer treatment? A Delphi study. *European Journal of Cancer Care*, *26*(2), e12488. doi.org/10.1111/ecc.12488

- Study III: Galán, S., Castarlenas, E., Racine, M., Sánchez-Rodríguez, E., Tomé-Pires, C., Jensen, M. P., & Miró, J. (2017). Factor Structure, Internal Consistency and Criterion Validity of the Full-form and Short-form Versions of the Centrality of Events Scale in Young People. Applied Cognitive Psychology. http://doi.org/10.1002/acp.3369

4.1 Study I

Needs of adolescents and young adults after cancer treatment: a systematic review.

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from prevention to palliation

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Needs of adolescents and young adults after cancer treatment: a systematic review

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The aim of this study was to conduct a systematic review of the literature on the needs of adolescents and young adults (AYAs) who have survived cancer. PRISMA recommendations for systematic reviews were followed, and the quality of the studies reviewed was also assessed with a specific checklist. The following databases were searched from their inception to May 2016: ERIC, EMBASE, MEDLINE, PILOTS, ProQuest, PsycARTICLES, PsycBOOKS, psycCRITIQUES, PsycINFO, Social Services Abstracts and Sociological Abstracts. Fourteen studies were identified and analysed. The results show that the most common needs for AYA cancer survivors are as follows: "individualised information and advice," "counselling and psychological support" and "social support, and social relationships." These results are different from those reported in studies on adults, which shows the importance of specifically addressing the needs of this population. In order to advance in this emerging area of study and facilitate the work of health professionals, it is crucial to reach a consensus on two central issues: how the needs of AYA survivors should be conceptualised and what the most valid and reliable procedure for assessing patient's needs is.

KEYWORDS
adolescent, cancer survivor, needs, systematic review, young adults

1 | INTRODUCTION

In many cases, cancer is no longer a deadly disease but a chronic one. For example, it has been estimated that by 2024, the population of cancer survivors will have increased to almost 19 million in the United States (Shaitelman et al., 2015). Specifically, the cancer mortality for adolescents in the United States declined by 52% from 1975–1977 to 2007–2010, and the 5-year overall survival rate among adolescents exceeded 80% for the years 2003–2007 (Smith, Altekruse, Adamson, Reaman, & Seibel, 2014). In Europe, the 5-year survival for all cancers was 87% for adolescents and young adults (AYAs; Gatta et al., 2009). The numerous definitions of cancer survivorship (Khan, Rose, & Evans 2012) include different actors (family members, friends and caregivers) and/or stages (acute, extended and permanent) in the survivorship experience (Miller, Merry, & Miller, 2008). Generally speaking, however, a cancer survivor is defined as the person who "has completed primary treatment or the major aspects of treatment and either desires or needs to 'get on with [his or her] life'." (Feuerstein, 2007, p. 7).

One of the reasons for this increase in AYA cancer survivorship is the headway that has been made in early detection and treatment. Although the development of new and more powerful treatments has resulted in this positive situation of longer lives, they still have a number of negative side effects. These so-called late effects are treatment specific—that is, the kind of side effect and its intensity will depend on the cancer treatment—but they all contribute to one extent or another to the deterioration of the quality of life of AYA cancer survivors (Bleyer, 2007), and that of their family members (Ljungman et al., 2014). For example, AYAs are more likely than either younger children or older adults to be diagnosed with Hodgkin lymphoma, melanoma, testicular cancer, thyroid cancer or sarcoma (Bleyer et al., 2008), and they have an increased risk of heart disease, high blood pressure, asthma and diabetes (Tai et al., 2012). Specific risks of young adults are also seen in cardiac toxicity, second malignancies, pulmonary complications and psychosocial difficulties when compared with older or younger cancer survivors (Woodward, Jessop, Glaser, & Stark, 2011). Therefore, they are treated differently, and the late effects are also expected to be different. But as well as type of illness, other factors justify why AYAs, as a group, require specific attention. For example, developmental aspects may affect reactions after cancer diagnoses (e.g., an adolescent may not be as able to cope with the fact that he/she has cancer; Compas, Jaser, Dunn, & Rodriguez, 2012). Of these health-related problems or so-called late effects, only some are really important or relevant for AYA survivors, and these become their needs, for example, social needs, information sharing and communication needs, and service provision needs (Tsangaris et al., 2014).

Therefore, although today many more patients survive cancer than before, healthcare plans must provide for the fact that cancer patients are likely to live longer, free of this once deadly disease, but suffering from a wide range of treatment-related problems.

Adolescent and young adult cancer survivors report that they have healthcare needs that are not satisfied by the healthcare system (Keegan et al., 2012; Miedema, Easley, & Robinson, 2013; Zebrack, 2009). In order for the healthcare system to fulfil these unmet needs, and provide the best possible care, clinicians and researchers should map out the terrain, identifying what these needs are and developing specific guidelines about how they can be satisfied. To the best of our knowledge, there is little structured information or guidelines about the specific needs of young cancer survivors and how they can best be addressed. The aim of this systematic review is to report on the needs of adolescent and young adult cancer survivors after their treatment.

2 | METHODS

A systematic review was conducted in accordance with the PRISMA recommendations for reporting systematic reviews and meta-analyses (Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group, 2009). The following electronic databases were consulted: ERIC, MEDLINE, EMBASE, PILOTS: Published International Literature on Traumatic Stress, ProQuest, PsycARTICLES, PsycBOOKS, psycCRITIQUES, PsycINFO, Social Services Abstracts, and Sociological Abstracts. The combinations of keywords used for the search were as follows: (adolescent* OR young adult* OR childhood OR children OR teenager OR AYA) AND (cancer OR oncolog*) AND (survivor* OR post-treatment OR disease-free OR off-treatment) AND (need*). The search included all records published before May 2016. In order to maximise the number of articles retrieved, reference lists of relevant articles were also checked for additional works not found during the computerised database searches.

An article was eligible if it met all of the following criteria: (1) it had been published in a peer-reviewed journal; (2) it had been reported as a full paper and not just a summary; (3) it was written in English or Spanish; (4) the participants were adolescents or young adults who had completed a cancer treatment, regardless of the age at the time of diagnosis; and (5) it focused on the assessment of biological, psychological and/or social needs. There is a clear inconsistency across the oncology literature regarding how the AYA age group is defined (Geiger & Castellino, 2011), with studies in different countries using different age ranges. In our study, we used the age range of 14–39 which is used in many works and also matches the recommendation for the upper age limit by a recent roundtable discussion with an international group of oncology researchers (Journal of Adolescent and Young Adult Oncology - Editors, 2011).

The articles were evaluated by two researchers (SG and RdlV) to check whether they met the inclusion criteria. If there was any disagreement about eligibility for inclusion, this was discussed until consensus was reached. A third researcher (JM) was asked to help make a decision, if there were any difficulties in reaching consensus.

To assess the quality of the studies in this review, a checklist for qualitative and quantitative studies was used. This checklist had been successfully used in a similar study by Hoekstra, Heins, and Korevaar (2014) that studied the needs of adult cancer survivors. Again, following the PRISMA protocol, and in order to avoid risk of bias, two researchers (SG, RdlV) independently assessed the articles selected using the checklist. If there were any differences, they were resolved by discussion. If no agreement could be reached, a third reviewer (JM) was asked to help reach a decision. For each study, it was determined whether: (1) the research question was relevant; (2) reasons had been given why a qualitative approach had been chosen; (3) the recruitment process and the characteristics of the participants were reported; (4) the process of data collection was described; (5) the authors had asked for informed consent and approval by an ethics committee; (6) there was an analysis section and (7) the conclusions were supported by the evidence and the limitations of the study were discussed. The quality score was determined number resulting from the sum of all positive response to the items divided by the total number of items. Additional information about the quality of the studies is reported in Table 1.

To make the extremely heterogeneous information manageable for analysis, the needs reported in the selected articles were classified according to their theme, in the same way as previous similar procedures (e.g., Hoekstra et al. 2014). For example, needs related to support groups, or meeting other survivors and sharing social activities, were included under the category of “Social network, social support and social relationships” because of their social theme. Similarly, issues alluding to a system for transitioning care from oncologists to general physicians or seeing a pain management specialist, a physical or occupational therapist was included under the category of “Adapted healthcare according to the new post-treatment status.” Eight categories were created after analysing the assessed needs to summarise the information: (1) *Individualised information and advice*: at the individual level, this category alludes to information on the surveillance and monitoring of late effects, diet and nutrition, and support services. At the family level, it includes the need for information on the risk of having cancer in the family or the possibility of having children; (2) *Adapted healthcare*: this category refers to the new status after treatment and includes a system for transitioning care from oncologist to general physician and the availability of professional care from nurses, physical or occupational therapists and pain management experts; (3) *Relapse detection*: this category provides information about the procedures for checking whether cancer has returned; (4) *Counselling and psychological support*: this category gives information about whether AYAs have access to psychologists or mental health professionals for

TABLE 1 Assessment of the quality of the reviewed studies

Author and year	Research question relevant	Reason qualitative approach	Recruitment	Selection bias avoided	Group characteristics	Methods of interviewing	Location	Duration and/or number	Role researchers described and influence considered	Confidentiality ensured	Approval of ethics committee	Analysis described	Theoretical foundation	Analysis validated	Raw data accessible to others	Counterexamples	Interpretation supported by findings	Conclusion clear	Limitations considered	Score (Y)	Per cent
D'Agostino and Edelstein (2013)	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	U	N	Y	Y	Y	15/19	79
Easley et al. (2013)	Y	N	Y	N	Y	Y	N	N	N	U	Y	Y	Y	Y	U	Y	Y	Y	Y	12/19	63
Gianinazzi et al. (2014)[a]	Y	–	Y	Y	Y	Y	–	N	–	Y	Y	Y	–	–	U	–	Y	Y	Y	11/13	84
Keegan et al. (2012)[a]	Y	–	N	Y	Y	Y	–	N	–	Y	Y	N	–	–	U	–	Y	Y	Y	9/13	69
Knijnenburg et al. (2010)[a]	Y	–	Y	Y	Y	Y	–	N	–	Y	N	Y	–	Y	U	–	Y	Y	N	10/13	77
McClellan et al. (2013)[a]	Y	–	Y	Y	Y	Y	–	N	–	Y	Y	Y	–	–	U	–	Y	Y	Y	11/13	84
Miedema et al. (2013)	Y	N	Y	Y	Y	Y	Y	N	N	U	Y	Y	Y	Y	U	N	Y	Y	Y	13/19	68
Millar et al. (2010)[a]	Y	–	N	U	N	Y	–	N	–	Y	Y	Y	–	–	U	–	Y	Y	Y	8/13	61
Rabin et al. (2011)	Y	N	Y	N	Y	Y	N	Y	N	Y	U	Y	Y	Y	U	Y	Y	Y	Y	13/19	68
Rabin et al. (2013)	Y	N	Y	N	Y	Y	N	Y	N	Y	U	Y	Y	Y	U	N	Y	Y	Y	12/19	63
Sundberg et al. (2012)[a]	Y	–	Y	N	Y	Y	Y	N	–	Y	Y	Y	Y	–	U	–	Y	Y	Y	12/13	92
Zebrack et al. (2006)	Y	Y	Y	Y	Y	Y	N	U	Y	U	Y	Y	Y	Y	U	Y	Y	Y	Y	15/19	79
Zebrack et al. (2007)[a]	N	–	Y	Y	Y	Y	–	Y	–	Y	Y	Y	–	–	U	–	Y	Y	Y	11/13	84
Zebrack (2009)[a]	Y	–	Y	Y	Y	Y	–	Y	–	Y	Y	Y	–	–	U	–	Y	Y	Y	12/13	92

Y, yes; N, no; U, unclear.

[a] These are quantitative studies; therefore, not all quality criteria are applicable herein.

the assessment and counselling on how to manage distress, unwanted thoughts or emotions; (5) *Financial support*: this category describes the financial assistance and benefits that are available to patients and families; (6) *Back to normal life and adaptation to the new role*: this category describes the help that can be given to AYAs so that they can return to normal life after experiencing the difficulties of cancer; (7) *Healthy lifestyle*: this category is about staying physically fit or doing exercise; and (8) *Social network, social support and social relationships*: this category contains information about social contact and support (meeting other survivors like themselves, joining support groups or getting support from family or friends). This categorisation was made by two researchers on the basis of the information obtained from the studies in the review. Discrepancies of opinion were resolved by asking a third researcher.

3 | RESULTS

In an initial screening of the 1,329 studies first identified, duplicate articles were identified and excluded, and a total of 1,301 titles and abstracts were reviewed. Of these, 1,240 articles were excluded by applying the inclusion/exclusion criteria and 61 articles were reviewed in full. After this in-depth analysis of the papers' content, a further 47 articles were excluded. Finally, 14 studies were selected for the final analysis and synthesis. Figure 1 describes the selection process used in this study.

All the studies retrieved had been conducted recently: no studies were found that had been published before 2006. Most studies (six) were conducted in the United States. But there are other studies from Canada (D'Agostino & Edelstein, 2013; Easley, Miedema, & Robinson, 2013; Miedema et al., 2013; Zebrack, 2009), Switzerland (Gianinazzi et al., 2014), the Netherlands (Knijnenburg, Kremer, van den Bos, Braam, & Jaspers, 2010), Sweden (Sundberg, Lampic, Arvidson, & Wettergren, 2012) and Australia (Millar, Patterson, & Desille, 2010). The sample size ranged from as few as 20 participants (Rabin, Simson, Morrow, & Pinto, 2011, 2013) to as many as 1,088 (Zebrack, Mills, & Weitzman, 2007). All the study samples consisted of AYA, with the exception of one study that also collected data from health professionals (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006) and another

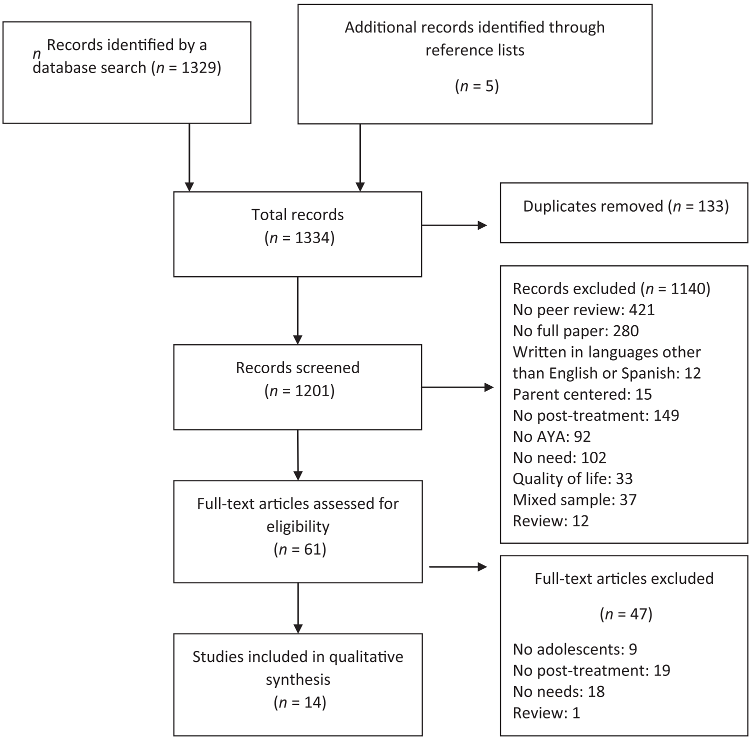

FIGURE 1 PRISMA protocol

that requested information from parents (Knijnenburg et al., 2010). All the studies had both male and female participants except for one that gave no information about the sex of the participants (Zebrack et al., 2006). For the most part, the participants were women (ranging from 53% to 75% of the samples). All samples included people with different types of cancer, although one article gave no information on this issue (Millar et al., 2010). One of the studies in this review had participants up to 44 years of age. Although our upper age range was 39, we made an exception for this specific study (Zebrack et al., 2006), because it included AYA participants and the mean age (31 years) was within the range of our criteria.

3.1 | Design and quality of the studies

Eight studies used a quantitative methodology and the other six used a qualitative methodology. Of those using a qualitative methodology, four used ad hoc open-ended questionnaires (Easley et al., 2013; Miedema et al., 2013; Rabin et al., 2011, 2013), one another used a focus group (D'Agostino & Edelstein, 2013) and a last one conducted a Delphi study that included patients and professionals (Zebrack et al., 2006). Of the eight using a quantitative methodology, six used a questionnaire (Gianinazzi et al., 2014; Keegan et al., 2012; Knijnenburg et al., 2010; McClellan et al., 2013; Millar et al., 2010; Sundberg et al., 2012; Zebrack, 2009) and the other one asked participants to put a list of needs provided by the authors in order of importance (Zebrack et al., 2007). No study used validated measures to assess their participants' needs. Their quality score ranged between 61 and 92 on a scale from 0 to 100, and the average was 75. Additional information about the quality of the studies is reported in Table 1.

3.2 | Main topic

The study questions of the reviewed studies differ greatly: 11 studies focused on perceived patients' needs (D'Agostino & Edelstein, 2013; Easley et al., 2013; Gianinazzi et al., 2014; Keegan et al., 2012; Knijnenburg et al., 2010; Miedema et al., 2013; Millar et al., 2010; Sundberg et al., 2012; Zebrack, 2009; Zebrack et al., 2006, 2007); two assessed the intervention programmes the patients might need and what these programmes should be like (Rabin et al., 2011, 2013); and a final study described the relationship between the intensity of the cancer treatment and the needs that patients have after the treatment (McClellan et al., 2013).

3.3 | Assessed needs

Three of the eight categories that we created to summarise the information about survivor needs coincided with what was most frequently assessed (in 12 of the 14 studies): individualised information and advice, counselling and psychological support, and social network, social support, and social relationships.

Finally, the categories that had been studied the least (in 3 of the 14 studies) were those that had to do with relapse detection, financial

TABLE 2 Summary of the needs assessed in each study, classified by categories

	D'Agostino and Edelstein (2013), Canada	Easley et al. (2013)	Gianinazzi et al. (2014)	Keegan et al. (2012)	Knijnenburg et al. (2010)	McClellan et al. (2013)	Miedema et al. (2013), Canada	Millar et al. (2010)	Rabin et al. (2011)	Rabin et al. (2013)	Sundberg et al. (2012), Sweden	Zebrack et al. (2006)	Zebrack et al. (2007)	Zebrack (2009)	Total number of times an item was assessed
Individualised information and advice[a]	*1*	–	*5*	*6*	*4*	*8*	–	*3*	*2*	–	*1*	*5*	*2*	*5*	*42*
Individualised information (having children, cancer risks to your family)	1	–	1	4	1	3	–	2	1	–	–	2	1	2	18
Surveillance and assessment of long-term effects of cancer treatment	–	–	1	1	–	3	–	–	–	–	–	2	–	–	7
Nutrition and diet	–	–		1	–	1	–	–	1	–	–	–	–	1	4
Guidelines for follow-up care	–	–	1	–	1	–	–	–	–	–	–	1	1	–	4
Information about support services and available help	–	–		–	–	–	–	1	–	–	1	–	–	1	3
Information about decreasing the risk of having cancer again	–	–	1	–	1	1	–	–	–	–	–	–	–	–	3
Internet site	–	–	1	–	1	–	–	–	–	–	–	–	–	1	3
Social network, social support, social relationships	*1*	*5*		*3*	–	*1*	–	–	*1*	*3*	*1*	*3*	*4*	*2*	*24*
Support groups	1	1	–	1	–	–	–	–	1	2	–	–	1	–	7
Opportunities to meet other survivors	–	1	–	1	–	–	–	–	–	1	–	1	1	–	5
Support, counselling from family and friends	–	1	–	–	–	–	–	–	–	–	1	–	1	1	4
How to talk about your cancer experience with family, coworkers and friends	–	–	–	1	–	1	–	–	–	–	–	–	–	–	2
Assistance to pursue social activities and relationships	–	1	–	–	–	–	–	–	–	–	–	1	1	–	3
Opportunities to get involved and "give back" to the cancer community	–	1	–	–	–	–	–	–	–	–	–	1	–	–	2
Child care	–	–	–	–	–	–	–	–	–	–	–	–	–	1	1
Counselling and psychological support	*1*	*1*	–	*2*	–	*1*	*2*	*4*	*1*	–	*1*	*2*	*2*	*4*	*21*
Psychological and behavioural risk assessment and counselling to manage distress (anxiety about recurrence)	–	–	–	–	–	1	1	–	–	–	–	1	1	–	4

(continues)

TABLE 2 (continued)

	D'Agostino and Edelstein (2013), Canada	Easley et al. (2013)	Gianinazzi et al. (2014)	Keegan et al. (2012)	Knijnenburg et al. (2010)	McClellan et al. (2013)	Miedema et al. (2013), Canada	Millar et al. (2010)	Rabin et al. (2011)	Rabin et al. (2013)	Sundberg et al. (2012), Sweden	Zebrack et al. (2006)	Zebrack et al. (2007)	Zebrack (2009)	Total number of times an item was assessed
Help with unwanted thoughts, emotions and images of the cancer experience	–	–	–	–	–	–	–	2	–	–	–	–	–	–	2
Seeing a psychiatrist, psychologist, social worker or mental health worker	–	–	–	1	–	–	–	–	–	–	–	–	–	1	2
Talking with a spiritual or religious counsellor about the cancer	–	–	–	1	–	–	–	–	–	–	–	–	–	1	2
Counselling	1	1	–	–	–	–	–	–	1	–	1	–	1	–	5
Living with uncertainty	–	–	–	–	–	–	–	–	–	–	–	1	–	–	1
Counselling related to sexuality or intimacy	–	–	–	–	–	–	1	–	–	–	–	–	–	1	2
Alcohol or drug abuse counselling	–	–	–	–	–	–	–	–	–	–	–	–	–	1	1
Help dealing with my parent/carer(s) being overprotective	–	–	–	–	–	–	–	1	–	–	–	–	–	–	1
Help dealing with loneliness	–	–	–	–	–	–	–	1	–	–	–	–	–	–	1
Adapted healthcare according to the new status of post-treatment	–	–	–	*3*	–	*1*	*2*	*1*	–	–	*2*	*3*	*3*	*2*	*17*
A system for transitioning care from oncologists to physicians	–	–	–	–	–	–	–	–	–	–	–	1	1	–	2
Availability of healthcare providers	–	–	–	–	–	–	1	1	–	–	1	–	1	–	4
Adequate health insurance	–	–	–	–	–	–	1	–	–	–	–	1	1	–	3
Recognition among healthcare professionals that off-treatment survival is a new stage of patient care	–	–	–	–	–	–	–	–	–	–	–	1	–	–	1
Getting or retaining health, life or disability insurance after cancer	–	–	–	–	–	1	–	–	–	–	–	–	–	–	1
Seeing a pain management expert	–	–	–	1	–	–	–	–	–	–	–	–	–	–	1
Seeing a physical or occupational therapist	–	–	–	1	–	–	–	–	–	–	1	–	–	–	2
Having a nurse come to your home	–	–	–	1	–	–	–	–	–	–	–	–	–	–	1
Camps, retreats	–	–	–	–	–	–	–	–	–	–	–	–	–	1	1
Transportation assistance	–	–	–	–	–	–	–	–	–	–	–	–	–	1	1

(continues)

TABLE 2 (continued)

	D'Agostino and Edelstein (2013), Canada	Easley et al. (2013)	Gianinazzi et al. (2014)	Keegan et al. (2012)	Knijnenburg et al. (2010)	McClellan et al. (2013)	Miedema et al. (2013), Canada	Millar et al. (2010)	Rabin et al. (2011)	Rabin et al. (2013)	Sundberg et al. (2012), Sweden	Zebrack et al. (2006)	Zebrack et al. (2007)	Zebrack (2009)	Total number of times an item was assessed
Back to normal life and adaptation to the new role	*–*	*–*	*–*	*–*	*–*	*–*	*1*	*8*	*–*	*1*	*1*	*3*	*–*	*–*	*14*
Getting back to normal, who I am	–	–	–	–	–	–	–	1	–	–	1	1	–	–	3
Ability to express and cope with feelings about cancer (frustration)	–	–	–	–	–	–	–	1	–	–	–	1	–	–	2
Help with thinking about the future (studies, career)	–	–	–	–	–	–	–	2	–	–	–	–	–	–	2
Finding enjoyment in my life	–	–	–	–	–	–	–	1	–	–	–	–	–	–	1
Help with coping with my loss of independence	–	–	–	–	–	–	–	1	–	–	–	–	–	–	1
Responsibility for one's own healthcare	–	–	–	–	–	–	–	–	–	–	–	1	–	–	1
Assistance in getting back to work	–	–	–	–	–	–	1	1	–	–	–	–	–	–	2
Help with focusing on tasks and/or remembering things	–	–	–	–	–	–	–	1	–	–	–	–	–	–	1
Need to balance personal needs and competing work, family and other demands	–	–	–	–	–	–	–	–	–	1	–	–	–	–	1
Financial support	*–*	*–*	*–*	*2*	*–*	*–*	*1*	*–*	*–*	*–*	*1*	*1*	*–*	*1*	*6*
Financial assistance and benefits		–	–	2	–	–	1	–	–	–	1	1		1	6
Relapse detection	*–*	*–*	*–*	*3*	*–*	*1*	*–*	*1*	*–*	*–*	*–*	*–*	*–*	*–*	*5*
Handling concern about the cancer returning or getting another type of cancer	–	–	–	2	–	–	–	–	–	–	–	–	–	–	2
How to check signs that cancer has returned	–	–	–	1	–	–	–	–	–	–	–	–	–	–	1
Symptoms that should prompt you to call your doctor	–	–	–	–	–	1	–	–	–	–	–	–	–	–	1
Help with dealing with the possibility of the disease returning	–	–	–	–	–	–	–	1	–	–	–	–	–	–	1
Healthy lifestyle	*–*	*–*	*–*	*1*	*–*	*1*	*–*	*–*	*2*	*–*	*–*	*–*	*–*	*1*	*5*
Staying physically fit or doing exercise	–	–	–	1	–	1	–	–	1	–	–	–	–	1	4
Relaxation (yoga, meditation, etc.)	–	–	–	–	–	–	–	–	1	–	–	–	–	–	1

–, not assessed. [a]The number represents the frequency that a need is assessed in the study (e.g., if a need is reported twice in an article, then it is coded with a "2").

support, and returning to normal life and adapting to the new role. Table 2 provides additional details.

3.4 | Reported outcomes

3.4.1 | Time after the end of the treatment and follow-up care

One study reported the differences in the types of need depending on the time elapsed since treatment (Millar et al., 2010). According to Millar et al. (2010), for participants who had undergone treatment less than a year before, the unmet needs were directly related to healthcare provision and the hospital experience. For participants who had undergone treatment more than 1 year before, however, most unmet needs were related to emotional/psychological issues, and particularly survivorship and life direction. According to Miedema et al. (2013), young adult cancer survivors have an inadequate cancer follow-up care.

3.4.2 | Type of treatment

The type of treatment that participants received is reported in two of the eight articles in the review (Keegan et al., 2012; McClellan et al., 2013). Participants treated with chemotherapy (versus surgery only) had greater unmet needs related to the possible long-term side effects of treatment (Keegan et al., 2012). However, the intensity of the treatment correlated with the number of late effects experienced (McClellan et al., 2013).

3.4.3 | Sex

Two studies reported the differences between the needs of men and women (Keegan et al., 2012; McClellan et al., 2013). According to these studies, men were more likely to report unmet information needs than women. However, women requested more information about fertility-related topics.

3.4.4 | Age

According to Keegan et al. (2012), older participants were more likely to report unmet needs related to treatment, possible long-term side effects, financial support for care, and concerns about getting another type of cancer. Zebrack et al. (2007) informed that younger respondents reported significantly more needs for fertility information and services and for scheduling treatments to fit their lifestyles. They gave greater importance to support from family and friends. Older respondents, however, attributed greater importance to availability of age-appropriate information, psychological counselling, and being responsible for one's own healthcare and decision-making. Finally, D'Agostino and Edelstein (2013) informed about many similar psychosocial and information needs that young adult cancer survivors have, for example, physical appearance, fertility, late effects, social relationships and changing priorities. These needs differ from those of paediatric and older adult survivors.

A summary of the domains assessed in each study and its outcomes are presented in Table 3.

4 | DISCUSSION

The percentage of young people surviving cancer has increased enormously in the last 30 years (Gatta et al., 2009; Steliarova-Foucher et al., 2004). Identifying their problems, understanding their needs and providing satisfactory therapeutic responses to the late effects of cancer treatment are critical if their quality of life is to be improved. To map out this area, we conducted a systematic review of the studied needs of young people who have completed a cancer treatment.

Some of our results coincide with the findings of a recent review of the needs of adults. Hoekstra et al. (2014) found that the most common needs of adult cancer survivors were "the need to receive support from the general practitioner" followed by "the need for help with medical issues" and "the need for information on cancer." In this review, we also found that the type of information that cancer survivors demand is mostly related to treatment and rehabilitation. However, Hoekstra et al. (2014) found that being able to talk about the impact of the disease, getting medical help for problems not related to cancer and obtaining information about their illness from their doctors were all key factors for adults. In our review of studies with AYA, patients tend to seek social support from their families and friends, not their doctors. Moreover, support and access to specialists (e.g. psychologists) is highly valued by young people but is not common in older cancer survivors. A recent systematic review of studies on both cancer survivors and patients also provides similar findings. In their review, Tsangaris et al. (2014) show that the most common needs in these two populations are sharing information and receiving psychological/emotional support. The divergence in the findings between these reviews and ours could be due to the fact that different evaluation tools were used to assess needs (in the study by Hoekstra et al., 2014) and the populations under study (in the study by Tsangaris et al., 2014). Our position is that the needs of teenagers and young adults who have completed a cancer treatment are different from those of adults. Needs might be influenced by developmental issues, life projects, social relationships, worries and other age-related issues. Differences in patients' needs might also be related to the sex of the patient. For example, in a study with a sample of 272 participants (53% women), McClellan et al. (2013) observed that women wanted more information about fertility-related topics than men.

Similarly, time also seems to be a factor that should be taken into account when support programmes for cancer survivors are designed. For example, Millar et al. (2010) showed that needs changed with time: at first, needs are directly related to healthcare provision and the hospital experience, but then they shift and change into needs that are more focused on emotional/psychological issues, particularly survivorship and life direction. However, some side effects appear several years after completing the treatment, so long-term follow-ups to study how these needs change are warranted.

TABLE 3 Sample description, measures and outcomes from the studies included in the review

Authors and country	Sample description	Measures and domains assessed	Reported outcomes
D'Agostino and Edelstein (2013), Canada	*N* = 22 (45% women) Age range: 18–35 ($\bar{X}$= no reported) Type of cancer – Brain – Breast – Testicular – Non-Hodgkin-lymphoma – Hodgkin lymphoma – Leukaemia	Four focus group: – Challenges – Current resources – Programme recommendations – Programming inclusion criteria – Additional comments	Common challenges – Appearance, fertility, late effects – Emotions, cognition, relationships, priorities Specific challenges: age at diagnosis – Identity, social isolation, protecting parents – Healthcare transitions, financial burden – Brain tumour diagnosis – Cognition, social skills, living with a brain tumour – Limited options, loss of autonomy Resource needs – Peer support, professional counselling – Probing for symptoms, age-specific information, education – Inclusion criteria for young adult programming
Easley et al. (2013), Canada	*N* = 12 (12% women) Age range: 28–38 ($\bar{X}$ 34) Type of cancer Thyroid cancer	Telephone interviews with 11 open-ended questions: – Socio-demographic information – Current cancer follow-up care – Broad current cancer follow-up care issues (i.e., physical, psychological, relationship and social) – Recommendations for improvement	– Psychological impact – Lack of support – Isolation from other cancer survivors – Isolation from peers without cancer – Isolation during treatment
Gianinazzi et al. (2014), Switzerland	*N* = 319 (44% women) Age range: >18 ($\bar{X}$ 21.4) Type of cancer: – Leukaemia – Lymphoma – Central nervous system tumour – Neuroblastoma – Retinoblastoma – Renal tumour – Hepatic tumour – Bone tumour – Soft-tissue sarcoma – Germ cell tumour	Online survey questions: – Socio-demographic information – Follow-up care – Information provision – Transition – Psychological distress – Quality of life	– The information survivors reported to have received on disease, treatment, follow-up, and late effects – Their information needs in these four domains and the format in which they would like it provided – The association with psychological distress and quality of life
Keegan et al. (2012), USA	*N* = 523 (37% women) Age range: 15–39 ($\bar{X}$ not reported) Type of cancer: – Lymphocytic leukaemia – Hodgkin's lymphoma – Non-Hodgkin's lymphoma – Germ cell cancer – Sarcoma	AYA HOPE survey (76% self-reported paper version, 22% online version and 2% telephone interview): – Demographic characteristics – Information needs – Service needs – Barriers to and quality of healthcare – Treatment and symptoms – Insurance status, information and service needs – The impact of cancer – Psychosocial and physical functioning	– Unmet information needs – Total and unmet service needs – Socio-demographic and health-related differences in reporting unmet needs

(continues)

TABLE 3 (continued)

Authors and country	Sample description	Measures and domains assessed	Reported outcomes
Knijnenburg et al. (2010), The Netherlands	*N* = 145 (19% women) Age range: >12 ($\bar{X}$ = 16.2) Type of cancer: – Leukaemia – Lymphoma bone tumour – Wilms' or any other kidney tumour – Neuroblastoma – Germ cell tumour – Central nervous system tumour – Retinoblastoma	Online survey questions: – Personal information – Evaluation of information supplied by the outpatient follow-up clinic – Internet availability, health-related Internet use and late effects-related Internet use – Information and functional requirements for, and expectations of, a late-effects website	– Internet use – Main information items requested
McClellan et al. (2013), USA	*N* = 272 (53% women) Age range: 18–38 ($\bar{X}$ = 24) Type of cancer: – Leukaemia or lymphoma – Solid tumour – Brain tumour	Self-report survey: – Demographic information – Cancer history – Side effects of treatment – Current health status – Survivor treatment summary – Survivor experience and needs	– Late effects from the functional domain – Correlation between treatment intensity and the number of side effects
Miedema et al. (2013), Canada	*N* = 53 (74% women) Age range: 18–39 ($\bar{X}$ = 29) Type of cancer: – Breast thyroid – Non-Hodgkin-lymphoma – Hodgkin lymphoma – Testicular – Other	Telephone interviews. Open-ended questions: – Socio-demographic information – Current cancer follow-up care (CFC) – Broad CFC (physical, psychological, relationship, and social) – Experiences and satisfaction with the participants' current CFC and their recommendations for improvement	– Need for age-specific care – Medical care needs – Psychological care needs – Social care needs – System care needs
Millar et al. (2010), Australia	*N* = 63 (63% women) Age range: 18–25 ($\bar{X}$= 20.4) Type of cancer: Not reported	The Cancer Needs Questionnaire for Young People (CNQ-YP): – Structure of care – Process of care – Relationships – Information – Daily living Cancer needs: Emotional/Psychological, School/Occupational 24 additional need items developed from previous qualitative research Depression, Anxiety and Stress Scales (DASS-21): – Depression – Anxiety – Stress	The top 10 unmet needs according to the time since treatment

(continues)

TABLE 3 (continued)

Authors and country	Sample description	Measures and domains assessed	Reported outcomes
Rabin et al. (2011)[a], USA	*N* = 20 (75% women) Age range: 18–39, ($\bar{X}$ = 33.5) Type of cancer: – Thyroid – Breast – Melanoma – Sarcoma – Rectal – Nasopharyngeal carcinoma – Leukaemia – Hodgkin's lymphoma – Endometrial – Brain	Face-to-face individual interview, with open-ended questions: – Programmes that might be helpful (needed and/or wanted) – Barriers that might interfere with participation in these programmes	Types of programme: – Physical activity – Relaxation – Emotional support – Information – Nutrition/weight management Programmes designed: Similarity of participants barriers: – Time – Being unaware of programmes – Health-related barriers – Psychosocial barriers
Rabin et al. (2013)[a], USA	*N* = 20 (75% women) Age range: 18–39, ($\bar{X}$ = 33.5) Type of cancer: – Thyroid – Breast – Melanoma – Sarcoma – Rectal – Nasopharyngeal carcinoma – Leukaemia – Hodgkin's lymphoma – Endometrial – Brain	Face-to-face individual interview with open-ended questions: – Types of programme that might be helpful for young adult cancer survivors – Programme delivery – Format (group or individual) – Barriers to programme participation	– Advantages/disadvantages of different types of intervention formats (telephone-based, print-based, computer-based, in-person) – Preferences (individual or group) – Need to balance personal needs and competing work, family and other demands – Importance of site and time being convenient – The key role of social support – Personal needs (e.g., to connect with other young adult cancer survivors) as well as their family, work and other commitments – Personal need for support from others (online)
Sundberg et al. (2012), Sweden	*N* = 224 (51% women) Age range: 18–37, ($\bar{X}$ = 24) Type of cancer: – Leukaemia – CNS tumours – Solid tumours	Telephone interview: – Questions about need of support – Sense of coherence (SOC) scale	Sense of coherence need for support: – Psychosocial – Medical – Physiotherapy – Financial – Educational – Support in daily activities
Zebrack et al. (2006), USA	*N* = 40 oncology professionals; 37 young adults (sex not reported) Age not reported. Age range of patients: 18–44 ($\bar{X}$ = 31) Type of cancer: – Brain tumour – Breast cancer – Endometrial – Germ cell, testicular or ovarian – Sarcomas – Hodgkin lymphoma – Leukaemia – Melanoma – Other	Delphi panel: three iterative rounds of mailed surveys for professionals and young adults: 1st round: (1) biomedical and/or psychosocial needs for young adult cancer patients (at diagnosis and during treatment and off-treatment survivors). (2) Vision of what optimal cancer care for young adults should be, from diagnosis through treatment, and into off-treatment survival or end-of-life 2nd round: (1) score the importance of each item, (2) rank order the five most important items within each category, and (3) add further items to the list, if necessary 3rd round: rank order items for each section	The top five needs of the following categories: – Biomedical treatment-related needs at diagnosis and during treatment – Counselling, information, and supportive care needs at diagnosis and during treatment – Other psychosocial needs at diagnosis and during treatment – Treatment and long-term healthcare needs – Counselling, information, and supportive care needs for off-treatment survivors – Other psychosocial needs for off-treatment survivors

(continues)

TABLE 3 (continued)

Authors and country	Sample description	Measures and domains assessed	Reported outcomes
Zebrack et al. (2007), USA	*N* = 1,088 (76% women) Age range: 18–39 ($\bar{X}$ = 30.8) Type of cancer: – Breast cancer – Hodgkin's disease – Non-Hodgkin's lymphoma – Leukaemia – Testicular cancer – Bone and other soft tissue sarcoma – Adenosarcomas and other carcinomas – Brain tumour – Other	Online assessment which included two different sets of questions (i.e., oncologists and patients) that asked respondents to rank order healthcare and supportive care needs of patients in treatment and off-treatment survivors: – Demographics – Healthcare needs – Supportive care needs – Medical characteristics	– Health and supportive care needs for patients in treatment, and variation in mean rank scores by current age, age at diagnosis, and years since diagnosis – Health and supportive care needs for off-treatment survivors, and variation in mean rank scores by current age, age at diagnosis, years since diagnosis
Zebrack (2009), USA and Canada	*N* = 20 (75% women) Age range: 18–39 ($\bar{X}$ = 33.5) Type of cancer: – Thyroid – Breast – Melanoma – Sarcoma – Rectal – Nasopharyngeal carcinoma – Leukaemia – Hodgkin's lymphoma – Endometrial – Brain	Online survey questions: – Needs for information – Practical support – Emotional support – Maintaining and establishing interpersonal relations – Addressing existential questions and issues such as uncertainty and mortality	– Demographic information – Information and supportive care needs – Medical/health status characteristics

[a] The sample and the procedure were the same for both studies.

Family is one of the most important sources of support for adolescent survivors of childhood cancer. As demonstrated by Alderfer, Navsaria, and Kazak (2009), adolescent survivors are more likely to exhibit cancer-related post-traumatic stress syndrome or post-traumatic stress disorder when their families have lower levels of problem-solving skills, affective responsiveness and affective involvement. In other chronic health problems, such as chronic pain, worse family functioning has been found to be related to greater disability in teenagers (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). However, none of the studies included in our review assessed the needs of the patient's family and/or the relationship with patient's outcomes.

Most studies focus on the individual as the only unit of analysis relevant to cancer survivor needs. However, other units are also central to this complex issue. Most important are the dyad and the context (Miró, 1990, 1994). The dyad has been conceptualised as two individual units of analysis and their relationship—for example, the cancer survivor and his/her spouse or child or parent—whereas the context has more than two individual units of analysis and their relationships. It is better understood in terms of the (physical) characteristics of the situation and the (social) configuration of the environment or milieu (in which the actors enact one or more roles and behaviours). Future work should focus on other units of analysis beyond the individual (e.g. analyse the relationship between family characteristics and patient outcomes).

Some of the studies in this review have used validated questionnaires to measure quality of life and the impact of cancer on patients and their families (e.g., Osborn, Demoncada, & Feuerstein, 2006; Wakefield et al., 2010), but there is no validated measure for assessing their needs. Thus, it is essential to reach a consensus on two fundamental issues: (1) How are the needs of these patients best defined? (2) What units or levels of analysis should be encompassed; and (3) How should the survivor's needs be assessed. Having validated questionnaires to assess the needs of AYA survivors would allow, for example, to compare between groups, over time and across cultures and languages (if appropriate, language validation procedures were conducted). Furthermore, having a validated questionnaire would also be of help to inform the development of preventive and intervention strategies, and thus facilitate the prioritisation of resources. A validated questionnaire for the assessment of health-related needs of adults is available (Cox et al., 2013), but there is not any for AYA survivors, to the best of our knowledge.

Research is also needed on how and whether these needs are met. In our review, only three studies were found that had evaluated whether patients' needs were met or not (Keegan et al., 2012; Miedema et al., 2013; Zebrack, 2009). In Zebrack (2009) and Keegan et al.'s (2012) studies, over 50% of participants indicated that their needs for information and services were unmet. Furthermore, on the basis of telephone interviews with AYA cancer survivors across Canada, Miedema et al. (2013) also concluded that current cancer follow-up care practices in Canada are inadequate, and therefore, the needs of these individuals are not being meet. Future studies should detect which of the identified needs are not adequately addressed and why so that specific support programmes can be developed.

This is a new area of study, and almost all the recently published specific work, starting in 2006, has been conducted in the United States. Therefore, additional studies are needed in other countries, not only to help raise awareness on this issue—survival rates have been shown to depend on the region of the world and the type of cancer (De Angelis et al., 2014)—but also to identify specific needs that might be culturally tied (World Health Organization, 2002).

Although we used a considerable number of key words to locate all the studies that have been published on the needs of AYA who have completed a cancer treatment, some may not have explicitly stated this information in the title or the abstract and, therefore, gone unnoticed. Similarly, studies that have been published in languages other than English or Spanish or in journals that are not included in international databases have not been considered. Thus, potentially relevant articles might have been missed. However, the search strategy used was exhaustive, so it is very unlikely that many relevant articles will have been left out of this review.

This article summarises important information about the needs of young people who have survived a treatment for cancer. Providing information and individualised counselling, tailored care in the post-treatment phase, and psychological help and social support seem to be the key needs and crucial to bringing people back to their normal lives. Reaching a consensus on how needs are conceptualised and measured is fundamental to the advancement of this study area.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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4.2 Study II

What are the needs of adolescents and young adults after a cancer treatment? A Delphi study.

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Original Article

What are the needs of adolescents and young adults after a cancer treatment? A Delphi study

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What are the needs of adolescents and young adults after a cancer treatment? A Delphi study

Advances in the early detection of cancer and the development of more effective treatments have resulted in a larger number of adolescents and young adults (AYAs), becoming cancer survivors. However, knowledge regarding their needs and if those needs are adequately addressed remains limited. The aims of this study were to: (1) better understand the needs of AYAs after cancer treatment; (2) analyse the importance of those needs; (3) determine which needs are not adequately addressed; and (4) test the hypothesis that AYA cancer survivors have different needs than adult survivors. Twenty-nine health oncology professionals, 17 AYA survivors and 12 relatives of AYA survivors participated in the Delphi study. The needs identified could be classified into six categories, and all were rated as highly important by all participants. The category perceived as least adequately addressed across the three groups was 'Counselling and psychological support.' The findings provide important new information regarding the needs of AYA cancer survivors that can inform the development of interventions to improve the quality of life of these individuals.

Keywords: needs, cancer survivors, adolescent and young adults, Delphi method.

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INTRODUCTION

Advances in the early detection of cancer and the development of more effective cancer treatments have resulted in a larger number of individuals, including adolescents, who become cancer survivors. Although these individuals have 'survived' cancer, 62% report at least one chronic condition and 27% a severe or life-threatening condition (Oeffinger *et al.* 2006). However, our knowledge regarding the negative impact of the late effects of cancer and cancer treatments and their potential solutions is still very limited.

In the United States, about 380 000 people have been estimated to be survivors of childhood or adolescent cancer (Bleyer *et al.* 2006). Furthermore, it has been suggested that by 2024 this population will increase to almost 19 million (Shaitelman *et al.* 2015). The survival rate in Europe is also rising; the EUROCARE-4 study reported a global survival rate of 52% (de Angelis *et al.* 2009), which is a 5% more than in their previous estimations (Sant 2003). Moreover, almost 80% of children and adolescents who receive a diagnosis of cancer become long-term survivors (National Cancer Institute 2005a).

The type and severity of the late effects of cancer and their treatment are influenced by a number of factors, such as the specific cancer diagnosis and the treatment(s) received. Among adolescents and young adults (AYAs), lymphoma, leukaemia, germ cell tumours (including testicular cancer), melanoma, central nervous system tumours, sarcomas, breast, cervical, liver, thyroid and colorectal cancers are the most common cancer diagnoses (National Cancer Institute 2005b). The treatments for these cancers are known to result in an increased risk for heart disease, high blood pressure, asthma and diabetes (CDC n.d.). Thirty per cent of long-term survivors of childhood leukaemia report significant fatigue (Meeske 2005) and 21% attribute the cause of ongoing chronic pain to the effects of cancer or its treatment (Lu *et al.* 2011). Consistent with these findings, 24% of AYA cancer survivors report having had 14 or more days of poor physical health in the previous month (CDC n.d.). Moreover, AYA survivors who received the highest level of cancer treatment intensity endorse more anxiety and fewer positive health beliefs than those who have received less intensive cancer treatment (Kazak *et al.* 2010). Cancer treatment side effects that often continue long after the treatment is completed result in a variety of needs and the deterioration of the quality of life of cancer survivors (Pemberger *et al.* 2005), which can severely impact the daily living and perceptions of well-being (Meeske *et al.* 2001; Speechley 2006) not only of survivors but also of their family members (Ljungman *et al.* 2014). In order to address these issues and ensure that cancer survivors have the best quality of life possible, it is important to understand their needs.

Research has recently begun to address the knowledge gap concerning the needs of cancer survivors from the United States, Australia and Canada (Zebrack *et al.* 2006, 2007; Zebrack 2009; Millar *et al.* 2010; Rabin *et al.* 2011, 2013; Keegan *et al.* 2012; McClellan *et al.* 2013). The results of these studies have shown that the needs of young survivors differ from those reported by adult survivors. For example, AYA cancer survivors report a greater need for social support from their family and friends and less support from their doctors than adult survivors (S. Galán, R. de la Vega, and J. Miró, J. unpublished data). Moreover, support from and access to specialists such as psychologists is highly valued by young people, whereas the need for this type of support is not expressed as often among older cancer survivors (Hoekstra *et al.* 2014).

Although researchers have begun to clarify AYA needs, further research in this area is needed. Specifically, researchers in this emerging field have noted the importance of (1) identifying the specific needs of AYA survivors (McClellan *et al.* 2013), (2) determining the extent to which those needs are satisfied (Zebrack *et al.* 2006) and (3) determining whether these needs differ as a function of age within the AYA population or over time since the original diagnosis of cancer (Millar *et al.* 2010). Such information is necessary in order to inform the development of tailored treatments (Rabin *et al.* 2011) that maximise the quality of life of AYA survivors (Zebrack 2009).

Moreover, the evidence indicates that family can play a very important role as caregivers of cancer survivors, perhaps more so in AYA populations than in adult cancer survivor populations. Family roles, family responsibilities, and the AYA survivor's day-to-day function can be altered to accommodate the needs of the family members (Long & Marsland 2011). Despite the need for information from the perspective of the survivors' families, to the best of our knowledge, there are no studies that have examined the views of relatives who are caregivers regarding the needs of the AYA survivors.

To address these issues, in the current study, we used the Delphi method (Landeta 1999; Gil & Pascual-Ezama 2012) to: (1) better understand the needs and importance of these needs of AYA after cancer treatment, including the caregivers' point of view and (2) indicate which of those needs are not adequately addressed currently. We hypothesised that there would be differences between the needs reported by AYA and those that have been reported by adult cancer survivors in the existing literature. Specifically, we anticipated that compared with adults survivors, a sample of AYA cancer survivors would endorse more needs related to support from psychologists, family and friends.

METHOD

Study design

We used the Delphi method to address the study aims. This involved identifying a group of 'experts' (i.e. knowledgeable individuals, including AYA who are cancer survivors) and then asking them their opinions about the topics of interest, in successive anonymous rounds, with the goal of achieving consensus among the expert participants. The Delphi method is commonly used to reach a consensus regarding key issues in the field, for example, of chronic pain (Miró *et al.* 2007), rehabilitation counselling (Vazquez-Ramos *et al.* 2007), health care quality indicators (Boulkedid *et al.* 2011), including cancer and its treatment (Zebrack *et al.* 2006; Efstathiou *et al.* 2007; Shaw & Coggin 2008; Dreesen *et al.* 2013).

Participants

In order to ensure a comprehensive view of the topic, we identified three expert groups: (1) AYA who had undergone cancer treatment (i.e. patients); (2) caregivers of AYA cancer patients; and (3) health oncology professionals who work with AYA cancer patients. In order to participate in the study as a patient, potential participants needed to be between 14 and 24 years old and have undergone a cancer treatment. They also had to be free of disease for at least 1 year. The patient participants could have had any cancer diagnosis and treatment(s). To participate in the caregiver group, the potential caregiver participant had to be either an immediate relative (including being a parent, a guardian, a sibling, or a grandparent) or an unrelated caregiver of the patient participants (i.e. nanny, baby-sitter). Health professional participants could be a physician, nurse, physiotherapist, social worker or psychologist with clinical experience in oncology.

In order to recruit the patient and caregiver participants, 32 organisations whose members were individuals with a history of cancer, their parents, or health care providers were identified through an Internet search using the Google search engine and Facebook. Information about the study was sent via email to the associations, and follow-up phone calls to the offices of associations were made to answer questions they might have about the study. The study was then evaluated by the board of directors of each association. If the board of directors agreed that the members of the organisation could be contacted for potential study participation, detailed information about the study was sent to a contact person within the association, who then forwarded this information to the organisation members via email or by phone. Members who were interested in participating then accessed a link that was provided in the information sheet to access the informed consent page. After consenting to participate, patient participants were then allowed to access the survey. Participants who were less than 18 years old ($n = 5$) were asked to provide signed consent forms from both themselves and at least one parent or guardian.

To recruit health care provider participants we used the so-called 'snowball' procedure (Snijders 1992); that is, the authors of this article identified specific health professionals known to us as treatment providers of AYA survivors, who were then invited via email to both participate and identify other health professionals they knew who might be interested in participating. We sent information about the study via email to the potential health care provider participants that included a link to access the informed consent and the survey questions. In all, 72 health professionals including oncologists ($n = 30$), nurses ($n = 6$), psychologists ($n = 28$) and social workers ($n = 8$) were sent emails inviting them to participate. A total of 47 individuals responded to an initial (Round 1) survey (22 health professionals, 13 AYA and 12 caregivers).

In order to maximise participation in a follow-up (Round 2) survey, we contacted the Round 1 participants again, and also made an effort to recruit additional participants by contacting another set of 32 organisations who allowed access to 72 health professionals for an initial contact. An email was sent to these individuals informing them about the beginning of the Round 2 survey, and providing the link to enable them to survey access. A total of 58 participants (29 health professionals, 17 AYA and 12 caregivers) completed the Round 2 survey. Of these, 62% had participated in Round 1.

Measures and procedures

The online survey used to collect the Round 1 and Round 2 data was made available to the study participants using LimeSurvey 2.00 (https://www.limesurvey.org/es). Before the survey was sent, it was first completed by four people including two of the authors of this paper (JM and RV) as well as two research colleagues of the research team, but who were otherwise not involved in this study. The reviewers provided feedback to help ensure that the survey was understandable and clear. Some minor changes in the survey were made as a result of this pilot testing.

Round 1 survey

The first round started in November 2014, and continued for 3 months. During this time, the individuals who agreed to participate but who had not responded to the survey yet were contacted via telephone or email to ensure they had received the link to the online survey and to address any questions they might have about their participation. Participants took around 17 min on average to complete the Round 1 survey. The survey contained questions that were developed to collect the information needed to address the aims of the study. The same survey was administered to all the three participant groups. We also collected socio-demographic data and asked an additional open question about the needs of AYAs to the patients' participant sample.

Round 2 survey

Round 2 began in February of 2015 and continued for 1.5 months. Two reminders were sent via email in order to encourage participation. Participants took around 17 min on average to complete the Round 2 survey. In the Round 2 survey, the specific needs mentioned by the Round 1 participants were listed and the participants were asked to indicate: (1) the importance of each need from 0 ('Not at all important') to 10 ('Critically important'); (2) any additional need that might not have been mentioned in Round 1; (3) the rank order of the needs in terms of importance; and (4) the extent to which these needs are currently adequately addressed from 0 ('Not addressed at all') to 10 ('Fully addressed').

Data analysis

Round 1

The participants' responses to the Round 1 survey questions regarding the needs of AYA were analysed using constant comparative analysis (Miles *et al.* 2014), and then classified into different categories, following the classification developed by S. Galán, R. de la Vega, and J. Miró (unpublished data). The categories were: (1) *Individualised information and advice*; (2) *Needs specific to post-cancer treatment and specialised care*; (3) *Relapse detection*; (4) *Counselling and psychological support*; (5) *Financial support*; (6) *Strategies for returning to a 'normal' life and adapting to this new role*; (7) *Maintaining a healthy lifestyle*; and (8) *Developing an adaptive social network*.

Round 2

We calculated the mean importance scores within each category of needs and for each participant group. We then computed rank scores by tabulating the number of times an item was ranked first, second, and third (following the key of awarding 3 points to an item for each time a respondent ranked it first, 2 points for each time a respondent ranked it second, and 1 point for each time a respondent ranked it third). The rank scores were then ordered to determine the 3 most highly ranked items within each category for each group of participants. This method has been effectively used in previous studies (Zebrack *et al.* 2006).

RESULTS

Round 1

Participants

The demographic characteristics of the three groups are summarised in Table 1.

Needs mentioned by participants

The needs of AYA cancer survivors mentioned by each participant type are summarised in Table 2, in alphabetical order. No need was identified by the study participants related to the categories 'Individualised Information and Advice' and 'Relapse Detection.' All the other categories of needs were reported by the three groups of participants except 'Maintaining Healthy Lifestyle' which was reported by the AYA and the relatives' samples, but not by the health care professionals' sample. The percentages with which needs from each category were mentioned or endorsed are shown in Figure 1.

Round 2

The demographic characteristics of the three groups that participated in the Round 2 survey are summarised in Table 3. The importance score was high across all categories of needs and for all three groups of participants. In order of importance, the mean scores for each category and for the three groups were: *Strategies for returning to 'normal' life and adapting to this new role* (9.17); *Needs specific to post-cancer treatment and specialised care* (8.85); *Financial support* (8.84); *Developing an adaptive*

Table 1. Sample characteristics from Round 1 ($n = 47$)

Type of participant:	Health professionals	AYA	Relatives
N	22 (Oncologists: 3, Nurses: 6, Psychologists: 10, and Social workers: 3)	13	12 (100% parents)
Age: mean (SD) and range:	39 (10; 26–62)	18 (2; 14–23)	46 (5; 35–54)
Sex: women (%)	86	54	91
Average of oncological experience in years, mean (SD):	10.63 (8)	–	–
Average of working with AYA in years, mean (SD):	10.45 (7)	–	–
Work situation	–	100% student	45% public servant 27% worker 27% other
Marital status	–	100% single	91% married 9% divorced
Age at diagnosis, mean (SD)	–	8.7 (8; 1–16)	–
Years after the last treatment	–	8.2 (5; 1–18)	–

–, not applicable.

social network (8.46); *Maintaining a healthy lifestyle* (8.34) and *Counselling and psychological support* (8.20). Importance scores are shown in Table 4.

The Round 2 participants reported seven additional needs not reported by the Round 1 participants. Because five of them were very similar to needs that were already in designated categories, we decided to include four of these as *Needs Specific to Post-Cancer Treatment and Specialised Care* and one as a *Need related to Counselling and Psychological Support* categories. The other two new needs were related to relatives' and caregivers' needs (Psychological Support for Relatives and Information and Training for Caregivers) and not AYA needs. Given the high degree of overlap in the results of the two rounds, we determined that we had reached saturation, and that therefore a third round was not necessary.

Regarding the ranking of the needs, the needs which peaked at number 1 for each category were: Help to be positive, Feel good at an emotional and physical level (category *Counselling and psychological support*); Feeling normal (category *Developing an adaptive social network*); Medical examinations and monitoring of the disease (category *Adapted health care according to the new status of post-treatment*); Efforts to feel health and be disease free (category *Strategies for returning to 'normal' life and adapting to the new role*); Advice for healthy habits (category *Maintaining a healthy lifestyle*) and Financing treatments (category *Financial support*). There was consensus in the three groups of participants to give the first position of the ranking to these needs for each category. As shown in Table 4, these are the needs that have achieved the first position for each category in the rankings despite other needs have also been scored high.

In relation to the average level of the extent to which participants perceived that the needs were adequately addressed, the average score (in a 0–10 scale) was 6.06 for the group of AYA, 6.23 for the group of professionals and 7.12 for the relatives' group. In order of address, the scores of the categories were: *Counselling and psychological support* (5.97); *Needs specific to post-cancer treatment and specialised care* (6.29); *Maintaining a healthy lifestyle* (6.34); *Financial support* (6.41); *Strategies for returning to 'normal' life and adapting to this new role* (6.72) and *Developing an adaptive social network* (7.08). The five needs perceived to be less adequately addressed by the three groups of participants were: Attention to sexual health (5.03); Advice on fertility (5.03); Neuropsychological assessment and treatment (5.33); Rehabilitation psychological consequences (5.56) and Coordination between primary and specialised care (5.78).

DISCUSSION

In this study, we used the Delphi method to better understand the needs of AYA cancer survivors as identified by AYA survivors, AYA survivor caregivers, and health professionals. A large variety of needs were identified. In general, all of the needs identified were rated as highly important, although some variability in overall importance was found. We also found variability in the extent to which the needs of AYA cancer survivors are currently being addressed. The study findings provide important new information that can inform the development of interventions that could effectively address the needs of AYA cancer survivors.

Table 2. Categories of needs and needs included in each category

- Counselling and psychological support
  - Attention to sexual health
  - Help on acceptance and management of constraints arising from the sequels
  - Help to be positive, feel good at an emotional and physical level
  - Help to manage relationships with parents (independence or overprotection)
  - Help to treat anxiety and/or depression. Stress management
  - Help with self-esteem/body image/feeling safe
  - Neuropsychological assessment and treatment (e.g. working memory, attention, language)
  - Psychological support
  - Rehabilitation psychological consequences
  - Support to manage the fear of a relapse
- Developing an adaptive social network
  - Accessing self-help groups among equals
  - Establishing healthy communication with the environment and to speak naturally about the disease
  - Feeling normal
  - Having healthy friendships
  - Having social and family support
  - Meeting other survivors
  - Returning to social reality
  - Returning to the peer group (no cancer)
  - Undertaking social leisure activities that provide personal enrichment
- Financial support
  - Financing treatments
  - Having free teachers at all levels of education
  - Standardise the criteria for assessing the degree of disability
- Maintaining a healthy lifestyle
  - Advice for healthy habits
  - Help to have a good nutrition
  - Physical exercise
  - Sleep hygiene
- Needs specific to post-cancer treatment and specialised care
  - Advice on fertility
  - Coordination between paediatric and adult care
  - Coordination between primary and specialised care
  - Ensure equal health care (regardless of geographic location or income level)
  - Having a reference medical specialist for chronic late effects
  - Medical examinations and monitoring of the disease
  - Rehabilitation of physical and sensory late effects
- Strategies for returning to 'normal' life and adapting to this new role
  - Having an alternative entertainment in the event of sequels
  - Standardisation of the disease and the new situation
  - Support for full return in life (family/social, academic/work, etc.)
  - Efforts to feel health and be disease free

Reported needs

Overall, most of the categories were identified by all three participant groups, showing a high consensus about what is needed. Nevertheless, the needs related to the category *Maintaining a healthy lifestyle* were not identified by health professionals. Therefore, in order to ensure a comprehensive assessment of AYA cancer survivors' needs, it is important that future research which seeks to understand AYA cancer survivor needs assess those needs from *all* the stakeholders, in order to ensure that a complete picture of the issues is obtained.

What are the most important needs?

The high level of importance of all needs across all three participant groups indicates a strong consensus regarding the needs of AYA cancer survivors. However, 'Developing an adaptive social network' was rated as extremely high by AYA, but not by the rest of participants. These results highlight how important the peer group is to adolescents. Again, in order to ensure that the perspective of the AYA survivors is taken into account, clinicians who assist or treat AYA survivors should seek to help those survivors find ways to increase the chances that they will obtain the social support they need and prefer.

Are there specific needs which are not well addressed?

In general, the three groups of participants perceived their needs as being addressed to a medium-high degree; however, the group of relatives reported greater degree of adequacy than the other two groups. Based on the responses of the AYA group, the categories with the most unmet needs were 'Maintaining a healthy lifestyle' and 'Counselling and psychological support.' These results are consistent with other studies which reported that the need for information about diet, exercise and weight management are not well addressed (James-Martin *et al.* 2014) and the strong interest of AYA cancer survivors in participating in diet and exercise interventions (Badr *et al.* 2013). In addition, an increasing number of studies report a critical association between a healthy lifestyle (i.e. having good nutrition and sleep hygiene and engaging in regular physical exercise) and higher levels of quality of life in cancer survivors (Schmitz *et al.* 2010; Grimmett *et al.* 2015). As a group, these findings suggest that focusing on healthy lifestyle in AYA cancer survivors may be particularly critical. Similarly, previous research indicates that access to mental health care is an important unmet need of AYA survivors (Zebrack 2009; Keegan *et al.* 2012). These results are also consistent with those from this study.

The needs that were rated as least adequately addressed in the current study were 'Attention to sexual health' and 'Advice on fertility'. These findings are consistent with another study with survivors aged 50 and under, which concluded that concerns about the potential loss of fertility was particularly important for younger cancer

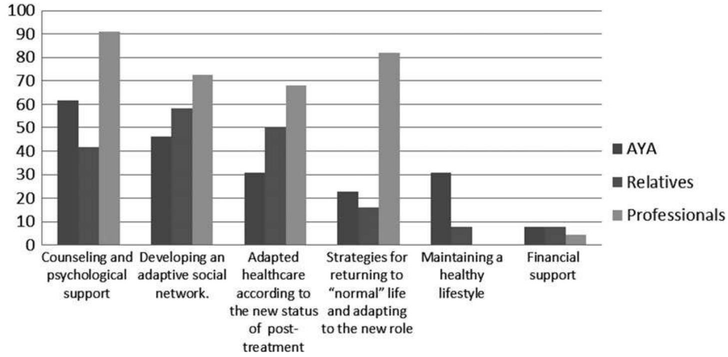

Figure 1. Percentages of participants in each group who reported each category of needs (Round 1).

Table 3. Sample composition from Round 2 (*N* = 58)

Type of participant:	Health professionals	AYA	Relatives
N	29 (oncologists: 10, nurses: 5, psychologists: 10, and social workers: 4)	17 (–)	12 (100% parents)
Age: mean (SD) and range	39 (10; 26–62)	20 (2; 15–24)	47 (5; 38–54)
Sex: women (%)	83	69	92
Average of oncological experience in years, mean (SD):	10 (7)		
Average of working with AYA in years, mean (SD):	10 (7)	–	–
Work situation	–	88% student 12% other	25% public servant 33% worker 33% housewife
Marital status	–	82% single 18% other	83% married 17% divorced
Age at diagnosis, mean (SD)	–	11 (2–17)	–
Years after the last treatment	–	7 (2–16)	–

–, not applicable.

survivors (Penrose *et al.* 2012). The findings also suggest that information related to this critical issue should be included in any intervention that is designed to address the needs of AYA cancer survivors.

What are the similarities and differences between the needs of AYA and adult cancer survivors?

By comparing our results with those obtained in a recent systematic review of adult survivors (Hoekstra *et al.* 2014), we can examine the similarities and differences about the reported needs after a cancer treatment in these two groups. The most often mentioned needs by our samples of participants and those in the studies reviewed by Hoekstra and colleagues (Hoekstra *et al.* 2014) are: having psychological support, participation in a social network, having medical examination and specialised care and financial support. However, there are also some important differences. Specifically, adult survivors have reported a need for general information, proactive contact from general practitioner and care for caregivers and family. However, our AYA sample reported a number of needs that have not yet been identified by adult survivors. These included, for example, (1) help with self-esteem, (2) to be positive and feel good at an emotional level, (3) social and family support, (4) healthy lifestyle and (5) support for a full return to life. The differences in reported needs by AYA and adult related samples confirm our hypothesis about the differences between AYA and adults. More importantly, they suggest that the strategies that might be most useful for addressing the needs of AYA cancer survivors may be different from the strategies that would be most useful for addressing the needs of adult cancer survivors.

For example, in the current study, social support was identified as being one of the most important needs. This is consistent with the findings from other studies that have examined the needs of AYA with chronic diseases, such as chronic pain, who are at risk for having peer relationship deficiencies (Forgeron *et al.* 2011). Having cancer

Table 4. Ranking and importance score of each need

	Health professionals		AYA		Relatives	
	Rank	I.S.	Rank	I.S.	Rank	I.S.
Counselling and psychological support						
Help to treat anxiety and/or depression. Stress management	3	7.76	–		3	9.00
Help to be positive, feel good at an emotional and physical level	1	8.10	1	9.18	1	8.92
Help with self-esteem/body image/feeling safe	2	8.28	–		2	9.00
Psychological support	–		2	8.35	3	9.08
Support to manage the fear of a relapse	–		3	8.47	–	
Developing an adaptive social network						
Having healthy friendships	–		3	8.29	–	
Returning to the peer group (no cancer)	3	8.48	2	8.53	2	8.42
Feeling normal	1	9.10	1	9.00	1	8.42
Returning to social reality	–		–		3	8.33
Having social and family support	2	8.41	3	9.35	–	
Adapted health care according to the new status of post-treatment						
Rehabilitation of physical and sensory late effects	2	8.38	3	8.88	3	9.08
Medical examinations and monitoring of the disease	1	8.59	1	9.47	1	9.42
Having a reference medical specialist for chronic late effects	3	8.55	–		–	
Ensure equal health care	–		2	9.24	2	9.33
Strategies for returning to 'normal' life and adapting to the new role						
Having an alternative entertainment in the event of sequels	–		–		3	9.17
Efforts to feel health and be disease free	1	9.21	1	9.41	1	9.33
Standardisation of the disease and the new situation	2	9.10	3	9.18	2	9.33
Support for full return in life	3	9.17	2	9.41	2	9.08
Maintaining a healthy lifestyle						
Help to have a good nutrition	3	8.15	1	7.62	2	8.58
Physical exercise	2	8.26	2	8.23	3	9.33
Sleep hygiene	–		–		3	9.08
Advice for healthy habits	1	8.11	1	7.92	1	9.17
Financial support						
Having free teachers at all levels of education	3	8.48	3	8.82	2	8.92
Standardise the criteria for assessing the degree of disability	2	8.79	2	8.41	3	8.33
Financing treatments	1	9.17	1	9.29	1	9.33

I.S., importance score; –, out of the top three for that group.

decreases the chances of establishing adaptive peer relationships (e.g. the sense of belonging to the group) in a period of time when peer relationships are of fundamental importance for proper development (Bagwell *et al.* 1998; La Greca & Prinstein 1999; Furman *et al.* 2008). Furthermore, cancer treatment may negatively impact physical development or result in other physical changes such as amputations, which could result in additional barriers for social interactions (Reuben 2004). These problems can be traumatic and negatively influence AYA's self-esteem and interfere with their personality development. As we mentioned previously, strategies developed to address the needs of this population should include alternatives to increase the chances that AYA cancer survivors would receive the social and professional support they so clearly identify as important. For example, such interventions could organise meetings for survivors to meet and support each other, or provide access to a paediatric psychologist. The current findings suggest that such a strategy – if found to be effective – could have a significant beneficial impact on the lives of AYA survivors.

Study limitations

In this study, we assessed the needs of a convenience sample of AYA cancer survivors (i.e. a sample of people willing to participate in the study) and their relatives who were recruited from patient associations. Therefore, the generalisability of the results to survivors that do not take part in such associations is not known. An important next step would be to replicate this study findings in samples of survivors that are not part of associations advocating for oncology patients. In addition, there is a wide difference in the number of years after treatment among the study participants (from 1 to 16 years in Round 1, and from 2 to 17 years in Round 2). It is unclear if this variability might have had any influence in the needs identified by participants, and the number of participants in our study did not allow us to determine if time since treatment had any influence on the findings. Future research, ideally with larger samples, will be needed to determine if time since last treatment has an impact on the needs of AYA cancer survivors, or how those needs should be addressed. Fourth, while consensus and saturation was achieved in the sample, it is also possible that other needs might have been identified, or that the relative importance rankings might have differed, had the sample been selected to be more representative of the population of patients, caregivers, and health care providers. This is another reason to replicate the current study with additional samples of AYA cancer survivors to help determine the generalisability of the findings. Fifth, the current study used a cross-sectional design, which does not allow for analyses or conclusions regarding how needs change over time and as the AYA survivors age. Longitudinal research would be needed to address these questions. Finally, we only examined the needs of AYA cancer survivors and not those of the relatives of AYA survivors. Research that examines the needs of caregivers would be useful to help understand how those needs might be better addressed, which could ultimately also improve the quality of life of AYA cancer survivors as well.

CONCLUSION

Despite the study's limitations, the findings provide important new information regarding the needs of AYA cancer survivors that could inform the development of interventions that could increase the quality of life in these individuals. We identified here a wide range of biological, psychological and social needs. While some of these needs are similar to those reported in studies with adult cancer survivors, a number appear to be specific to, or at least of particular importance of, AYA survivors. These include unmet needs related to: fertility and sexual health, healthy lifestyle maintenance, social and family support, and peer relationships. The findings have important implications for better understanding the needs of AYA who are cancer survivors and for the development of treatments that would benefit this population.

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4.3 Study III

Factor structure, internal consistency and criterion validity of the full- and short-form versions of the Centrality of Events Scale in young people.

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Factor Structure, Internal Consistency and Criterion Validity of the Full-form and Short-form Versions of the Centrality of Events Scale in Young People

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Summary: The perceived centrality of a traumatic event has been hypothesized to impact subsequent responses to that event and shown to be positively associated to a number of psychological problems. In order to understand the role of this construct in adjustment to stress and trauma, reliable and valid measures are needed. The objective of this study was to evaluate the factor structure, internal consistency and convergent validity of the full-form and short-forms of the Centrality of Event Scale when used with young people. A sample of 262 undergraduate students completed this study. Confirmatory factor analyses, Cronbach alpha coefficients and Pearson correlation coefficients were performed. The findings support a one-factor structure of the full 20-item and the short 7-item versions. We also found that both versions provide reliable and valid scores when used with young people. We recommend the use of the 7-item version to minimize assessment burden. Copyright © 2017 John Wiley & Sons, Ltd.

INTRODUCTION

People often have vivid memories of traumatic and highly stressful events (Berntsen, 2001). The vividness of such memories may explain why people with a history of trauma are at a higher risk to overestimate both the frequency of these events and the likelihood of experiencing a similar trauma in the future (Tversky & Kahneman, 1973). Traumatic experiences can also change the view of oneself, especially if the person experiences persistent traumatic psychological effects (Sutherland & Bryant, 2008). In such instances, the trauma may come to occupy a central place in that person's individual identity (Berntsen & Rubin, 2006).

The perceived centrality of a traumatic/stressful event — that is, how central the event is to a person's identity and life story — has been shown to be positively related to a number of psychological problems, such as depressive (Peterson & Seligman, 1984) and Post-traumatic stress disorder (PTSD) symptoms (Greening, Stoppelbein, & Docter, 2002). These findings support the need for research to better understand the role that perceived centrality of an event plays in psychological function. Such research requires the availability of a valid and reliable measure of perceived centrality.

To address this need, Berntsen and Rubin (2006) developed the Centrality of Events Scale (CES). These authors found one factor structure for the 7-item version using the iterated principle factor analyses with a varimax rotation. For the 20-item version, although three eigenvalues were found to be greater than 1.00 (9.38, 1.41 and 1.02), given the very large decrease from the first to the second eigenvalue (i.e. scree test) the authors concluded that the items best represent a single factor. The scores from both measures have *good* (α = 0.88; 7-item version) to *excellent* (α = 0.94; 20-item version) internal consistency (Berntsen & Rubin, 2006). Scores from both the 20-item and 7-item versions of the CES have also evidenced construct validity via their significant and positive associations with PTSD symptom severity and depressive symptomatology in a sample of 707 undergraduate students from four different North American universities (Berntsen & Rubin, 2006).

The original English version of the CES has been used successfully in a number of studies in samples with a variety of conditions. For example, in one study with individuals with chronic pain, the CES was found to be a significant predictor of both psychological distress and pain interference (Perri & Keefe, 2008). CES scores have also been shown to be positively associated with important cognitive variables including memory intrusiveness and rumination in individuals with depression (Newby & Moulds, 2011). Moreover, in a study about romantic conflict and breakup, levels of event centrality for romantic conflicts prospectively predicted subsequent negative mental health outcomes in a sample of 312 community volunteers (Boals, 2014). CES scores have also been shown to be correlated with posttaumatic stress disorder symptom severity, depession severity and self-esteem in a sample of 102 women with a history of childhood sexual abuse (Robinaugh & McNally, 2011).

While the preliminary research with the CES is promising, there remains some controversy about its factor structure. For example, in an exploratory principal components analysis, the Brazilian Portuguese version of the 20-item evidenced three components with eigenvalues greater than one in a sample

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of young adults (Gauer, de Souza, da Silveira, & Sediyama, 2013). Robinaugh and McNally (2011) also found that the 20-item version of the CES best represented three factors (Robinaugh & McNally, 2011). In a more recent study, using Portugal Portuguese versions of the 7-item and 20-item versions of the CES with a sample of 1079 adolescents, confirmatory factor analyses (CFA) showed different structures for the two versions: a three-factor structure for the 20-item version and a one-factor structure for the 7-item version (Vagos, Ribeiro da Silva, Brazao, & Rijo, 2016).

It is unclear whether the reported differences in the structure of the CES items in different samples are related to inconsistent or inadequate translations of the questionnaire, possible cultural differences or other factors. The majority of studies have been conducted in English speaking samples in the United States and the only translated versions that have been evaluated are in Portuguese (from Brazil and Portugal). Furthermore, the limited number of translated versions of the CES means that the extent to which the role that event centrality plays in response to trauma in non-English or non-Portuguese speaking samples cannot be evaluated; that is, we cannot yet determine which findings are consistent across languages and cultures. To address these issues, additional translated and validated versions of the CES are needed.

In order to address the needs to (i) clarify the factor structure of the CES with a non-English speaking sample and (ii) further evaluate the association of the centrality of events scores with measures of adjustment, the current study sought to translate the CES into Spanish and evaluate the factor structure, internal consistency and criterion validity of the full-form and short-form versions of the CES in a sample of young people who speak Spanish, and then examine the associations of the CES scale or scales with measures of anxiety and depression. Based on the findings from previous research using the original English version of the CES, we hypothesized that (i) the CES items would evidence a single factor structure, (ii) the CES scores would have at least an adequate level of reliability (i.e. internal consistency coefficient of at least 0.70) and (iii) the CES scores would evidence concurrent criterion validity (defined as the concurrent association between the measure and measures of domains of related constructs; Higgins & Straub, 2006), operationalized here as moderate and positive associations (i.e. correlation coefficients of 0.30 or greater) with measures of depressive and anxious symptoms. Moreover, we anticipated that the CES scores would show a convergent validity, defined as moderate to strong associations between the measure being evaluated and measures that are thought to assess the same construct (Higgins & Straub, 2006), and here indicated by a moderate to strong and positive associations with scores from a measure of post-traumatic symptoms severity (i.e. correlation coefficients of 0.30 or greater).

MATERIAL AND METHODS

Participants

The study included a convenience sample of 262 undergraduates from the Universitat Rovira i Virgili (Catalonia, Spain). They were invited in the classroom to participate in a study of stressful events. Potential participants had to be able to speak and read Spanish and to be between 18 and 24 years old. The average age was 20 years (*SD* = 1.7), and 207 (79%) were women. See Table 1 for additional sample descriptive information.

Procedures

Translation of the questionnaire

This translation and adaptation of the CES was authorized by its authors. The CES was translated into Spanish using a back-translation procedure as described by Miró (1997). That is, it was first translated from English into Spanish by two psychologists fluent in English. Next, a native professional translator translated the Spanish version back into English. Finally, the back-translated version was sent to one of the authors of the questionnaire to determine if the Spanish version was faithful to the original one. The original authors agreed that the back-translated version preserved the denotation and connotation of the instructions and items of the questionnaire. Thus, no additional work was required as both forms were found to be linguistically equivalent.

The study protocol was approved by the Internal Review Board of the Universitat Rovira i Virgili. The study questionnaires were administered to groups of students enrolled in different degrees at the Universitat Rovira i Virgili (Psychology, Teaching, Journalism, Publicity and Public Relations and Audiovisual Communication). We also sought permission from the teachers of these programmes to allow participants to self-administer the questionnaires during class time. Students interested in participating signed an informed consent form before responding to the survey. Approximately, it took 20 min for participants to complete the survey.

Measures

Demographic and descriptive variables

Questions about age, sex and university degree/studies were used to provide a description of the sample (see Table 1 for details).

Table 1. Demographic information of participants (*N* = 262)

Variable	Per cent (%)	*N*	Mean (*SD*)	Range
Age (years)		262	20.04 (1.72)	18–24
Sex				
Boys		21	55	
Girls		79	207	
Recently studies				
Psychology	44.7	117		
Teaching	18.3	48		
Journalism	12.6	33		
Publicity and public relations	10.3	27		
Audiovisual communication	9.9	26		
Others	4.2	10		
HADS anxiety		262	7.89 (3.48)	0–18
HADS depression		262	3.50 (2.67)	0–15
PCL-C		262	34.57 (14.7)	17–78

Note: HADS, Hospital Anxiety and Depression Scale; PCL-C, PTSD Checklist-Civilian

Centrality of Events Scale

The CES (Berntsen & Rubin, 2006) is a 20-item scale that measures the degree to which the memory of a stressful event is a point of reference for personal identity and the assignment of meaning to other experiences in the life of an individual. Respondents are asked in a 5-point scale, anchored with 1 (strongly disagree) and 5 (totally agree), about the degree of agreement with the statement contained in each of the items, taking into account the most stressful or traumatic event in their lives. As mentioned previously, scores from the 20-item and 7-item versions of CES have shown good to excellent internal consistency in English speaking community samples (Berntsen & Rubin, 2006). Score from the full CES have been shown to correlate 0.38 with PTSD symptom severity and 0.23 with depression (Berntsen & Rubin, 2006). In order to evaluate the psychometric properties of both the original and shortened versions here, we computed scores for both using the participants' responses to the original version.

Post-traumatic symptom severity

We assessed post-traumatic symptom severity using the 17-item PTSD Checklist-Civilian version (PCL-C) (Miles, Marshall, & Schell, 2008); these 17 items correspond to the DSM-III-R symptoms of PTSD. This questionnaire can be used as a continuous measure of PTSD symptom severity by summing scores across the 17 items or can be used to derive a PTSD diagnosis by considering a score of 3 or greater on the responding scale as indicative of the presence of the symptom assessed by that item (Weathers, Litz, Herman, Huska, & Keane, 1993). Participants rated the degree to which they were bothered by each symptom on a scale ranging from 1 (not at all) to 5 (extremely). Scores from the Spanish version of the PCL-C have shown solid psychometric properties (α = 0.97 and test–retest reliability of 0.96) (Weathers et al., 1993). In one study comparing the English and Spanish versions, the Spanish version also demonstrated good psychometric properties (Marshall, 2004). In the current sample, scores also demonstrated excellent internal consistency (Cronbach's alpha for the total scale = 0.93).

Depression and anxiety

Depressive and anxious symptomatology were assessed using the 14-item Hospital Anxiety and Depression Scale (HADS). This commonly used measure is a self-assessment scale for measuring symptoms of anxiety (seven items) and depression (seven items). HADS has been specifically designed for its use with medically ill patients (Zigmond & Snaith, 1983), but it has also been shown to be useful, valid and reliable with healthy individuals (Terol-Cantero, Cabrera-Perona, & Martín-Aragón, 2015). Respondents are requested to rate the severity of each symptom during the previous week on a variety of different 4-point Likert scales, depending on the item (e.g. for some items, 0 = 'not at all' and 3 = 'most of the time', 'very often', or 'very definitely' and 'quite badly'). The Spanish version of the HADS scales has shown adequate internal consistency in a sample of healthy individuals (anxiety, 0.77 and depression, 0.71) and test–retest stability over a 15-day period (anxiety, 0.77 and depression, 0.74). Sensitivity and specificity for diagnosing anxiety and depression are satisfactory when using the HAD total scale score with adults (>.80) (Terol et al., 2007). In the current sample, the HADS scales scores also demonstrated adequate internal consistency (Cronbach's alpha for anxiety and depression were respectively 0.76 and 0.67).

Data analysis

We first computed descriptive statistics of the demographic variables (percentages, means and standard deviations) to describe the study sample. Before performing the planned factor structure analyses of the CES items for both the 7-item and 20-item versions, we evaluated whether the data met the assumptions for the planned analyses by (i) examining the skewness and kurtosis of each item distribution (ii) performing the Kaiser-Meyer-Olkin test (KMO) (Kaiser, 1970) and (iii) computing the Bartlett's statistic (Bartlett, 1950). We then performed a confirmatory factor analyses (CFA) using the Mplus programme (https://www.statmodel.com/orderonline/categories.php?category=Mplus-Software) to evaluate the factor structure of the CES items for the two versions. We used the maximum likelihood mean adjusted as the extraction method because the data were not found to be normally distributed. The following indexes were used to test the goodness of fit of the solution: chi square ($\mathcal{X}^2$), comparative fit index (CFI), standardized root mean square residual (SRMR) and root mean square error of approximation (RMSEA). The adjustment of the measurement model may be considered good if the CFI values range from 0.95 to 1.00, RMSEA <0.05 and SRMR <0.1. Alternatively, it may be considered acceptable if CFI values range from 0.90 to 0.95, RMSEA values are less than 0.08 and SRMR values are lower than 0.10 (Schweizer, 2010).

We then computed Cronbach alpha coefficients to assess the internal consistency of the scores of the two versions of the CES and the alpha if items were deleted; the item-total correlations were also calculated. Finally, we performed Pearson correlation coefficients between scores on both versions of the CES and (i) depression and (ii) anxiety scores (convergent validity) and between scores on both versions of CES and post-traumatic symptom severity scores (criterion validity). All analyses were performed using SPSS 17.0 for Windows (IBM,http://www01.ibm.com/software/analytics/spss/), except for the computation of skewness, kurtosis, KMO and Bartlett's statistics, which were evaluated using Factor v.10.4. (http://psico.fcep.urv.es/utilitats/factor/) and CFA using Mplus 5.1 (http://www.statmodel.com).

RESULTS

Factor structure analyses of the CES items

The 20-item version of the CES met criteria supporting the use of the planned factor analysis [KMO = 0.95 and Bartlett's statistic = 307.0 ($df = 190$, $p < 0.001$)]. Also, when using the MLM method, the data adjusted well to a one factor model in the CFA. The $\mathcal{X}^2$ statistic was 413.9, $p < 0.0001$. The adequacy of a one factor model was shown by the CFI = 0.89 (it is considered adequate if >0.90), the SRMR = 0.080 (it is considered good if ≤0.10) and the RMSEA = 0.074 (it is considered good if ≤0.08).

The findings also indicated that the shortened 7-item version of the CES was suitable for factor analysis: KMO = 0.89, Bartlett's statistic = 711.8 ($df = 21$: $p < 0.001$). The results of the CFA supported a one-factor model, as indicated by the $\mathcal{X}^2$ statistic (30.628, $p < 0.005$), the CFI (0.97), the SRMR (0.031) and the RMSEA (0.067).

Internal consistency of the CES

The 20-item version CES scores showed excellent internal consistency (Cronbach's α = 0.93). The values of alpha, when any one item was deleted, remained at 0.93, providing further support for the reliability of the total scale score. The item-total correlations ranged from 0.48 to 0.75, all of which were above the recommended cut point of 0.30 for retaining items (Field, 2013). The scores on the 7-item version of the CES also evidenced good internal consistency (Cronbach's α = 0.84). All values of alpha when one item was deleted are 0.80. The correlation coefficients between each item and the total score ranged from 0.30 to 0.61. The minimum loading value of each version of the CES was .50 for the 7-item version and .52 for the 20-item version. See Table 2 for additional information.

Validity

Validity of the scores of both versions of the CES was evidenced by moderate and positive significant correlations with anxiety (HADS anxiety, rs = 0.29 and 0.29, ps < 0.01, 20-item and 7-item version, respectively) and depression symptoms (HADS depression, rs = 0.28 and 0.28, ps < 0.01, 20-item and 7-item version, respectively). The CES scores also evidenced moderate and significant positive associations with post-traumatic symptom severity scores (rs = 0.37 and 0.35, ps < 0.01, 20-item and 7-item versions, respectively).

DISCUSSION

The aim of this study was to evaluate the factor structure, internal consistency and criterion validity of the full-form and short-form versions of the Spanish version of the CES in a sample of young adults. The results show that the single factor model showed a good fit for both the full 20-item and the brief 7-item version of the CES in our sample. Scores from both versions showed good internal consistency and evidenced validity via their moderate and significant associations with measures of depressive, anxious and post-traumatic symptoms severity.

The original study (Berntsen & Rubin, 2006) concluded that a one factor structure was most appropriate for both the 20-item and 7-item CES. However, recent studies with non-English speaking samples with different cultural backgrounds have shown different factor structures. For example, the Brazilian Portuguese version of the 20-item CES (Gauer

Table 2. Spanish version of the items in the centrality scale

Item	Mean	*SD*	Loading values	
Este acontecimiento se ha convertido en un punto de referencia para la manera en la que yo entiendo nuevas experiencias	3.48	1.24	.74	
Automáticamente veo conexiones y similitudes entre este acontecimiento y las experiencias de mi vida actual	3.01	1.24	.58	
Siento que este acontecimiento se ha convertido en parte de mi identidad	3.30	1.34	.74	.70*
Este acontecimiento puede ser considerado como un símbolo o una marca de asuntos importantes en mi vida	3.37	1.26	.75	
Este acontecimiento está transformando mi vida en algo diferente a la vida de la mayoría de las otras personas	2.35	1.30	.66	
Este acontecimiento se ha convertido en un punto de referencia para la forma en la que me entiendo a mí mismo y al mundo	3.13	1.30	.72	.67*
Creo que las personas que no han experimentado este tipo de acontecimientos piensan diferente a mí.	2.90	1.48	.52	
Este acontecimiento explica mucho de quién soy yo	2.95	1.35	.77	
A menudo veo la conexión y las similitudes entre este acontecimiento y mi relación actual con otras personas	2.87	1.39	.71	
Siento que este acontecimiento se ha convertido en una parte central de la historia de mi vida	2.75	1.41	.75	.77*
Creo que las personas que no han experimentado este tipo de acontecimientos, tienen una manera diferente de mirarse a sí mismos de la que tengo yo	2.70	1.31	.65	
Este acontecimiento ha influido en la forma en la que pienso y siento sobre otras experiencias	3.40	1.22	.77	.74*
Este acontecimiento se ha convertido en un punto de referencia para la manera en la que veo mi futuro		3.05	1.37	.72
Si fuera a tejer una alfombra sobre mi vida, este acontecimiento estaría situado en el medio de ella con fibras saliendo en dirección hacia muchas otras experiencias	2.25	1.17	.66	
La historia de mi vida se puede dividir en dos capítulos principales: uno antes y otro después de que este acontecimiento sucediera.	2.59	1.40	.67	
Este acontecimiento cambió definitivamente mi vida	2.53	1.40	.80	.76*
A menudo pienso sobre los efectos que este acontecimiento tendrá sobre mi futuro	2.55	1.34	.67	.66*
Este acontecimiento fue un punto de inflexión en mi vida	3.11	2.30	.78	.50*
Si este acontecimiento no me hubiese pasado, yo sería una persona distinta hoy	3.18	1.49	.75	
Cuando reflexiono sobre mi futuro, a menudo pienso en este acontecimiento.	2.57	1.34	.63	

*Loading values for the seven items version.

et al., 2013) evidenced three factors for both versions, and the Portugal Portuguese Adolescent version showed a three-factor structure for the 20-item version but a one-factor structure for the 7-item version (Vagos et al., 2016). In addition, the study conducted by Robinaugh and McNally (2011) also found a three-factor structure with the original 20-item version (Robinaugh & McNally, 2011). Our findings are consistent with the original studies supporting a single-factor structure for both long and short versions of the CES. The differences in findings across studies may be related to the differences in analytic approaches used. The principal components analysis — the approach used by Gauer and collaegues (Gauer et al., 2013) and Robinaugh and McNally (2011) — is known to sometimes result in more factors than are truly represented in a data (Ferrando & Anguiano-Carrasco, 2010). Thus, on the basis of our results and those from others, we recommend using the one-factor structure for the Spanish version of the CES. By keeping in line with the one-factor structure the Spanish version, it may be more suitable for multicultural studies addressing the associations between centrality of events and psychopathology, given that previous works have used a one-factor solution.

The findings, including the results from this study, have shown that scores of the 20-item CES demonstrate a good to excellent internal consistency, in all versions and samples: the Cronbach's α was 0.94 in the original study, α = 0.95 in the Brazilian Portuguese version, α = 0.87 (*factor 1*), 0.89 (*factor 2*) and 0.85 (*factor 3*) in the Portuguese adolescent's version, α = 0.94 in the Robinaugh and McNally's (2011) study and α = 0.93 in our study. The Cronbach's α for the 7-item version was 0.88 in the measure development sample, 0.89 in the Brazilian Portuguese version, 0.90 in the Portuguese adolescent version and 0.84 in the current sample (Berntsen & Rubin, 2006; Gauer et al., 2013). These results indicate that the 7-item version is reliable across settings and cultures. Thus, the use of this version, instead of the full 20-item version, would be appropriate when there are concerns about subject assessment burden (i.e. large scale survey studies).

The finding of moderate associations between the CES scores and measures of both depression and anxiety symptoms provides evidence for the concurrent criterion validity of the scores obtained with the CES in our sample. Support for the convergent validity of the CES scores comes from their moderate and significant positive associations with post-traumatic symptom severity scores (*r*s = 0.37 for the full version and 0.35 for the 7-item version). Our results are consistent with the study hypotheses and those from the original scale development sample, where a correlation between CES and the PTSD Checklist of 0.38 was reported (Berntsen & Rubin, 2006). In our study, the correlation values for centrality and traumatic symptomatology were of a higher magnitude than those for centrality and anxious or depressed symptomatology, although they were all statistically significant.

This study has a number of limitations that should be considered when interpreting the results. The study data were collected from a convenience sample of young adults. It is possible that the findings might have been different had we used a different group of participants; for example, a clinical sample of individuals diagnosed with PTSD. Additional research with clinical and healthy samples is needed to fully establish the reliability and validity of the CESs scores in Spanish speaking populations. In addition, although our findings supported a single factor consistent with the findings from the measure development study, they were not consistent with a previous study which supported a three-factor structure for the CES items in a sample of youths (Gauer et al., 2013). Our results showed a good fit for the data for the single factor model, but we did not compare these to alternative models; therefore, on the basis of these results, it is not possible to know whether alternative models would or would not show a better fit. Thus, additional research would be useful to help evaluate the factor structure of the CES in different samples of individuals.

Despite the study's limitations, the findings provide important additional information regarding the validity and reliability of the scores obtained with the CES to assess centrality in a sample of Spanish young adults and its consistency across different languages and cultures. These results support the use of the CES across groups of individuals who speak different languages and from different cultures, to help determine the importance of centrality to adjustment to traumatic events, and evaluate what role, if any, language and culture may be playing in these relationships. According to our findings, the CES is a reliable and valid assessment tool in young people, and the 7-item version is highly recommended in order to minimize assessment burden.

CONFLICTS OF INTEREST

The authors declare that they have no conflict of interest related to this study.

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5. Discussion

This dissertation is focused on the psychosocial needs of adolescents and young adults after finishing a cancer treatment. The results of our studies show that the needs of AYAs are somewhat different from those seen in adults and some of them are not well addressed.

5.1 Needs in AYA cancer survivors

The needs of AYA cancer survivors are mainly related to: (1) individualized information and advice, (2) counselling and psychological support, and (3) social networks, social support, and social relationships. But these needs may vary according to the time elapsed after the end of the treatment, the type of treatment received, the sex and/or the age of the AYA. The differences between AYA needs and those found in the adult systematic reviews (Hoekstra et al., 2014) might be due to the fact that different cancer and treatments produce different needs (Bleyer et al., 2008) and the developmental stage of the AYAs (Barnett et al., 2016).

In this work, there are several finding to be highlighted. First, we found that only one study considered the point of view of the oncology professionals (Zebrack, 2006) and none of the studies considered the point of view of the patient’s family. Because of the crucial role that family has, especially for this age range, future studies should take family members into account. Second, none of the studies used validated measures to assess AYAs needs. Having validated measures could help in the assessment and treatment of these needs and might guarantee a good communication between health care professionals. This tool is available in adults (Cox et al., 2013). In AYAs population several questionnaires have been developed, such as the Cancer Needs Questionnaire - Young People (CNQ-YP) (Clinton-McHarg, Carey, Sanson-Fisher, D’Este, & Shakeshaft, 2012) and the Survivor Unmet Needs Survey (SUNS) (Hall, D’Este, Tzelepis, Sanson-Fisher, & Lynagh, 2014) but the evidence supporting their psychometric properties is still limited. Third, only three studies evaluated whether patients’ needs were met or not (Keegan et al., 2012; Miedema et al., 2013; Zebrack, 2009a) and concluded that needs like cancer or treatment information, services and age-specific follow-up are not being met in AYA cancer survivors. Finally, most of the studies have been conducted in the USA. AYAs needs may vary depending on the region in which the study is conducted (Jemal et al., 2011). Therefore, in order to have a holistic view of the problem, it is important to carry out studies in countries other than the USA.

In order to address some of these issues we carried out Study II, in which we found that the most important needs in Spanish AYA cancer survivors were those related to being positive and feeling normal, feeling healthy at an emotional and physical level; medical examinations and monitoring of the disease; having advice for healthy habits and financing treatments. In comparison with the findings of our systematic review, participants did not identify ‘Individualized Information and Advice’ and ‘Relapse Detection’ as needs; instead, receiving medical examinations and monitoring of the disease were reported as needs. This finding may be due to the differences in the sample. The systematic review included studies where survivors aged between 14 and 40 years were included. In the Delphi study, the sample of survivors was composed by adolescents between 14 and 24 years old, and also included their relatives and health professionals.

Although there was considerable consensus between the answers of the three groups of participants in the Delphi study, we found some differences that are noteworthy. For example, having a healthy lifestyle was evaluated as a need by the AYA and relatives groups but not by the health care professionals group. Taking into account the risk of developing a cardiovascular disease in this population (Armstrong et al., 2013, 2016), the study of this need, and the implementation of an intervention would have a positive effect in the quality of life of this population. In addition, these results are in line with those studies that show the interest of AYA survivors in participating in this type of interventions (Stolley, Restrepo, & Sharp, 2010). Moreover, social issues were rated as extremely high by AYAs, but not by the rest of participants. The peer group have unique implications for adaptive development in this age (Bagwell, Newcomb, & Bukowski, 1998) so the call for attention to this need should not be disregarded. The rest of the agents involved in the care of these patients should take this factor into account in order to offer targeted care.

5.2 Centrality of event scale

The third and final objective of this dissertation was to assess the psychometric properties of the full- and short-forms of the Centrality of Event Scale (CES). The results showed a good fit of the model for a single factor structure, good internal consistency of the scale, and evidenced validity via the moderate and significant associations of the scores with those obtained with measures of depressive, anxious and post-traumatic symptoms severity.

The original validation study of the CES (Berntsen & Rubin, 2006) concluded that a one factor structure was most appropriate for both the 20- and 7-item versions of the scale. Our findings are consistent with those results for both long and short versions.

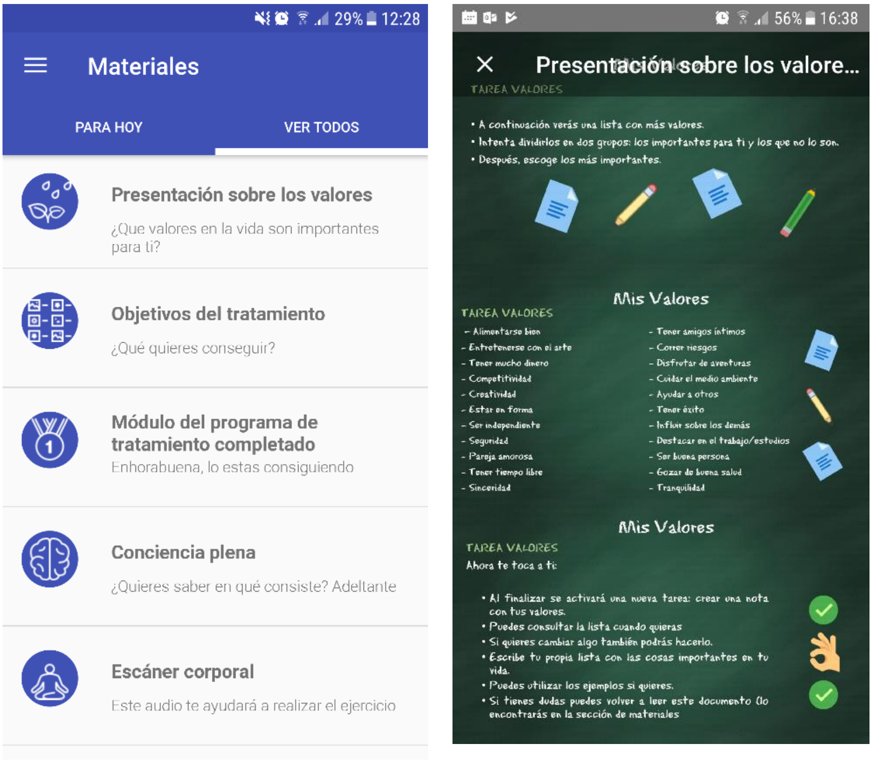
5.3 Looking into the future

Despite the high number of different psychosocial needs reported by AYA cancer survivors (Galán et al., 2016), there are few treatments available, and fewer have been tested. Therefore, future research should test specific treatments specifically tailored to the needs of this population.

Recent studies have pointed out that practical factors may be limiting the participation of some adolescents in the treatments (Judge Santacroce et al., 2010; Mays et al., 2011). This population could have specific barriers when following an intervention. Some of them could be time consuming obligations (e.g., studying and working) and physical limitations (e.g., chronic fatigue) (Arroyave et al., 2008). Therefore interventions using e-/m-Health could be used as a strategy to solve some of these barriers and decrease treatment costs in this population.

In this last section we want to present, briefly, a mobile application in which we have been working that will be tested very soon: iCan. This *app* includes a Smartphone-delivered program designed to help improve the quality of life of AYAs cancer survivors. A team of clinical psychologists and engineers with experience in developing health-related apps have been working in its development. The treatment is condensed in 5 weeks of work and contains the following modules: (1) general information- education about the period after finishing the cancer treatment such as tips to go back to "normal" life, important information to consider during medical visits, cancer relapse and sexuality; (2) life values and goals through the metaphor of Hayes' birthday party (Hayes, Strosahl, & Wilson, 1999) and the SMART mnemonic acronym (Bovend'Eerdt, Botell, & Wade, 2009) the user is invited to think about what their values are, and setting their own goals; (3) mindfulness: the content of this section has been adapted from the Mindfulness-Based Stress Reduction programme developed at the

Massachusetts Medical Centre (Kabat-Zinn, 1982); (4) self-esteem: information and exercises about self-esteem and how to improve it; (5) sleep quality: information and recommendations about sleep disorders and sleep hygiene; (6) physical activity: several guidelines about the types of physical exercises that can be done, and techniques to start or increase the level of physical activity and (7) healthy diet, where suggestions for changing eating habits and healthy recipes are provided. Figure 1 shows some screenshots showing some of its content.



Presentación sobre los valores
¿Que valores en la vida son importantes para ti?

Objetivos del tratamiento
¿Qué quieres conseguir?

Módulo del programa de tratamiento completado
Enhorabuena, lo estas consiguiendo

Conciencia plena
¿Quieres saber en qué consiste? Adelante

Escáner corporal
Este audio te ayudará a realizar el ejercicio

TAREA VALORES

- A continuación verás una lista con más valores.
- Intenta dividirlos en dos grupos: los importantes para ti y los que no lo son.
- Después, escoge los más importantes.

TAREA VALORES

- Alimentarse bien
- Entretenerse con el arte
- Tener mucho dinero
- Competitividad
- Creatividad
- Estar en forma
- Ser independiente
- Seguridad
- Pareja amorosa
- Tener tiempo libre
- Sinceridad
- Tener amigos íntimos
- Correr riesgos
- Disfrutar de aventuras
- Cuidar el medio ambiente
- Ayudar a otros
- Tener éxito
- Influir sobre los demás
- Destacar en el trabajo/estudios
- Ser buena persona
- Gozar de buena salud
- Tranquilidad

TAREA VALORES
Ahora te toca a ti:

- Al finalizar se activará una nueva tarea: crear una nota con tus valores.
- Puedes consultar la lista cuando quieras
- Si quieres cambiar algo también podrás hacerlo.
- Escribe tu propia lista con las cosas importantes en tu vida.
- Puedes utilizar los ejemplos si quieres.
- Si tienes dudas puedes volver a leer este documento (lo encontrarás en la sección de materiales

Figure 1. Screenshots of the app.

This *app* is part of WellTech, a digital platform that offers online health and behavioral treatments. The treatment is delivered using an app that has been used to deliver other treatments also developed using WellTech technology. The usability and acceptability of the app has been successfully tested in a previous study (de la Vega, Roset, Galán, & Miró, 2016).

6. Conclusions

The main conclusions of this dissertation can be summarized as follows:

1. AYA cancer survivors have specific needs such as receiving information and individualized counselling, tailored care in the post-treatment phase, and psychological help and social support.

2. AYA cancer survivors have several unmet needs that are mainly related to: fertility and sexual health, healthy lifestyle maintenance, social and family support, and peer relationships.

3. The CES is a reliable and valid assessment tool in young people, which can help determine the importance of centrality to adjustment to cancer events.

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