"Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care

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Abstract (199/200)

Objective: This mixed-method study assessed 1) survivors' and parents' information needs; and 2) associations between unmet information needs and clinical and socio-demographic characteristics.

Methods: Stage 1: CCS and parents of CCS, >5 years post-diagnosis completed a questionnaire on information needs, overall health and perceived risk. Predictors for unmet information needs were assessed by multivariable regression. Stage 2: participants were interviewed in-depth on these topics.

Results: Questionnaires were completed by 485 participants comprising 322 survivors (mean age: 26.7years, SD=7.9; time since diagnosis: 19.7years, SD=8.8) and 163 parents (child age: 12.9years, SD=2.4; time since diagnosis: 9.7years, SD=2.3), and complemented by 70 interviews. Survivors reported unmet information needs about late effects (57.5%) and parents for fertility issues (62.5%). Survivors had more unmet needs for medical information whereas parents had significantly more regarding sexual issues and lifestyle. Being a parent ($p=0.001$), dissatisfaction with follow-up care ($p=0.003$), lower overall health ($p=0.014$), higher perceived risk of late effects ($p<0.001$), and greater anxiety/depression ($p<0.001$) were significantly associated with more unmet needs.

Conclusion: Unmet information needs were common for survivors and parents of CCS.

Practice implications: Future efforts towards tailoring information on potential late effects, healthy lifestyles and follow-up care may help to address unmet information needs.

1. Introduction (3962/4000)

Childhood cancer diagnosis and treatment are traumatic experiences for patients and their families [1]. During treatment, the child and parents have to cope with a lot of new nontrivial medical information to make informed decisions, continuing in the years post-treatment and into survivorship. Childhood cancer survivors (CCS) are at high risk of developing late effects decades after treatment has ended, due to the cancer and/or treatment they received as a child [2]. Lifelong, risk adapted follow-up care is therefore recommended [3, 4]. Optimal participation in health care including follow-up necessitates having appropriate information, [5, 6] and access to more information leads to greater involvement in treatment-related decision-making [7] and possibly awareness of late effects [8-10].

Among support needs reported by childhood cancer patients, information needs are commonly unmet, [11, 12] and can vary over time. Shortly after treatment parents and survivors report wanting information on fertility and about the challenges of being off treatment [13]. Many years after treatment, parents and survivors report unmet information needs particularly for medical topics such as late effects and follow-up care [12, 14, 15]. Two long-term Swiss studies showed over 60% of survivors and more than 50% of parents had information needs about follow-up care or late effects more than a decade after diagnosis [14, 15]. In the Netherlands, even after visiting a late effects outpatient clinic, almost 30% of survivors/parents had unanswered questions mainly regarding recognizing late effects [16].

Adult cancer survivors with lower information needs, and fewer information barriers, report better health-related quality of life (QoL) and less anxiety and depression [17, 18]. Clinical and socio-demographic factors associated with increased information needs in CCS and parents have rarely been studied. There is some evidence that high information needs are associated with lower QoL, and higher psychological distress [15] and cancer related

anxiety/fear [12]. Survivors who are female, younger at diagnosis, and of poor physical health more frequently report unmet information needs [19]. In parents of CCS, high information needs are reported by parents with a migration background and those with greater concerns about cancer recurrence [14]. However, some CCS feel stressed and overwhelmed with the amount of information they have received and report no need for additional information [20]. Some parents also report resisting further information for fear of its potentially negative impact [21]. Therefore, it is important to find a balance of delivering the right amount of information at the right time [22].

No studies have previously investigated the information needs and possible correlates of long-term CCS and their parents in Australia and New Zealand. Meeting information needs and detecting those at highest risk is important to ensure engagement in follow-up care. This mixed-method study investigated information needs of long-term survivors and parents of CCS in a bi-national cohort where health care (including follow-up care) is publically available, but not consistently accessed. We aimed to 1) assess information needs of survivors and parents of CCS; and 2) investigate associations between unmet information needs and clinical and socio-demographic characteristics of survivors and parents.

2. Methods

This is a two-stage mixed-methods study. In stage 1, questionnaires were distributed to CCS and parents of CCS. In the second stage we conducted in-depth telephone interviews with participants who completed the questionnaire and indicated consent to an interview in the questionnaire. Quantitative data from the questionnaire was used to inform qualitative data from interviews. The qualitative findings are then used to explain the quantitative results [23].

Participants

Eligible survivors were diagnosed with any form of cancer before age 16years, > 5years post-diagnosis, had completed active treatment, were proficient in English and were alive and in remission. For survivors below 16years, we invited parents to participate on behalf of their child. One questionnaire was completed per survivor or parent. Packages sent to survivors between 16-18years included two letters, one each addressed to the parent(s) and the survivor, and the decision was left to the family as to whether who completed the questionnaire. Survivors over 18years of age completed their own questionnaires.

Procedure

Participants were identified through medical records of each hospital. We also advertised the study through national media to reach CCS who were dis-engaged from their treating hospital or follow-up clinic. We mailed questionnaires to CCS and parents of CCS treated at eight paediatric hospitals in Australia and New Zealand. Potential participants were posted an invitation letter from a lead clinician at the hospital at which they were treated, consent form, questionnaire and reply-paid envelope. Questionnaires could also be completed online. Non-respondents were telephoned after four weeks up to four times, or after surveys were resent twice at the participant's request, whichever came first.

Semi-structured telephone interviews were administered by a clinical psychologist and piloted. The interviews were recorded and transcribed verbatim.

The study was approved by the relevant ethics authority for all participating hospitals and was endorsed by the Australian and New Zealand Children's Haematology Oncology Group.

Measures

The questionnaire was designed by an expert committee and piloted with five survivors and five parents. It assessed participants' information needs (met or unmet); and demographic and clinical characteristics (**Table 1**). All responses were anonymous..

Outcome

Information needs: We assessed information needs related to medical topics, psychosocial needs, and lifestyle behaviors using a purpose designed 22-item questionnaire. Response options were: 1='not needed', 2='needed but not received', 3='needed and received some' and 4='needed and received enough'. For the analysis we dichotomized the variable into *total information needs*: No needs=answer 1, yes=answer 2, 3 or 4; and into *unmet information needs*: No=answer 1 or 4, and yes=answer 2 or 3.

Explanatory variables assessed by questionnaire

Socio-demographic information

We assessed survivor's age, survivor's sex, relationship to survivors, survivors' and parents' ethnic background, survivors' and parents' place of residence, survivors' and parents' education level (no post-school qualification/post-school qualification: apprenticeship, TAFE [vocational tertiary education] certificate/ diploma, college, university degree, post-graduate degree) and survivors' and parents' employment status, survivors' and parents' income and having private health insurance (Table 1).

Medical characteristics (self-reported)

Attendance at long-term follow-up (LTFU) clinic (yes/no), receipt of treatment summary and/or survivorship care plan (SCP, 0=none received, 1=treatment summary only, 2=treatment summary/SCP), date of diagnosis, date of treatment completion, treatment received and whether their cancer had relapsed, were self-reported. Participants reported their, or their child's diagnosis, which we categorized into leukemia, lymphoma, brain tumor and 'other', according to International classification of childhood cancer (ICCC-3) [24] for statistical analysis.

Additional explanatory variables assessed by questionnaire:

Overall health: Participants rated their overall health on a 6-point scale: 1='very poor' to 6='excellent health'. For the analysis, responses were categorized into: poor (answer=1, 2 or 3), good (answer=4) and very good (answer=5 or 6). *Anxiety/depression (child-self, parent-self):* Measured using the anxiety/depression item of the EuroQol EQ-5D-5L [25]. Five response options ranged from 1='I am not anxious or depressed' to 5='I am extremely anxious and depressed'. For the analysis we created a binary variable as an indicator of level of anxiety/depression: no problems (answer= 1 or 2) vs any problems (answer=3,4 or 5) according to the developer's instructions [26].

Fear of cancer recurrence (child-self, parent-proxy): Assessed using a modified version of the fear of cancer recurrence inventory severity subscale [27]. Four items assessed participants' perceived risk of, and worry about, the cancer returning and developing late effects on a 5-point scale (1='Not at all' to 5='A great deal'). For the analysis we categorized responses into 'not at all' (answer=1), 'a little at risk' (answer=2) and 'at high risk' (answer=3, 4 or 5).

Global satisfaction with care (child-self, parent-proxy): Assessed using one item asking how satisfied the participant was with cancer-related follow-up care on a 5-point scale (1='very unsatisfied' to 5='very satisfied'), as used previously [28, 29]. For the analysis we grouped

the variable into three categories: ‘unsatisfied’ (answer=1 or 2), ‘neither’ (answer=3), or ‘satisfied’ (answer=4 or 5).

Topics addressed in the interviews included discussion of participants’:

1. information needs regarding late effects,
2. perception of risk of developing late effects,
3. health management in future

Statistical analysis

All analyses were performed using Stata 14.1. We used descriptive statistics and chi-square tests to describe the study population, information needs and unmet information needs and to compare survivors’ and parents’ information needs. For the regression analysis we calculated the total sum of unmet information needs (in total 22 items). Cronbach’s alpha for total unmet information needs was good (alpha=0.90). We used univariable and multivariable linear regression models to analyze associations of clinical and socio-demographic characteristics with total unmet information needs. Variables that were statistically significant at $p < 0.05$ in the univariable model were included in the subsequent multivariable model.

Interview data was analyzed using content analysis to enable the thematic organization of responses, supplemented with the methodology described by Miles and Huberman [30].

NVivo11 was used to code participants’ responses. Responses were coded line by line by two coders (JV and CS). 10% of randomly selected interviews were coded by both coders, and compared to ensure consistency (91.35% agreement, 0.79 coefficient).

Discrepancies were resolved through discussion between researchers. Matrix coding was used to cross-analyze themes and participant characteristics (e.g. separating survivor and parent responses).

3. Results

In total, 827 survivors and parents of CCS were contacted and 485 responded (response rate 59%). Questionnaires were completed by 322 survivors (mean age: 26.7years, SD=7.9; time since diagnosis: 19.7years, SD=8.8) and 163 parents (child age: 12.9years, SD=2.4; time since diagnosis: 9.7years, SD=2.3; **Table 1**). Respondents and non-respondents did not differ in sex ($p=0.318$), time since diagnosis ($p=0.328$) and age at study ($p=0.521$). Out of 285 willing to be interviewed, 70 (39 survivors and 31 parents) were interviewed, at which point thematic saturation was apparent. Leukemia was the commonest diagnosis (40.7% CCS and 46.6% parents). Forty-three percent of survivors and 78.5% of parents reported attending a LTFU clinic. Seventeen percent of survivors and 16.0% of parents received a treatment summary only and 40.1% of survivors and 36.8% of parents received a combined treatment summary/SCP. There were no significant differences in interviewee respondents and non-respondents in sex ($p=0.796$), time since diagnosis ($p=0.935$) and age at study ($p=0.954$).

Total information needs

The majority of survivors and parents reported at least one area of information need (76.7% of survivors, 76.6% of parents) confirmed by many interviewees: *“You can never have too much information.”* (28-year-old female) or as stated by a parent of a 15-year-old male survivor: *“The more information you have the more options it gives you. You don’t necessarily have to do anything with the information you’re given but I think it’s important that you at least know”*.

Overall, survivors’ and parents’ information needs were highest for late effects (85.0% of survivors, 90.2% of parents) and cancer recurrence (79.7% of survivors, 84.6% of parents). Financial/employment advice (18.2% of survivors, 15.6% of parents) and community support services (11.3% of survivors, 15.6% of parents) were the lowest areas of information needs for survivors and parents (**Supplemental Figure 1**).

Unmet information needs

Unmet information needs were classified as having received some information but not enough or not having received information at all. 23.3% of survivors and parents reported no unmet information needs (**Figure 1**): *“There’s more than enough information. It’s the old story of the facts and who can tell the facts”* (parent of 13-year-old male survivor). The remaining quarter of survivors (22.4%) and parents (26.4%) reported more than 11 unmet information needs. Survivors described a positive relationship between increased information and empowerment for self-care: *“I think with more information, I’m happy to be in charge of my own follow-up, as long as I’m informed about what that follow-up should be.”* (28-year-old female survivor) Other interviewees were undecided about how much information they desired to receive, from having too much information to too little information: “I don’t know - I think I’m in two minds about that, because (1) quite frankly - you’re pleased ... it’s over...but (2) you do want to know, but you don’t really want to know either. I don’t know, because you just want to move on, actually” (parent of 13-year-old male survivor) or as described by a 29-year-old survivor: “[Information is a] two-edged sword.”

Similar to high reported need for information on late effects and second cancers, these areas were the most frequently unmet need for survivors (unmet information needs in late effects: 57.5%; development of second cancers: 53.4%). Parents had highest unmet needs for information about fertility issues (62.5%) and late effects (53.8%). As described by one parent of a 12-year-old male survivor: *“I think that information [about late effects] and knowledge is always useful; knowing when not to have to panic or being prepared if something does happen. You can say, well yeah I knew that might have been a risk. You’re sort of almost prepared for it - forewarned and forearmed.”*

When comparing survivors’ and parents’ unmet information needs, more survivors reported unmet needs for medical aspects such as cancer treatment ($p=0.004$) and cancer recurrence

($p=0.004$), whereas parents had more unmet need for information about their child's fertility ($p<0.001$), lifestyle factors such as current health behavior ($p<0.001$), sun protection ($p<0.001$) and melanoma/skin cancer ($p<0.001$) and sexual issues ($p<0.001$; **Figure 2**). One mother of a 10-year-old survivor described the anticipation of these potential long-term fertility issues: *"As she's getting older, things like hitting puberty, getting the monthly periods and all that sort of stuff. ...maybe [she] wants to have children, I think that's the biggest concern for me."*

Many survivors admitted that they relied on their parents or didn't remember having received information: *"That [information on late effects] was information I never really got. I mean I may have but I was a kid and I don't recollect getting any of that information. ... I kind of had to find [out] other things along the way."* (36-year-old male survivor)

Deficiencies in knowledge transfer from parents not only related to survivors' medical history, but also resulted in a lack of knowledge about future health and screening recommendations: *"I think probably the information was always given to my parents and I think I never really had any information about the future, like I've never been told if I should have check-ups or I shouldn't have check-ups and stuff like that."* (38-year-old female survivor)

Associations with unmet information needs

In multivariable regression, more unmet information needs remained associated for being a parent responder ($b=1.80$, 95%CI 0.68-6.48, $p=0.001$), self-report anxiety/depression ($b=1.72$, 95%CI: 0.70-2.74, $p<0.001$) and greater self-reported risk of late effects ($b=3.37$, 95%CI: 1.74-5.01, $p<0.001$) (**Table 2**). Negative associations with unmet information needs and satisfaction with follow-up care ($b=-1.82$, 95%CI -3.15 to -0.49, $p=0.003$) and better overall health ($b=-1.96$, 95%CI: -3.36 to -0.56), $p=0.014$) remained.

Socio-demographic factors were not associated with unmet information needs. Having received a treatment summary/SCP and LTFU clinic attendance were not associated with unmet information needs. Qualitatively, participants reported that the treatment summaries were sometimes not understood and contained too much medical jargon: *“All the drugs don't mean a lot to me. The top half of the information about the way that he was treated and when he was diagnosed, when he was treated and what he was treated for, that's been quite useful. Not so much the drug side of it. Some of it doesn't really mean a thing to me.”* (Parent of a 14-year-old male survivor)

4. Discussion and Conclusion

4.1 Discussion

This is the first mixed-method study of long-term survivors and parents of CCS assessing unmet information needs and potential predictors in Australia and New Zealand. We found 75% of survivors and parents of survivors had at least one unmet information need, centring mostly on medical topics. Survivors reported more frequent unmet information needs for medical topics and parents' needs more frequently related to fertility issues, lifestyle factors, and sexual issues. In multivariable regression, total unmet information needs were associated with being a parent, lower satisfaction with follow-up care, poorer self-reported overall health, self-reported anxiety/depression and greater self-reported risk of developing late effects.

Consistent with previous studies, our survivors reported the highest unmet information needs for medical topics [11, 12, 15, 19]. Although lower than previously reported in Swiss CCS [14, 15], we found a significant proportion of Australian and New Zealand survivors and parents reported unmet needs for information about late effects. This is concerning as survivors' knowledge of their risk of late effects and appropriate follow-up care is essential to promoting health and well-being and engage self-care throughout survivorship [31-33]. A lack of knowledge about a survivors' risk of late effects may prevent seeking information and consequently result in less information needs [7]. Consistent with previous research, parents reported more unmet information needs (10, 11). As parents are the primary caregivers of a child they may experience greater concern about their child's health and therefore have more needs [14]. More information may offer reassurance and help parents adjust to their child's diagnosis and ongoing health care needs [21]. Parents are responsible for their child's health during treatment but also many years after requiring knowledge transfer to their child through

adolescence and young adult years. Some interviewees made it clear that they still rely on their parents' knowledge many years after treatment has ended. Differences in information needs between parents and survivors suggest that across this transition adult survivors may require different information from their health care providers than what was provided to their parents.

Our results indicate that unmet information needs did not differ between participants who had or had not received a written treatment summary or SCP. While based on international guidelines [34], there is no consistent way of formulating treatment summaries and SCP across sites Australia and New Zealand. The SCP should include personal information on potential late effects and appropriate follow-up care in a non-medical, easy to understand, language. Our findings question the efficacy of SCPs in addressing survivor and parent unmet information needs, and is consistent with previous literature in adult cancer survivors which found that provision of SCPs was not associated with improved patient-reported outcomes [35, 36]. Information provided in SCPs should be tailored to the individual's need and explained to the survivor and parents of CCS when distributed, with planned reassessment and discussion in future appointments. Survivors and parents might benefit from additional information through pre-clinic information, and innovative education resources such as specific well-designed websites or smart phone applications.

No difference in information needs were found for survivors or parents of CCS attending, or not attending LTFU clinics. However, survivors and parents who reported greater satisfaction with their follow-up care reported fewer unmet information needs. These results suggest that level of satisfaction with the information received during survivorship may moderate the efficacy of information provision via treatment summaries, SCP or attending LTFU clinic. Checking survivors' and parents' level of satisfaction with the information they have received

may help to encourage the use of SCP to discuss health concerns and potential risk for late effects with their health professionals either at a LTFU clinic or general clinic.

Clinical and socio-demographic characteristics were not associated with unmet information needs in our sample. However, other studies have found that unmet information needs are associated with younger at age at diagnosis or lower income [12, 19]. Our lack of significant findings may be explained by the publically available Australian/New Zealand health care system, which should enable survivors and families accessing appropriate lifelong follow-up at any income level.

In line with other studies we found lower reported overall health was associated with more need for information [19]. Consistent with other studies, several psychosocial factors were associated with more unmet information needs, such as greater self-reported risks of developing late effects and anxiety and depression [12, 17]. Subjective illness perceptions may influence level of unmet information needs. Lower reported overall health might be related to lower health appraisal, poorer coping and lower adjustment to disease overall, resulting in more unmet needs [37]. Conversely, survivors reporting better overall health might be more satisfied with their follow-up care and level of information provision [17], while low perceived risk of late effects predict low knowledge of late effect risk at follow-up [38]. However, knowledge about late effects might only be acquired once diagnosed with late effects, a point during survivorship when higher information needs may be apparent [33]. As also shown by our results, dissatisfaction with follow-up care was related to more unmet needs. These results suggest that additional tailored information assessing subjective needs and personal risk and informing survivors about screening recommendations and long-term follow-up may therefore help them to feel less worried, more satisfied and experience less needs.

Limitations and strengths

We have no information on self-reported unmet needs of survivors below the age of 16 years. Due to the cross-sectional design of our study we could not assess information needs along the cancer trajectory, even though unmet information needs might differ from the point of diagnosis till later survivorship. However, we did not find any association between time since last follow-up and total unmet information needs, suggesting that at least in our sample, total amount of unmet information needs were fairly stable over time. Our data do not allow causal or directional inferences to be made. It is unclear whether factors such as level of anxiety/depression and fear of cancer recurrence cause greater unmet information needs or are a result of having a high number of unmet information needs. Participants self-reported their level of anxiety/depression using a single item measure, which may not fully capture the psychological wellbeing of survivors and parents, but may be considered an indicator of possible difficulties with anxiety/depression, similar to the distress thermometer [39].

Major strengths of this study are the mixed-method approach, which provided an in-depth understanding of survivors and parents information needs, and corroboration of the quantitative data obtained from our large population-based sample (n=322 CCS, n=163 parents). An additional strength is that survivors who are not currently engaged with long-term follow-up clinics participated in this study, whose information needs may previously have been unaccounted for.

4.2 Conclusion

Unmet information needs were common for survivors and parents of CCS in this large binational cohort. Unmet information needs were more pronounced for parents, survivors and parents of survivors who were dissatisfied with their follow-up care, who self-reported greater risk of late effects, lower overall health and greater anxiety/depression. Results did

not differ between survivors and parents of CCS who had received a treatment summary/SCP. This is concerning because survivors need to be aware of potential late effects which might occur many years after treatment has ended. Future efforts towards tailoring information on potential late effects, healthy lifestyles and follow-up care may help to address unmet information needs.

4.3 Practice implications

The results of this study show potential areas for improvement in long-term follow-up care of childhood cancer survivors across Australia and New Zealand. Even though treatment summary and SCPs had been provided to survivors and parents, there was no difference in unmet information needs. Our study cannot indicate how SCPs are best provided. Previous research shows information given in survivorship ideally should be repeated (9, 36), offered at least in written format, but preferably in multiple formats (11, 12, 34) and information needs should be reassessed along the cancer trajectory [12]. Checking level of satisfaction with follow-up care may provide an indicator of whether information needs have been met or not.

Our data indicate survivors and parents who perceive they are at high risk for cancer recurrence, report greater anxiety/depression and lower overall health may benefit from additional attention from health care professionals. However, the need for additional information is subjective, and some survivors and parents may not want more information (17). Regular assessment of survivors and parents during survivorship may therefore allow health care providers to identify survivors and parents in need of more information and an opportunity to provide additional trustworthy information.

Conflict of Interest: The authors declare that they have no conflict of interest.

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Table 1: Survivors' and parents' of survivors' characteristics

	Survivors (N=322)	Parents (N=163)
Socio-demographic characteristics		
Survivors' age in years: Mean (SD)	26.7 (7.9)	12.9 (2.4)
Range	16-61	7-19 ^a
Survivors' sex: N (%)		
Male	145 (45.2)	97 (59.5)
Female	176 (54.8)	66 (40.5)
Relationship to survivor: N (%)		
Mother	-	137 (84.0)
Father	-	23 (14.1)
Ethnic background		
Australian/New Zealand	167 (51.9)	95 (58.3)
European	129 (40.1)	56 (34.4)
Asian	17 (5.3)	7 (4.3)
Other	9 (2.7)	5 (3.1)
Place of residence		
Urban	194 (60.2)	93 (57.1)
Rural	55 (17.1)	41 (25.2)
Education: N (%)		
No post-school qualifications	150 (46.6)	93 (57.1)
Post-school qualifications	63 (19.6)	25 (15.3)
Employment		
Not employed	92 (28.6)	34 (20.9)
Employed	224 (69.6)	127 (77.9)
Income		
< \$60,000	162 (50.3)	34 (20.9)
>60,000	104 (32.3)	112 (68.7)
No answer	56 (17.4)	17 (10.4)

	Survivors (N=322)	Parents (N=163)
Medical characteristics		
Attendance long-term follow-up clinic		
No	180 (55.9)	34 (20.9)
Yes	139 (43.2)	128 (78.5)
Private health insurance		
No	111 (34.5)	46 (28.2)
Yes	204 (63.4)	114 (69.9)
Treatment summary/SCP received		
No	122 (37.9)	67 (41.1)
Treatment summary only	55 (17.1)	26 (16.0)
Treatment summary/SCP	129 (40.1)	60 (36.8)
Satisfaction with follow-up care		
Neither	56 (17.4)	16 (9.8)
Unsatisfied	48 (14.9)	15 (9.2)
Satisfied	207 (64.3)	129 (79.1)
First cancer diagnosis: N (%)		
Leukemia	131 (40.7)	76 (46.6)
Lymphoma	49 (15.2)	14 (8.6)
Brain Cancer	33 (10.2)	7 (4.3)
Other	107 (33.2)	65 (39.9)
Time since diagnosis, mean in years, (SD); range		
	19.7 (8.8); 5-59	9.7 (2.3); 5-18
Time since last follow-up, mean in years, (SD)		
	4.0 (6.1)	0.8 (1.2)
Surgery		
Yes	148 (46.0)	84 (51.3)
No	139 (43.2)	65 (39.9)

Chemotherapy		
Yes	289 (89.8)	151 (92.6)
No	23 (7.1)	10 (6.1)
Radiotherapy		
Yes	160 (49.7)	45 (27.6)
No	131 (40.7)	97 (59.5)
Transplant		
Yes	54 (16.8)	31 (19.0)
No	219 (68.0)	108 (66.3)
Relapse		
Yes	54 (16.8)	20 (12.3)
No	258 (80.1)	140 (85.9)
Overall health		
Poor	81 (25.2)	16 (9.8)
Good	107 (33.2)	33 (20.2)
Very good	134 (41.6)	107 (65.6)
Anxiety/Depression		
No	162 (50.3)	89 (54.6)
Yes	158 (49.1)	70 (42.9)
Perceived risk of recurrence		
Not at all at risk	121 (37.6)	26 (15.9)
A little at risk	115 (35.7)	77 (47.2)
At high risk	84 (26.1)	60 (36.8)
Perceived risk of late effects		
Not at all at risk	99 (30.7)	14 (8.6)
A little at risk	93 (28.9)	65 (39.9)
At high risk	126 (39.1)	84 (51.5)

^aPackages sent to survivors between 16-18 years included two letters, one each addressed to the parent(s) and the survivor, and the decision was left to the family as to whether the survivor or parent completed the questionnaire. One survivor was over 19 years when questionnaire was completed as the parent requested to complete the survey on their child's behalf as they were unable to.

Abbreviations: N: Number of participants; NA: Not assessed, or not applicable; SD: Standard deviation, SCP, survivorship care plan.

Numbers may not add up to 100% due to missing values

Table 2: Clinical and socio-demographic associations with unmet information needs from linear regression (significant differences bold)

	Univariable regression			Multivariable regression		
	Coeff	95% CI	p-value	Coeff	95% CI	p-value
Socio-demographic characteristics						
Survivors age in years	0.01	-0.05-0.06	0.921			
Population			0.048			0.001
Survivors	5.82					
Parents	1.06	0.01-2.12		1.80	0.68-6.48	
Survivors' sex			0.991			
Male	6.12					
Female	-0.01	-0.10-0.99				
Relationship to survivor			0.678			
Mother	6.92					
Father	0.58	-2.20-3.36				
Ethnic background			0.334			
Australian/New Zealand	6.10					
European	-0.16	-1.2-0.90				
Asian	1.56	-0.79-3.91				
Other	1.82	-1.20-4.84				
Place of residence			0.520			
Urban	6.05					
Rural	0.42	-0.87-1.72				
Education			0.617			
No post-school qualifications	6.48					
Post-school qualifications	0.34	-1.00-1.68				
Employment			0.165			
Not employed	6.79					
Employed	-0.81	-1.96-0.33				

Income			0.627		
<\$60,000	6.43				
>\$60,000	-.53	-1.62-0.57			
No answer	-0.13	-1.73-1.48			
Medical characteristics					
Attendance long-term follow-up clinic			0.160		
No	6.54				
Yes	-0.71	-8.60-4.18			
Private health insurance			0.539		
No	5.92				
Yes	0.33	-0.73-1.40			
Treatment summary/SCP received			0.085		
No	7.01				
Treatment summary only	-1.23	-2.69-0.23			
Treatment summary/SCP	-1.16	-2.29to-0.03			
Satisfaction with follow-up care			<0.001		0.003
Neither	7.85				
Unsatisfied	0.31	-1.54-2.16		-0.03	-1.81-1.75
Satisfied	-2.29	-3.79-(-1.00)		-1.82	-3.15-(-0.49)
First cancer diagnosis			0.305		
Leukemia	6.29				
Lymphoma	0.24	-1.34-1.82			
Brain Cancer	0.99	-0.90-2.88			
Other	-0.67	-1.81-0.46			
Time since last follow up	0.09	-0.02-0.19	0.103		
Surgery			0.780		
No	6.06				
Yes	0.15	-0.90-1.20			
Chemotherapy			0.843		

No	6.39				
Yes	-0.20	-2.19-1.79			
Radiotherapy			0.008		0.293
No	5.60				
Yes	1.41	0.37-2.45		0.53	-0.47-1.53
Transplant			n.a.		
No	6.12				
Yes	n.a.	n.a.			
Relapse			0.075		
No	5.90				
Yes	1.25	-0.13-2.62			
Overall health			<0.001		0.014
Poor	9.05				
Good	-2.47	-3.87-(-1.07)		-0.79	-2.17-0.59
Very good	-4.26	-5.53-2.99		-1.96	-3.36-(-0.56)
Anxiety/Depression			<0.001		<0.001
No	4.63				
Yes	3.22	2.25-4.18		1.72	0.70-2.74
Perceived risk of recurrence			<0.001		0.130
Not at all at risk	4.05				
A little at risk	1.95	0.80-3.10		0.12	-1.21-1.45
At high risk	4.05	3.34-5.80		1.35	-0.22-2.93
Perceived risk of late effects			<0.001		<0.001
Not at all at risk	2.76				
A little at risk	2.95	1.70-4.20		2.08	0.61-3.54
At high risk	5.60	4.42-6.78		3.37	1.74-5.01

Abbreviations: coeff, coefficient; n.a.: not available, value omitted as 100% of values in met need group

Figure 1. Total unmet information needs stratified by survivors and parents

Abbreviation: CCS, childhood cancer survivor

Figure 2. Comparison of unmet information needs between survivors and parents

Data ordered by highest unmet information needs of survivor