Perceived information provision and information needs in adolescent and young adult cancer survivors

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ABSTRACT

Knowledge on former diagnosis, treatment and survivorship is important for adolescent and young adult cancer survivors (AYACS) to make informed health care decisions. We aimed to 1) describe the information AYACS reported to have received, 2) identify current information needs and survivors' preferred format of communication, and 3) examine associations between information needs and cancer-related/socio-demographic characteristics, psychological distress and health-related quality of life (HRQoL). We identified AYACS (16-25 years at diagnosis; ≥ 5 years since diagnosis) through the Cancer Registry Zurich and Zug. Survivors received a questionnaire on information received and current IN, socio-demographic information, psychological distress (Brief Symptom Inventory-18) and HRQoL (SF-12). Clinical characteristics were available from the cancer registry. We used descriptive statistics and univariable regression models. Of 160 responders, most reported to have received information on disease (96.3%), treatment (96.3%), and follow-up (89.4%), fewer on late effects (63.1%). Survivors reported information needs on late effects (78.7%), follow-up (71.3%), disease (58.1%) and treatment (55.6%). Information needs were associated with experiencing psychological distress and lower mental HRQoL. Most Swiss AYACS have information needs, especially on follow-up and late effects. Therefore, AYACS should be personally, continuously and proactively informed about their disease, treatment, follow-up care and late effects.

Key words: Adolescent and young adult cancer survivors; information needs; information provision; cancer registry; Europe; questionnaire survey

INTRODUCTION

Adolescent and young adult (AYA) cancer patients and survivors form a distinct group with special needs that fall between the paediatric and adult care (Adolescent and Young Adult Oncology Progress Review Group, 2006; Olsson, Jarfelt, Pergert, & Enskar, 2015; Palmer, Mitchell, Thompson, & Sexton, 2007). They are facing unique physical, emotional and social challenges due to their age and developmental life stage (Adolescent and Young Adult Oncology Progress Review Group, 2006; Albritton & Bleyer, 2003; Mader et al., 2017). Although survival of AYA cancers has improved significantly in the past decades, reaching nowadays 87% (Gatta et al., 2009), survivors are at risk for late effects such as neoplasms, cardiovascular diseases or poor mental health (Oeffinger et al., 2006; Rugbjerg & Olsen, 2016; Tai et al., 2012; Zhang et al., 2014). Therefore, continued follow-up care is recommended for survivors of childhood and AYA cancers (Hewitt, Greenfield, & Stovall, 2006; Oeffinger, Eshelman, Tomlinson, Buchanan, & Foster, 2000; Zhang et al., 2014). In Switzerland, to date there is no standardized follow-up care for survivors and procedures depend on the treating clinic and paediatric oncologist (Meier et al., 2017). A study in AYACS in Switzerland showed that 57.5% reported still attending follow-up care after a mean time of almost 12 years since diagnosis (Christen et al., 2016).

AYA cancer survivors (AYACS) expressed that adequate information regarding survivorship was important for them to make health care decisions (Wong et al., 2017). However, many AYACS reported a need for more information regarding their disease, treatment and late effects (DeRouen et al., 2015; Keegan et al., 2012; Shay, Parsons, & Vernon, 2017; Zebrack, 2009). A patient information need can be defined as “recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time” (Ormandy, 2011). In Switzerland, 80% of childhood cancer survivors (CCS) and 70% of parents of CCS reported to have information needs on late

effects (Gianinazzi et al., 2014; Vetsch et al., 2015). Additionally, more than 12 years after diagnosis, over 60% of CCS expressed information needs regarding their disease, treatment and follow-up (Gianinazzi et al., 2014). Swiss AYACS rated “information on potential late effects” as an important aspect of a follow-up consultation (Christen et al., 2016).

It has also been shown that survivors who were satisfied with their state of knowledge, had better health-related quality of life (HRQoL) (DeRouen et al., 2015; Husson, Mols, & van de Poll-Franse, 2011), and lower levels of depression and anxiety (Husson et al., 2011).

To provide patient-centred care, it is pivotal to identify and meet patients’ information needs (Lie, 2017; Ormandy, 2011). At the same time it should be taken into account that information needs differ across age groups, cultural background, educational levels and coping styles (Husson et al., 2011). To date, little is known about AYACS’ information needs and their perception of information provision. In the present study we therefore aimed to 1) describe the information Swiss AYACS reported to have received from a health professional, 2) identify current information needs and preferred format of communication, and 3) examine the association of information needs with cancer-related and socio-demographic characteristics, psychological distress and HRQoL.

METHODS

Sample and procedure

For this cohort study, we identified AYACS through the Cancer Registry Zurich and Zug (Switzerland). Survivors were eligible if they had been diagnosed with cancer between January 1990 and December 2005, aged 16-25 years at diagnosis and survived ≥ 5 years after diagnosis. To allow direct comparison with paediatric patients of the related Swiss Childhood Cancer Survivor Study, (Kuehni et al., 2012), we restricted the sample to the following

diagnoses: leukaemia, germ cell tumour, lymphoma, central nervous system (CNS) tumour, neuroblastoma, renal, hepatic and bone tumour, and soft tissue sarcoma.

Participants' addresses were available from the Cancer Registry Zurich and Zug, and we updated them by web search and by contacting the community of last residence. We pilot tested the questionnaire with 30 randomly selected AYACS. We sent eligible survivors a cover letter, the study information, an informed consent sheet, the questionnaire and a pre-paid return envelope. After 4 weeks, we sent non-responders a reminder letter and the same questionnaire. We sent the questionnaires between August 2010 and January 2012. The Cantonal Ethics Committee of Zurich provided ethical approval and all participants provided informed consent.

Measurements

The questionnaire included questions about follow-up care, perceived information provision and information needs, socio-demographic characteristics, clinical characteristics, HRQoL and psychological distress.

Perceived information provision

Survivors were asked whether they remembered ever having received information from a medical doctor or health professional about the original disease, treatment of the original disease, follow-up, late effects and other information. For each topic, they could indicate whether they had ever received oral information, written information or no information. Survivors not remembering having received information on a topic could indicate whether they would have liked to have received this information after the treatment on a 3-point Likert scale (very important/important/unimportant).

Information needs

We asked survivors whether they currently had information needs on their original disease, treatment of the original disease, follow-up, late effects, or other information. They could specify their preferred format of information communication (oral information by their doctor, general written information, personal written information, general information online, other format of communication; multiple answers were possible), or that they had no information needs.

Socio-demographic and clinical characteristics assessed by questionnaire

We assessed survivors' age, sex, educational achievement (primary education: compulsory schooling only; secondary education: vocational training or high school degree; tertiary education: college or university degree) (Kuehni et al., 2012), partnership (if they currently had a partner or were married: yes/no), and migration background (survivors were classified as having a migration background if they were not Swiss citizens since birth or were not born in Switzerland). We asked survivors whether they had had a cancer relapse (yes/no) and whether they suffered from any serious late effects (yes/no).

Health-related Quality of Life (HRQoL)

HRQoL was assessed using the 12-Item Short-Form Health Survey (SF-12) (Ware, Kosinski, & Keller, 1996). The SF-12 provides two summary scores: the physical component summary (PCS) and the mental component summary (MCS). We constructed the PCS and MCS using norms from the German Socio-Economic Panel (SOEP) (Andersen, Mühlbacher, Nübling, Schupp, & Wagner, 2007). The PCS and MCS scores were standardized into T-scores (mean=50, SD=10), with higher scores indicating higher HRQoL.

Psychological distress

We used the Brief Symptom Inventory-18 (BSI-18) to identify symptoms of psychological distress (Derogatis, 2000). The German translation showed good psychometric qualities (Franke et al., 2017; Spitzer et al., 2011). The BSI-18 assesses three dimensions: somatization, depression and anxiety (6 items each), and a Global Severity Index (GSI; all 18 items). Participants were asked to report how much they were disturbed by symptoms in the past 7 days. They rated all items on a 5-point Likert scale (1=not at all to 5=strongly). To identify psychological distress among individuals, sum raw scores were T-standardized (mean=50, SD=10) (Derogatis, 2000). As suggested by Zabora et al., and as previously done in a study of Swiss CCS, participants with a T-Score ≥ 57 were defined as distressed (Gianinazzi et al., 2013; Zabora et al., 2001).

Clinical information from the Cancer Registry Zurich and Zug

We received medical information on diagnosis, treatment, age at diagnosis and time since diagnosis from the cancer registry. We classified diagnosis according to the International Classification of Childhood Cancer-3rd Edition (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). For the analyses, diagnoses were grouped into four categories: leukaemia/lymphoma, CNS tumour, germ cell tumour and other tumours. Treatment was hierarchically coded as surgery only, chemotherapy (may have had surgery, but not radiotherapy) or radiotherapy (may have had surgery and/or chemotherapy).

Statistical analysis

We conducted all analyses using STATA 14.0 (StataCorp LP, College Station, TX). We compared participants and non-participants of the study with descriptive statistics, chi-square tests and t-tests. For aim 1, we used descriptive statistics. We generated four new variables for each topic (disease, treatment, follow-up, late effects), which reflected survivors'

perception of information provision in the respective topics (ever received information (written or oral): yes/no). We also generated an overall variable indicating the format by which the information was provided (oral, written, oral & written, no information). For aim 2, we generated an overall variable that indicated any current information need (yes/no), and used descriptive statistics to describe current information needs and preferred format of communication. We used descriptive statistics and chi-square tests to compare the format of information provision with having an information need. For aim 3, we used univariable logistic regression models to analyse associations of cancer-related and socio-demographic characteristics, psychological distress, and HRQoL with current information needs.

RESULTS

Study population

Of 469 eligible survivors, we traced and contacted 389 (**Supplemental Fig. 1**). Of those, 160 (41.1%) returned the questionnaire. Participants' mean age at study was 34.0 years (SD=5.8; range 20-46 years), mean age at diagnosis was 21.6 years (SD 2.9; range 16-25 years) and mean time since diagnosis was 12.4 years (SD=4.8; range 5-21 years; **Table 1**). Most participants had been diagnosed with leukaemia/lymphoma (n=73, 45.6%) or germ cell tumours (n=46, 28.7%). Socio-demographic and clinical characteristics did not differ between participating and non-participating survivors (**Table 1**).

Aim 1: Perceived information provision

Most of the survivors reported to have received information on disease (n=154, 96.3%), treatment (n=154, 96.3%) and follow-up (n=143, 89.4%) (**Fig. 1**). Of the survivors who reported not to have received information, the majority rated the importance of receiving information as "very important" or "rather important" (disease n=4, 66.7%; treatment n=4, 66.7%; follow-up n=14, 82.4%). Many survivors did not remember ever having received

information on late effects (n=59, 36.9%) (**Fig. 1**). Most of these 59 survivors rated the importance of receiving information about late effects as “very important” or “rather important” (n=48; 81.4%). Two survivors (1.3%) reported not having received any information at all.

Overall, most survivors reported having received oral information (n=83, 51.9%) or oral and written information (n=73, 45.6%). Two survivors reported having received written information only (1.3%).

Aim 2: Current information needs & preferred format of information communication

Overall, more than half of survivors reported to have information needs on disease (n=93, 58.1%) and treatment (n=89, 55.6%) and around three quarter reported information needs on follow-up (n=114, 71.3%) and late effects (n=126, 78.7%; **Fig. 2**). Across all topics, 26 survivors (16.3%) reported to have no information needs at all. Besides two exceptions (no information received on treatment; only written information received on late effects), survivors who reported to have received written and oral information were the ones with least information needs for all topics (disease p=0.500; treatment p=0.388; follow-up p=0.222; late effects p=0.251) (**Fig. 3**). For each topic, the preferred format was oral information from the doctor (disease: 48%; treatment: 49%; follow-up: 45%; and, late effects: 47%) followed by personal written information (disease: 39%; treatment: 39%; follow-up: 32%; and, late effects: 40%; **Fig. 4**). General online information was the least preferred format (disease: 26%; treatment: 21%; follow-up: 23%; and, late effects: 23%).

Aim 3: Associations with information needs

No socio-demographic or clinical characteristics were associated with information needs. In univariable logistic regression models, significantly more survivors with psychological distress ($BSI \geq 57$) reported information needs on disease (OR=2.50; 95% CI: 1.08-5.77;

$p=0.025$). Similarly, survivors with higher MCS (higher mental HRQoL) reported fewer information needs on disease ($OR=0.96$; $95\%CI:0.92-0.99$; $p=0.006$) and treatment ($OR=0.97$; $95\%CI:0.94-1.00$; $p=0.041$; **Table 2**).

DISCUSSION

The majority of Swiss AYACS reported having received information on disease, treatment and follow-up, but many did not remember receiving information on late effects. More than 80% of survivors reported to have current information needs. Survivors' preferred format of information provision was oral information from the doctor or personal written information. Having information needs were associated with experiencing psychological distress and lower mental HRQoL.

We can assume that all Swiss AYACS or their parents received specific information about their disease, treatment, follow-up recommendations and possible late effects by a health care professional. However, similar to studies in CCS (Gianinazzi et al., 2014; Lie et al., 2015), more than one third of survivors reported never having received information on late effects. This might have several reasons: in younger AYA cancer patients, comprehensive information about their disease and treatment is often provided to parents (Palmer et al., 2007), and younger AYACS may not have been provided with all the information personally. However, survivors themselves expressed the wish to be offered comprehensive information (Palmer et al., 2007). Additionally, it has been shown with increasing amounts of information presented to the patient, the proportion of correctly recalled information is getting smaller (McGuire, 1996). Additionally, the memory for medical information is affected by the perceived importance of the information (Kessels, 2003). At the time of diagnosis and treatment, a huge amount of information is presented to patients and their families, and the

importance of information on late effects might be perceived as low – as the focus lies on surviving the cancer. Patients and their families might focus on disease- and treatment-related information and it might seem less important to memorize information on follow-up and late effects. Survivors themselves further wished that information were continuously available (Lie et al., 2015). Survivorship and late effects, as well as the provision of information have become an important part in the care of AYACS in the last decade. This might result in lower information needs in only recently diagnosed AYACS. Overall, information on follow-up and late effects should be provided at different points of the cancer trajectory, particularly at the end of treatment and during follow-up consultations, when survivors have the capacity to focus on this information.

Four studies have previously addressed information needs in AYACS (DeRouen et al., 2015; Keegan et al., 2012; Shay et al., 2017; Zebrack, 2009). Two North American studies found that more than half of survivors reported a need for information about their disease, treatment, cancer recurrence and late effects (DeRouen et al., 2015; Shay et al., 2017), and one found that 78% of survivors reported a need for information about late effects (Shay et al., 2017), which is in line with our results. Zebrack (2009) found that being unmarried, unemployed, not being a college graduate, younger at diagnosis, having more health problems and a poorer health status were associated with reporting unmet information needs about cancer. Keegan et al. (2012) found that males were generally more likely to report unmet information needs, older age at study was associated with unmet needs related to treatment, late effects and cancer recurrence, and a poor health status was associated with unmet needs related to late effects and getting a new cancer. In contrast to this, we found no associations between information needs and sex, level of education, partnership, migration background, and clinical characteristics. This is reassuring, as it indicates that among Swiss

AYACS and regarding socio-demographic and clinical characteristics, there is no specific subgroup at risk for unmet information needs.

In our study, more than 70% of survivors reported current information needs on follow-up and late effects, and more than half of survivors reported current information needs on disease and treatment. This is similar to the information needs in Swiss CCS and in parents of Swiss CCS (Gianinazzi et al., 2014; Vetsch et al., 2015). Although it is known that information needs vary across the cancer trajectory (Fletcher, Flight, Chapman, Fennell, & Wilson, 2017), this is a remarkable proportion of survivors with information needs. Partly, this may have methodological reasons. Survivors might not have felt a need for information before being prompted by the questions on information needs in our questionnaire. However, even if our questionnaire made participants aware of information needs, these needs are real and have to be taken seriously. In AYACS, it has been shown that survivors who received a written treatment summary were less likely to report information needs (Shay et al., 2017). Offering information pro-actively, which has been desired by CCS (Lie et al., 2015), may contribute to satisfy information needs (Lie, 2017). Also, among young adult cancer survivors, a survivorship care plan was associated with higher confidence in managing their survivorship care (Casillas et al., 2011). In Switzerland, it is planned to provide all CCS and AYACS with a survivorship passport (Lack, 2016; Poplack et al., 2014). This passport will contain comprehensive information on survivor's cancer diagnosis and treatment, and individual recommendations for follow-up care (Lack, 2016). Our study and a previous study (Gianinazzi et al., 2014) have shown that survivors value personalized information. The survivorship passport complies with this preference. It will contribute to improving survivors' knowledge about their diagnosis and treatment, fulfil basic information needs on disease, treatment, follow-up care and late effects and empower the survivors to manage their own

follow-up care. Additionally, for Swiss AYACS who currently attend regular or irregular follow-up (Christen et al., 2016), follow-up consultations provide an opportunity for survivors and health-care professionals to meet survivors' information needs.

In our study, survivors reporting information needs had higher psychological distress and lower mental HRQoL. This is similar to other studies, which found that fulfilled information needs were associated with higher HRQoL (DeRouen et al., 2015; Husson et al., 2011) and lower levels of depression and anxiety (Husson et al., 2011).

A previous study in Swiss CCS found that their preferred format of information provision was written personal information, followed by oral information (Gianinazzi et al., 2014). This is in line with our results, as both groups of survivors seem to favour personalized information. In contrast, a study from the UK examining health behaviour information needs and preferences of AYACS found that survivors preferred online information, apps or short leaflets about health behaviour (Pugh, Hough, Gravestock, Jackson, & Fisher, 2017).

Although Swiss AYACS value personalized information highly, oral advice only is not very successful, and should be complemented with written information (Kessels, 2003). Similarly, we found that survivors who reported to have received oral and written information were less likely to have information needs than those who reported to have received oral information only.

A systematic review found that it is common for AYACS to access online health information (Sansom-Daly et al., 2016), although some AYACS reported to specifically avoid the internet (Lin, Sansom-Daly, Wakefield, McGill, & Cohn, 2017). Online information was the least preferred format of communication in our study. However, a reason for this might be that

90% of the participants of our study were born before 1985 and, therefore, most of them are not digital natives. It is possible that survivors born after that time have a higher preference for online information, as for them the internet and digital media are omnipresent. It was suggested that a website with specific and age-appropriate information can be a valuable resource to improve survivors' knowledge (Knijnenburg et al., 2013). Recently, an online platform (www.kinderkrebs-schweiz.ch) with general information about childhood and adolescent cancer, follow-up and late effects has been set up for Swiss childhood and AYACS. Due to the inclusion of paediatric oncology experts in the development of the content, survivors might trust this platform more than other online information; Survivors even have the possibility to ask specific questions regarding their disease, treatment, follow-up or late effects online. CCS have suggested an interactive website to be important for information provision (Lie et al., 2015), and AYACS may value the personal aspect of an interactive website. In addition to the personal contact with the doctor or other healthcare professionals during follow-up care consultations, this platform might help to meet survivors' information needs.

A limitation of this study is the relatively low response rate (41.1%), which has been a challenge in other studies of AYACS (Harlan et al., 2011). A relatively large number of AYACS could not be traced in our study (17.1%). A reason for this might be that the AYACS population is very mobile. Therefore, they are difficult to reach for research and to be tracked for follow-up care (Tonorezos & Oeffinger, 2011). Although participants and non-participants were comparable, non-participants may have other information needs and preferences. Moreover, a qualitative approach could provide more in-depth insights into AYACS information needs. The cross-sectional study design further precludes establishing causal inferences. Another limitation is that only basic medical information was available

through the Cancer Registry Zurich and Zug, so we had to rely on the survivors' self-reported information on late effects and relapse.

A major strength of this study is the population-based sample of AYACS for a large region in Switzerland (Canton of Zurich). Another strength is the self-reported information about perception of information provision and current information needs. We were interested to see what information survivors remembered to have received and were able to gain an understanding of the survivors' current information needs.

Swiss AYA cancer survivors have a need for more information especially on follow-up and possible late effects, and prefer personalized information orally from their doctor or personalized written information. In Switzerland, the survivorship passport and the platform "Childhood Cancer Switzerland" are initiatives that may help meeting survivors' needs. In addition to this, despite being young, AYACS should be personally, continuously and proactively informed about their disease, treatment, follow-up care and late effects.

CONFLICT OF INTEREST STATEMENT

No conflict of interest for any of the authors.

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TABLE 1. Characteristics of the study population, comparing participants and non-participants to the study

	Participants (N=160)		Non-Participants ^a (N=309)		
	n	% ^b	n	% ^b	p-value
<i>Socio-demographic characteristics</i>					
Sex					0.110 ^c
Male	98	61.3	210	68.0	
Female	62	38.7	96	31.0	
Missing	0	0.0	3	1.0	
Migration background					
No migration background	125	78.1	n.a.	n.a.	
Migration background	35	21.9	n.a.	n.a.	
Partnership					
Partner	123	76.9	n.a.	n.a.	
No partner	37	23.1	n.a.	n.a.	
Education					
Primary	13	8.1	n.a.	n.a.	
Secondary	74	46.3	n.a.	n.a.	
Tertiary	72	45.0	n.a.	n.a.	
Missing	1	0.6			
Employment					
Not employed	10	6.3	n.a.	n.a.	
Employed	145	90.6	n.a.	n.a.	
In education	4	2.5			
Missing	1	0.6			
<i>Clinical characteristics</i>					
Diagnosis					0.124 ^c
Leukemia/Lymphoma	73	45.6	119	38.5	
Germ cell tumour	46	28.7	117	37.9	
CNS tumour	15	9.4	36	11.6	
Other tumour ^d	26	16.3	37	12.0	
Treatment					0.428 ^c
Surgery only	57	35.6	109	35.3	
Chemotherapy ^e	36	22.5	75	24.3	
Radiotherapy ^e	41	25.6	60	19.4	
Missing	26	16.3	65	21.0	

	Participants		Non-Participants ^a		
	n	% ^b	n	% ^b	p-value
Self-reported relapse					
No	136	85.0	n.a.	n.a.	
Yes	24	15.0	n.a.	n.a.	
Self-reported late-effects					
No	111	69.4	n.a.	n.a.	
Yes	45	28.1	n.a.	n.a.	
Missing	4	2.5	n.a.	n.a.	
	mean	SD	mean	SD	p-value
Age at study	34.0	5.8	34.2	5.6	0.754 ^f
Age at diagnosis	21.6	2.9	21.7	2.9	0.706 ^f
Time since diagnosis	12.4	4.8	12.5	4.8	0.884 ^f

Abbreviations: n.a.= not available; CNS= central nervous system; SD=standard deviation

^aNon-participants include: AYA survivors who did not respond (n=208), with unknown address (n=80) or who refused to participate (n=21)

^bColumn percentages are given

^cP-value calculated from Chi-square statistic not including the missings

^dOther: Neuroblastoma, renal tumour, hepatic tumour, bone tumour or soft tissue sarcoma

^eChemotherapy may include surgery; radiotherapy may include chemotherapy and/or surgery

^fP-value calculated from two sample t-test

TABLE 2. Factors associated with information needs for each of the four topics disease, treatment, follow-up and late effects (from univariable logistic regression models)

	Information need: disease				Information need: treatment				Information need: follow-up				Information need: late effects			
	% ^a	OR	95% CI	P-value	% ^a	OR	95% CI	P-value	% ^a	OR	95% CI	P-value	% ^a	OR	95% CI	P-value
Sex				0.733				0.874				0.950				0.640
Male	59.2	1.00			56.1	1.00			71.4	1.00			77.6	1.00		
Female	56.5	0.89	0.47 1.70		54.8	0.95	0.50 1.80		71.0	0.98	0.48 1.97		80.7	1.21	0.55 2.65	
Education				0.647				0.238				0.885				0.294
Secondary education	58.1	1.00			59.5	1.00			73.0	1.00			78.4	1.00		
Primary education	69.2	1.62	0.46 5.75		69.2	1.53	0.43 5.44		69.2	0.83	0.23 3.01		61.5	0.44	0.13 1.54	
Tertiary education	55.6	0.90	0.47 1.74		48.6	0.64	0.34 1.24		69.4	0.84	0.41 1.72		81.9	1.25	0.55 2.83	
Partnership				0.568				0.591				0.791				0.173
Partner	59.4	1.00			54.5	1.00			70.7	1.00			76.4	1.00		
No partner	54.1	0.81	0.38 1.69		59.5	1.23	0.58 2.59		73.0	1.12	0.49 2.54		86.5	1.97	0.70 5.53	
Migration background				0.152				0.170				0.184				0.794
No migration background	55.2	1.00			52.8	1.00			68.8	1.00			79.2	1.00		
Migration background	68.6	1.77	0.80 3.92		65.7	1.71	0.78 3.74		80.0	1.81	0.73 4.51		77.1	0.89	0.36 2.18	
Psychological distress^b				0.025				0.078				0.979				0.238
Not distressed	53.6	1.00			52.0	1.00			71.2	1.00			76.8	1.00		
Distressed	74.3	2.50	1.08 5.77		68.6	2.01	0.91 4.46		71.4	1.01	0.44 2.32		85.7	1.81	0.64 5.10	
HRQoL																
MCS ^c	56.3	0.96	0.92 0.99	0.006	53.8	0.97	0.94 1.00	0.041	69.4	0.99	0.96 1.02	0.580	76.3	0.98	0.95 1.02	0.377
PCS ^c	56.3	1.00	0.95 1.06	0.896	53.8	0.99	0.94 1.04	0.655	69.4	0.99	0.93 1.04	0.661	76.3	0.99	0.93 1.06	0.846
Diagnosis				0.363				0.514				0.707				0.325
Leukemia & Lymphoma	64.4	1.00			57.5	1.00			75.3	1.00			80.8	1.00		
CNS tumour	60.0	0.83	0.27 2.59		53.3	0.84	0.28 2.57		73.3	0.90	0.25 3.18		60.0	0.36	0.11 1.17	
Germ cell tumour	47.8	0.51	0.24 1.07		47.8	0.68	0.32 1.42		67.4	0.68	0.30 1.53		78.3	0.85	0.34 2.12	
Other tumour ^d	57.7	0.75	0.30 1.88		65.4	1.39	0.55 3.54		65.4	0.62	0.23 1.63		84.6	1.31	0.39 4.40	

	Information need: disease				Information need: treatment				Information need: follow-up				Information need: late effects			
	%	OR	95% CI	p-value	%	OR	95% CI	p-value	%	OR	95% CI	p-value	%	OR	95% CI	p-value
Treatment				0.998				0.663				0.398				0.544
<i>Surgery only</i>	56.1	1.00			57.9	1.00			70.2	1.00			73.7	1.00		
Chemotherapy ^e	55.6	0.98	0.42	2.26	55.6	0.91	0.39	2.11	75.0	1.28	0.50	3.28	83.3	1.79	0.62	5.14
Radiotherapy ^e	56.1	1.00	0.44	2.24	48.8	0.69	0.31	1.55	61.0	0.66	0.28	1.55	78.1	1.27	0.49	3.27
Relapse				0.982				0.772				0.138				0.542
<i>No</i>	58.1	1.00			55.2	1.00			69.1	1.00			77.9	1.00		
Yes	58.3	1.01	0.42	2.44	58.3	1.14	0.47	2.74	83.3	2.23	0.72	6.94	83.3	1.42	0.45	4.46
Late effects				0.929				0.748				0.692				0.319
<i>No</i>	58.6	1.00			55.0	1.00			72.2	1.00			77.5	1.00		
Yes	57.8	0.97	0.48	1.95	57.8	1.12	0.56	2.26	68.9	0.86	0.40	1.83	84.4	1.58	0.63	3.96
Age at diagnosis (years)				0.920				0.733				0.269				0.463
<i>16-20</i>	58.6	1.00			57.1	1.00			75.7	1.00			81.4	1.00		
21-25	57.8	0.97	0.51	1.82	54.4	0.90	0.48	1.68	67.8	0.67	0.33	1.36	76.7	0.75	0.35	1.63
Time since diagnosis (years)				0.202				0.425				0.271				0.615
<i>5-10</i>	61.0	1.00			59.3	1.00			78.0	1.00			81.4	1.00		
11-15	64.7	1.17	0.54	2.55	58.8	0.98	0.46	2.10	70.6	0.68	0.29	1.60	80.4	0.94	0.36	2.44
16+	48.0	0.59	0.28	1.26	48.0	0.63	0.30	1.35	64.0	0.50	0.22	1.17	74.0	0.65	0.26	1.62

Note: Statistically significant values (p<0.05) are highlighted bold. Abbreviations: OR, Odds Ratio; CI, Confidence Interval; HRQoL, Health-related quality of life; MCS, mental component summary (SF-12); PCS, physical component summary (SF-12); CNS, Central Nervous System

^aPercentage of survivors of the respective category who indicated to have information needs in the corresponding topic

^bMeasured with the Brief Symptom Inventory-18 (BSI-18)

^cMCS and PCS are included in the model as continuous variables. An OR<1 indicates that survivors with higher MCS/PCS (higher HRQoL) are less likely to have information needs, whereas an OR>1 indicates that survivors with higher MCS/PCS (higher HRQoL) are more likely to have information needs.

^dOther: Neuroblastoma, renal tumour, hepatic tumour, bone tumour or soft tissue sarcoma

^eChemotherapy may include surgery, radiotherapy may include chemotherapy and/or surgery

FIGURE 1. Perceived information provision on disease, treatment, follow-up and late effects by format of communication (only oral, only written, oral & written, no information) in adolescent and young adult cancer survivors (N=160 for each topic).

FIGURE 2. Current information needs regarding disease, treatment, follow-up and late effects in adolescent and young adult cancer survivors (N=160 for each topic).

FIGURE 3. Current information needs regarding disease, treatment, follow-up and late effects stratified by format of previously received information (received oral information only, received written information only, received oral and written information, received no information).

FIGURE 4. Preferred format of communication for information provision regarding disease, treatment, follow-up and late effects in adolescent and young adult cancer survivors with information needs.

Note: Proportions do not add up to 100% for each topic, as participants could indicate more than one preferred format of communication.

SUPPLEMENTAL FIGURE 1 Participants and non-participants of the study