

# 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**

### **Abstract**

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) analyze 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 “Counseling 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

## 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 A, O’Leary M, Barr R, 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 EURO CARE-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, 2005).

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, leukemia, germ cell tumors (including testicular cancer), melanoma, central nervous system tumors, sarcomas, breast, cervical, liver, thyroid, and colorectal cancers are the most common cancer diagnoses (Institute, n.d.). 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 percent of long-term survivors of childhood leukemia 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 USA, Australia and Canada (Keegan et al, 2012; McClellan et al, 2013; Millar et al, 2010; Rabin et al, 2011, 2013; Zebrack, 2009; Zebrack et al, 2006, 2007). 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 (Galán, S., de la Vega, R., Miró, J. Unpublished work). 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 maximize 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 and 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 (Gil and Pascual-Ezama, 2012; Landeta, 1999; Velez-Pareja, 2003) 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 hypothesized 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 counseling (Vazquez-Ramos et al, 2007), healthcare quality indicators (Boulkedid et al, 2011), including cancer and its treatment (Dreesen et al, 2013; Efstathiou et al, 2007; Shaw and Coggin, 2008; Zebrack et al, 2006).

### ***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 one 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 organizations 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 organization 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 organization 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 e-mail 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 maximize 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 organizations 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 4 people including two of the authors of this paper (JM and RV) as well as 2 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 three months. During this time, the individuals who agreed to participate but who had not responded to the survey yet were contacted via telephone or e-mail 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 minutes 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 e-mail in order to encourage participation. Participants took around 17 minutes 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 analyzed using constant comparative analysis (Miles et al, 2014), and then classified into different categories, following the classification developed by Galán, S., de la Vega, R., Miró, J. (Unpublished works). The categories were: (1) *Individualized information and advice*; (2) *Needs specific to post-cancer treatment and specialized care*; (3) *Relapse detection*; (4) *Counseling 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 summarized in Table 1.

[Insert Table 1 about here.]

**Needs mentioned by participants.** The needs of AYA cancer survivors mentioned by each participant type are summarized in Table 2, in alphabetical order. No need was identified by the study participants related to the categories “Individualized 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.

[Insert Figure 1 and Table 2 about here]

### Round 2

The demographic characteristics of the three groups that participated in the Round 2 survey are summarized 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 specialized care* (8.85); *Financial support* (8.84); *Developing an adaptive social network* (8.46); *Maintaining a healthy lifestyle* (8.34) and *Counseling and psychological support* (8.20). Importance scores are shown in Table 4.

[Insert Table 3 about here]

The Round 2 participants reported 7 additional needs not reported by the Round 1 participants. Because 5 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 Specialized Care* and one as a *Need related to Counseling 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 *Counseling and psychological*

*support*); Feeling normal (category *Developing an adaptive social network*); Medical examinations and monitoring of the disease (category *Adapted healthcare 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.

[Insert Table 4 about here]

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 to 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: *Counseling and psychological support* (5.97); *Needs specific to post-cancer treatment and specialized 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 specialized 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.

#### ***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 "*Counseling 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 (Grimmett et al, 2015; Schmitz et al, 2010). 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 (Keegan et al, 2012; Zebrack, 2009). 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 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 specialized 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 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 et al., 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 organize meetings for survivors to meet and support each other, or provide access to a

pediatric 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 generalizability 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 generalizability 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.

ACCEPTED MANUSCRIPT

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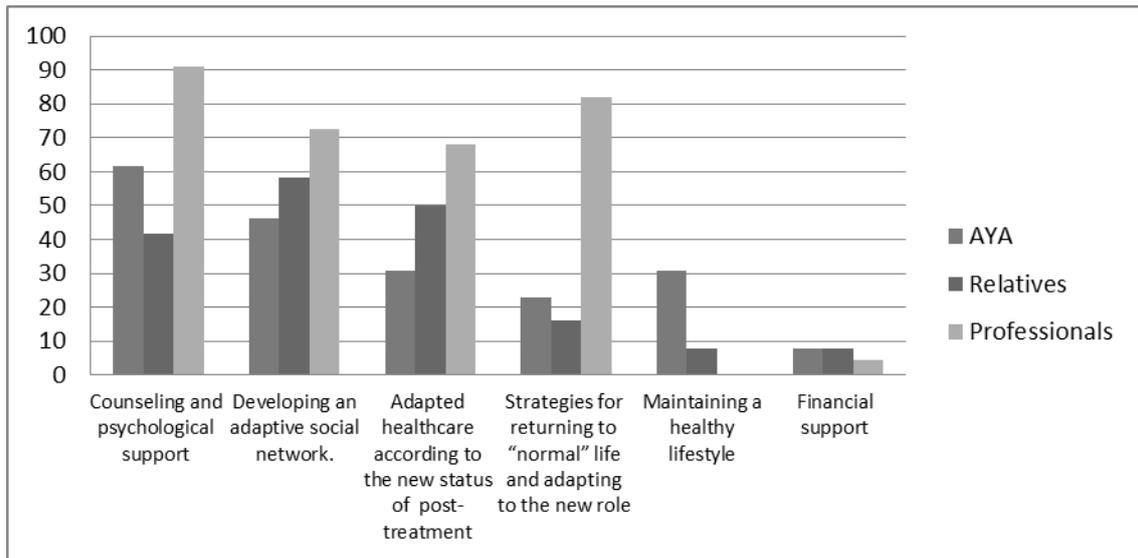


Figure 1. Percentages of participants in each group who reported each category of needs (round 1).

## Tables

Table 1. Sample characteristics from Round 1 (N=47)

Type of participant	Health Professionals (N=22)	AYA (N=13)	Relatives (N=12)
	Oncologists: 3 Nurses: 6 Psychologists: 10 Social workers: 3		100% parents
Age, Mean (SD) and range	Range (26-62) Mean= 39	Range (14-23) Mean= 18	Range (35-54) Mean= 46
Sex	86% women	54% women	91% women
Average of oncological experience in years, Mean (SD)	10.63 (SD)	-	-
Average of working with AYA in years, Mean (SD)	10.45 (SD)	-	-
Work situation	-	100% student	45% public servant 27% worker 27% other
Marital Status	-	100% single	91% married 9% divorced
Age at diagnosis, Mean (SD)	-	Range (1-16) Mean= 8.7	-
Years after the last treatment	-	Range (1-18) Mean= 8.2	-
(-) Not applicable			

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

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 Counseling 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

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## 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

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## Financial support

Financing treatments

Having free teachers at all levels of education

Standardize the criteria for assessing the degree of disability

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#### Maintaining a healthy lifestyle

Advice for healthy habits

Help to have a good nutrition

Physical exercise

Sleep hygiene

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#### Needs specific to post- cancer treatment and specialized care

Advice on fertility

Coordination between pediatric and adult care

Coordination between primary and specialized 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

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#### Strategies for returning to “normal” life and adapting to this new role

Having an alternative entertainment in the event of sequels

Standardization 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

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

Type of participant	Health Professionals (N=29)	AYA (N=17)	Relatives (N=12)
	Oncologists: 10	-	100% parents
	Nurses: 5		
	Psychologists: 10		
	Social workers: 4		
Age, Mean (SD) and range			
	Range (26-62)	Range (15-24)	Range (38-54)
	Mean= 39	Mean= 20	Mean= 47
Sex			
	83% women	69% women	92% women
Average of oncological experience in years, Mean (SD)			
	10 (SD)	-	-
Average of working with AYA in years, Mean (SD)			
	10 (SD)	-	-
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)			
	-	Range (2-17) Mean= 11	-
Years after the last treatment			
	-	Range (2-16) Mean= 7	-
(-) Not applicable			

Table 4. Ranking and importance score of each need.

	Health Professionals		AYA		Relatives	
	Rank	I.S.	Rank	I.S.	Rank	I.S.
<b>Counseling and psychological support</b>						
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	-	-
<b>Developing an adaptive social network</b>						
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	-	-
<b>Adapted healthcare according to the new status of post-treatment</b>						
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
<b>Strategies for returning to “normal” life and adapting to the new role</b>						
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

Standardization 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
Standardize 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