

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

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CITATION: Galán S, de la Vega R, Miró J. Needs of adolescents and young adults after cancer treatment: a systematic review. *Eur J Cancer Care (Engl)*. 2018 Nov;27(6):e12558. doi: 10.1111/ecc.12558. Epub 2016 Aug 10. PMID: 27507260.

ABSTRACT

The aim of this study was to conduct a systematic review of the literature on the needs of adolescents and young adults (AYA) 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: “individualized 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 conceptualized and what the most valid and reliable procedure for assessing patient’s needs is.

Keywords: cancer survivor; adolescent; young adults; needs; systematic review.

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 1975–77 to 2007–2010, and the 5-year overall survival rate among adolescents exceeded 80% for the years 2003 to 2007 (Smith et al. 2014). In Europe, the five-year survival for all cancers was 87% for adolescents and young adults (Gatta et al, 2009). The numerous definitions of cancer survivorship (Khan et al, 2012) include different actors (family members, friends and caregivers) and/or stages (acute, extended and permanent) in the survivorship experience (Miller et al, 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 adolescent and young adult (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, AYA 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 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 et al. 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 AYA, 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 et al,

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, health care 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 et al, 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.

METHODS

A systematic review was conducted in accordance with the PRISMA recommendations for reporting systematic reviews and meta-analyses (Moher et al, 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: (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 maximize the number of papers retrieved, reference lists of relevant papers were also checked for additional works not found during the computerized 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 RdIV) 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 et al. (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, RdIV) independently assessed the papers 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 were included under the category of “Adapted healthcare according to the new post-treatment status”. Eight categories were created after analysing the assessed needs to summarize the information: (1) *Individualized 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 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 categorization 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.

RESULTS

In an initial screening of the 1329 studies first identified, duplicate articles were identified and excluded, and a total of 1301 titles and abstracts were reviewed. Of these, 1240 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 were excluded. Finally, 14 studies were selected for the final analysis and synthesis. Figure 1 describes the selection process used in this study.

[Insert Figure 1 about here]

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 USA. But there are other studies from Canada (Easley et al. 2013; D'Agostino et al. 2013; Miedema et al. 2013; Zebrack, 2009), Switzerland (Gianinazzi et al, 2014), Netherlands (Knijnenburg et al, 2010), Sweden (Sundberg et al. 2012) and Australia (Millar et al, 2010). The sample size ranged from as few as 20 participants (Rabin et al, 2011; Rabin et al, 2013) to as many as 1088 (Zebrack et al, 2007). All the study samples consisted of adolescents and young adults, with the exception of one study that also collected data from health professionals (Zebrack et al, 2006) and another 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 paper 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.

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 (Rabin et al, 2011; Rabin et al, 2013; Easley et al, 2013; Miedema et al, 2013), one another used a focus group (D'Agostino et al, 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.

[Insert Table 1 about here]

Main topic

The study questions of the reviewed studies differ greatly: eleven studies focused on perceived patients' needs (Easley et al, 2013; Gianinazzi et al, 2014; Keegan et al, 2012; Knijnenburg et al, 2010; D'Agostino et al, 2013; Miedema et al, 2013; Millar et al, 2010; Sundberg et al, 2012; Zebrack et al, 2007; Zebrack, 2009; Zebrack et al, 2006); two assessed the intervention programs the patients might need and what these programs 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).

Assessed needs

Three of the eight categories that we created to summarize the information about survivor needs coincided with what was most frequently assessed (in twelve of the fourteen studies): individualized 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 three of the fourteen studies) were those that had to do with relapse detection, financial support, and returning to normal life and adapting to the new role. Table 2 provides additional details.

[Insert Table 2 about here]

Reported outcomes

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. (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 one 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.

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). On the other hand, the intensity of the treatment correlated with the number of late effects experienced (McClellan et al, 2013).

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. On the other hand, women requested more information about fertility-related topics.

Age. According to Keegan et al. (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 health care and decision-making. Finally, D'Agostino et al. (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 pediatric and older adult survivors.

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

[Insert Table 3 about here]

DISCUSSION

The percentage of young people surviving cancer has increased enormously in the last thirty 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 is 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 adolescents and young adults, patients tend to seek social support from their families and friends, not their doctors. Moreover, support and access to specialists (for example, 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 and colleagues (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), McClelland 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 programs for cancer survivors are designed. For example, Millar and colleagues (Millar et al, 2010) showed that needs changed with time: at first, needs are directly related to health care 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.

Family is one of the most important sources of support for adolescent survivors of childhood cancer. As demonstrated by Alderfer and colleagues (Alderfer et al, 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 et al, 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 conceptualized 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 (for example, 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 et al, 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 prioritization 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 (2013) 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 met. Future studies should detect which of the identified needs are not adequately addressed and why so that specific support programs 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 USA. 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 adolescents and young adults 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 papers might have been missed. However, the search strategy used was exhaustive, so it is very unlikely that many relevant papers will have been left out of this review.

This paper summarizes important information about the needs of young people who have survived a treatment for cancer. Providing information and individualized 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 conceptualized and measured is fundamental to the advancement of this area of study.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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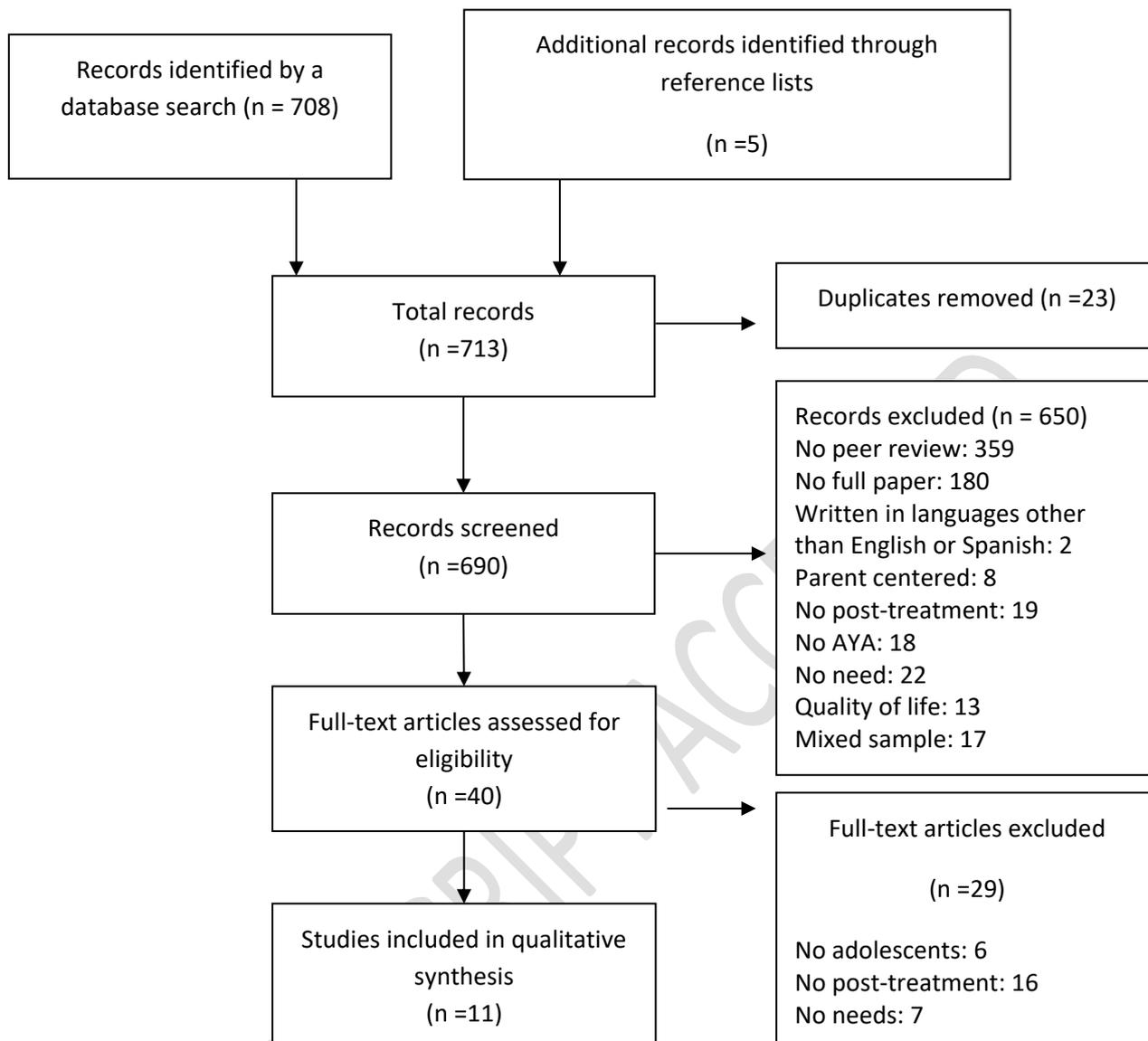


Figure 1. PRISMA Protocol

TABLES

Table 1. Assessment of the quality of the reviewed studies

Author & 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)	Percentage
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)*	Y	-	Y	Y	Y	Y	-	N	-	Y	Y	Y	-	-	U	-	Y	Y	Y	11/13	84
Keegan et al. (2012)*	Y	-	N	Y	Y	Y	-	N	-	Y	Y	N	-	-	U	-	Y	Y	Y	9/13	69
Knijnenburg et al. (2010) *	Y	-	Y	Y	Y	Y	-	N	-	Y	N	Y	-	Y	U	-	Y	Y	N	10/13	77
McClellan et al. (2013)*	Y	-	Y	Y	Y	Y	-	N	-	Y	Y	Y	-	-	U	-	Y	Y	Y	11/13	84
Millar et al. (2010)*	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
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)*	N	-	Y	Y	Y	Y	-	Y	-	Y	Y	Y	-	-	U	-	Y	Y	Y	11/13	84
Zebrack et al. (2009)*	Y	-	Y	Y	Y	Y	-	Y	-	Y	Y	Y	-	-	U	-	Y	Y	Y	12/13	92

* These are quantitative studies; therefore not all quality criteria are applicable herein.

Note: (Y): Yes; (N): No; (U): Unclear

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

	Gianinazzi et al. (2014)	Keegan et al. (2012)	Knijnenburg et al. (2010)	Easley et al. (2013)	McClellan et al. (2013)	Millar et al. (2010)	Rabin et al. (2011)	Rabin et al. (2013)	Zebrack et al. (2006)	Zebrack et. al. (2007)	Zebrack et. al. (2009)	Total number of times an item was assessed
Individualized information and advice *	5	6	4	-	8	3	2	-	5	2	5	31
Individualized information (having children, cancer risks to your family)	1	4	1	-	3	2	1	-	2	1	2	15
Surveillance and assessment of long-term effects of cancer treatment	1	1	-	-	3	-	-	-	2	-	-	6
Nutrition and diet		1	-	-	1	-	1	-	-	-	1	4
Guidelines for follow-up care	1	-	1	-	-	-	-	-	1	1	-	2
Information about support services and available help		-	-	-	-	1	-	-	-	-	1	2
Information about decreasing the risk of having cancer again	1	-	1	-	1	-	-	-	-	-	-	1
Internet site	1	-	1	-	-	-	-	-	-	-	1	1
Social network, social support, social relationships		3	-	5	1	-	1	3	3	4	2	17

Support groups	-	1	-	1	-	-	1	2	-	1	-	5
Opportunities to meet other survivors	-	1	-	1	-	-	-	1	1	1	-	4
Support, counselling from family and friends	-	-	-	1	-	-	-	-	-	1	1	2
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	-	2
Opportunities to get involved and “give back” to the cancer community	-	-	-	1	-	-	-	-	1	-	-	1
Child care	-	-	-	-	-	-	-	-	-	-	1	1
Counselling and psychological support	-	2	-	1	1	4	1	-	2	2	4	16
Psychological and behavioural risk assessment and counselling to manage distress (anxiety about recurrence)	-	-	-	-	1	-	-	-	1	1	-	3
Help with unwanted thoughts, emotions & 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	-	2
Living with uncertainty	-	-	-	-	-	-	-	-	1	-	-	1
Counselling related to sexuality or intimacy	-	-	-	-	-	-	-	-	-	-	1	1
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	1	-	-	3	3	2	13
A system for transitioning care from oncologists to physicians	-	-	-	-	-	-	-	-	1	1	-	2
Availability of health care providers	-	-	-	-	-	1	-	-	-	1	-	2
Adequate health insurance	-	-	-	-	-	-	-	-	1	1	-	2
Recognition among health care 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
Having a nurse come to your home	-	1	-	-	-	-	-	-	-	-	-	1
Camps, retreats	-	-	-	-	-	-	-	-	-	-	1	1
Transportation assistance	-	-	-	-	-	-	-	-	-	-	1	1
Back to normal life and adaptation to the new role	-	-	-	-	-	8	-	1	3	-	-	12
Getting back to normal, who I am	-	-	-	-	-	1	-	-	1	-	-	2
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 health care	-	-	-	-	-	-	-	-	1	-	-	1
Assistance in getting back to work	-	-	-	-	-	1	-	-	-	-	-	1
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

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
Financial support	-	2	-	-	-	-	-	-	1	-	1	4
Financial assistance and benefits	-	2	-	-	-	-	-	-	1		1	4

(-) Not assessed

Note. 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”)

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
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: - Sociodemographic 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: -Leukemia -Lymphoma - Central Nervous System tumor -Neuroblastoma -Retinoblastoma -Renal tumor -Hepatic tumor -Bone tumor -Soft tissue sarcoma -Germ cell tumor	Online Survey questions: - Sociodemographic 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 health care -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 -Sociodemographic and health-related differences in reporting unmet needs
Knijnenburg et al. (2010) Netherlands	N = 145 (19% women)	Online Survey questions: -Personal information	-Internet Use -Main information items requested

	<p>Age range: >12 (\bar{x}= 16.2)</p> <p>Type of cancer: -Leukemia -Lymphoma Bone tumor -Wilms' or any other kidney tumor -Neuroblastoma -Germ cell tumor -Central Nervous System tumor -Retinoblastoma</p>	<p>-Evaluation of information supplied by the outpatient follow-up clinic</p> <p>-Internet availability, health-related Internet use and late effects-related Internet use</p> <p>-Information and functional requirements for and expectations of a late effects web site.</p>	
<p>McClellan et al. (2013)</p> <p>USA</p>	<p>N = 272 (53% women)</p> <p>Age range: 18-38 (\bar{x}= 24)</p> <p>Type of cancer: -Leukaemia or lymphoma -Solid tumour -Brain tumour</p>	<p>Self-report survey: -Demographic information -Cancer history -Side effects of treatment -Current health status -Survivor treatment summary -Survivor experience and needs</p>	<p>-Late effects from the functional domain</p> <p>-Correlation between treatment intensity and the number of side-effects</p>
<p>Millar et al. (2010)</p> <p>Australia</p>	<p>N = 63 (63% women)</p> <p>Age range: 18-25 (\bar{x}= 20.4)</p> <p>Type of cancer: Not reported</p>	<p>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</p> <p>24 Additional Need Items developed from previous qualitative research</p> <p>Depression, Anxiety and Stress Scales (DASS-21): -Depression -Anxiety -Stress</p>	<p>-The top 10 unmet needs according to the time-since-treatment.</p>
<p>Rabin et al. (2011)*</p> <p>USA</p>	<p>N = 20 (75% women)</p> <p>Age range: 18-39, (\bar{x}= 33.5)</p> <p>Type of cancer: -Thyroid -Breast -Melanoma -Sarcoma -Rectal -Nasopharyngeal carcinoma</p>	<p>Face to face individual interview, with open-ended questions: -Programs that might be helpful (needed and/or wanted) -Barriers that might interfere with participation in these programs</p>	<p>Types of program: -Physical activity -Relaxation -Emotional support -Information -Nutrition/weight management</p> <p>Programs designed: -Similarity of participants</p> <p>Barriers: -Time -Being unaware of programs</p>

	<ul style="list-style-type: none"> -Leukaemia -Hodgkin's lymphoma -Endometrial -Brain 		<ul style="list-style-type: none"> -Health-related barriers -Psychosocial barriers
<p>Rabin et al. (2013)*</p> <p>USA</p>	<p>N = 20 (75% women)</p> <p>Age range: 18-39, (\bar{x}= 33.5)</p> <p>Type of cancer:</p> <ul style="list-style-type: none"> -Thyroid -Breast -Melanoma -Sarcoma -Rectal -Nasopharyngeal carcinoma -Leukaemia -Hodgkin's lymphoma -Endometrial -Brain 	<p>Face-to-face individual interview with open-ended questions:-</p> <p>Types of program that might be helpful for young adult cancer survivors.</p> <ul style="list-style-type: none"> -Program delivery -Format (group or individual) -Barriers to program participation 	<ul style="list-style-type: none"> -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)
<p>Zebrack et al. (2006)</p> <p>USA</p>	<p>N = 40 oncology professionals; 37 young adults (sex not reported)</p> <p>Age not reported. Age range of patients: 18-44 (\bar{x}= 31)</p> <p>Type of cancer:</p> <ul style="list-style-type: none"> -Brain tumour -Breast cancer -Endometrial -Germ cell, testicular or ovarian -Sarcomas -Hodgkin lymphoma -Leukaemia -Melanoma -Other 	<p>Delphi panel: 3 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.</p> <p>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.</p> <p>3rd round: rank order items for each section</p>	<p>The top five needs of the following categories:</p> <ul style="list-style-type: none"> -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 Health Care Needs -Counselling, Information, and Supportive Care Needs for Off-Treatment Survivors -Other Psychosocial Needs for Off-Treatment Survivors
<p>Zebrack et al. (2007)</p> <p>USA</p>	<p>N = 1,088 (76% women)</p> <p>Age range: 18-39 (\bar{x}=30.8)</p> <p>Type of cancer:</p> <ul style="list-style-type: none"> -Breast cancer 	<p>Online assessment which included two different sets of questions (i.e., oncologists and patients) that asked respondents to rank order health care and supportive care needs of patients in treatment and off-treatment survivors:</p> <ul style="list-style-type: none"> -Demographics 	<ul style="list-style-type: none"> -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

	<ul style="list-style-type: none"> -Hodgkin's disease -Non-Hodgkin's lymphoma -Leukaemia -Testicular cancer -Bone and other soft tissue sarcoma -Adenosarcomas and other carcinomas -Brain tumour -Other 	<ul style="list-style-type: none"> -Health care needs -Supportive care needs -Medical characteristics 	mean rank scores by current age, age at diagnosis, years since diagnosis.
<p>Zebrack et al. (2009)</p> <p>USA and Canada</p>	<p>N = 20 (75% women)</p> <p>Age range: 18-39 (\bar{x} = 33.5)</p> <p>Type of cancer:</p> <ul style="list-style-type: none"> -Thyroid -Breast -Melanoma -Sarcoma -Rectal -Nasopharyngeal carcinoma -Leukaemia -Hodgkin's lymphoma -Endometrial -Brain 	<p>Online Survey questions:</p> <ul style="list-style-type: none"> -Needs for information -Practical support -Emotional support -Maintaining and establishing interpersonal relations -Addressing existential questions and issues such as uncertainty and mortality 	<ul style="list-style-type: none"> -Demographic information -Information and supportive care needs -Medical/health status characteristics

* The sample and the procedure were the same for both studies.

MANUSCRIPT ACCEPTED