

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 information needs, 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.

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Funding:

This work was supported by the Swiss National Science Foundation (Ambizione grant PZ00P3_121682/1 and PZ00P3-141722 to GM; Grant 100019_153268 / 1). CSR has received funding from the European Union Seventh Framework Programme (FP7-PEOPLE-2013-COFUND) under grant agreement n° 609020 - Scientia Fellows.

This version of the manuscript was submitted to the **European Journal of Cancer Care** on November 28th 2017 and was accepted for publication on June 15th 2018.

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). However, due to their differing developmental stage AYACS’ information needs may differ. In a study that focused on preferences for follow-up care, 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. The term “late effects” was introduced and defined in lay language at the beginning of the questionnaire (“By ‘late effects’ we mean all health problems which occurred in connection with the tumor or leukemia, or as a result of the cancer treatment.”). 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 physical or psychological 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

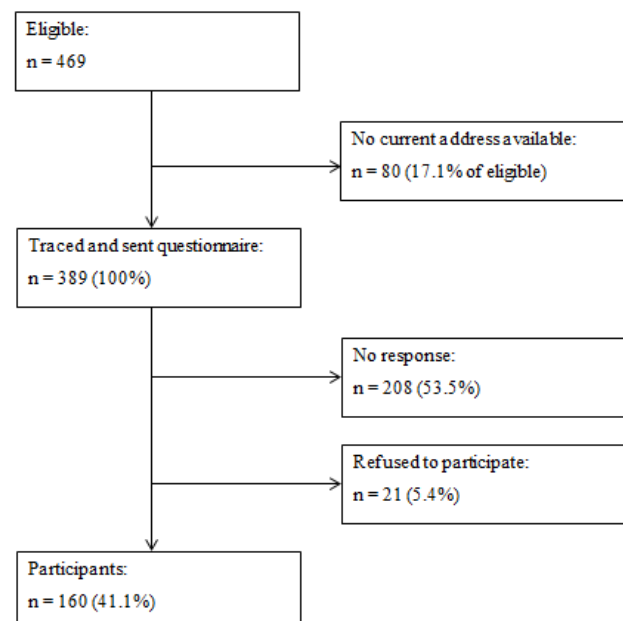
al., and as previously done in a study of Swiss CCS, participants with a T-Score ≥ 57 were defined as distressed (Gianinazzi et al., 2013; Zabora et al., 2001).

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



Supplemental Figure 1. Participants and non-participants of the study

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.

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

	Participants (N=160)		Non- Participants ^a (N=309)		p-value
	n	% ^b	n	% ^b	
<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	

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

Table 1. (continued)

	Participants (N=160)		Non-Participants ^a (N=309)		p-value
	n	% ^b	n	% ^b	
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

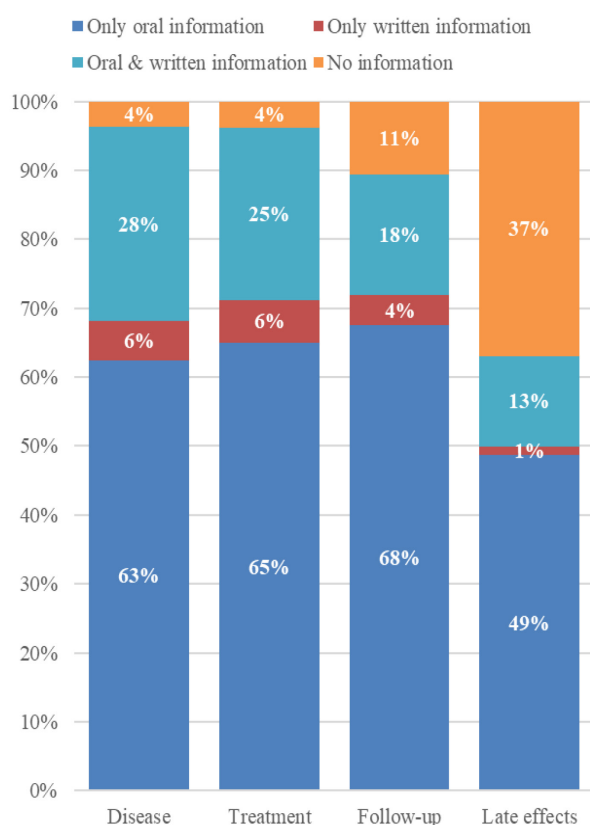


Figure 1. Perceived information provision on disease, treatment, follow-up and late effects by format of communication (only oral, only written, oral & written, no information) in adolescent and young adult cancer survivors (N=160 for each topic).

late effects (n=59, 36.9%) (**Fig. 1**). They were significantly longer after diagnosis compared to those who reported to have received information on late effects ($p=0.007$). 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.

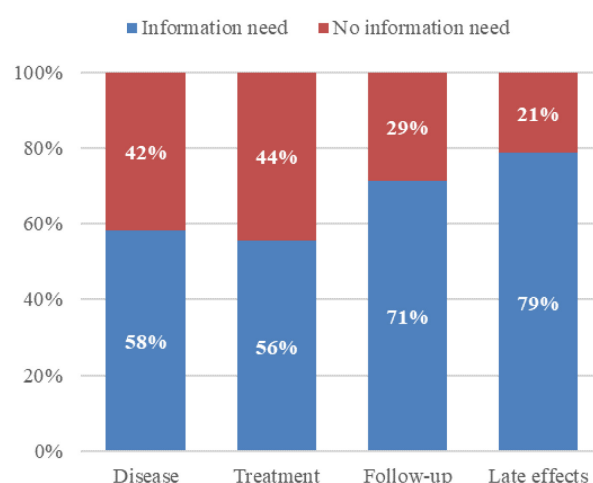


Figure 2. Current information needs regarding disease, treatment, follow-up and late effects in adolescent and young adult cancer survivors (N=160 for each topic).

Survivors who reported to have received written and oral information generally had least information needs for all topics compared to survivors who had received no information, or only written, or only oral information, but the differences were not statistically significant (**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

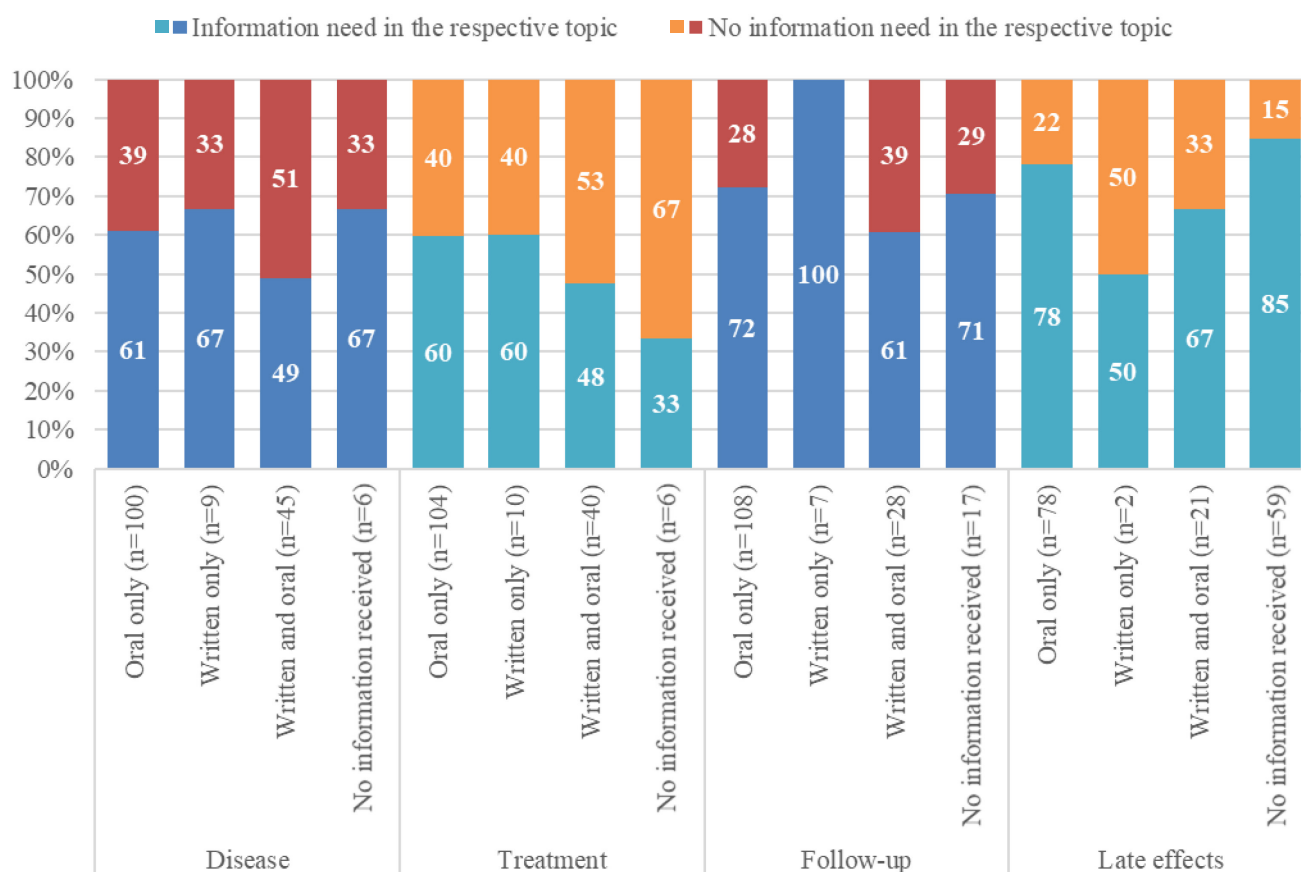


Figure 3. Current information needs regarding disease, treatment, follow-up and late effects stratified by format of previously received information (received oral information only, received written information only, received oral and written information, received no information).

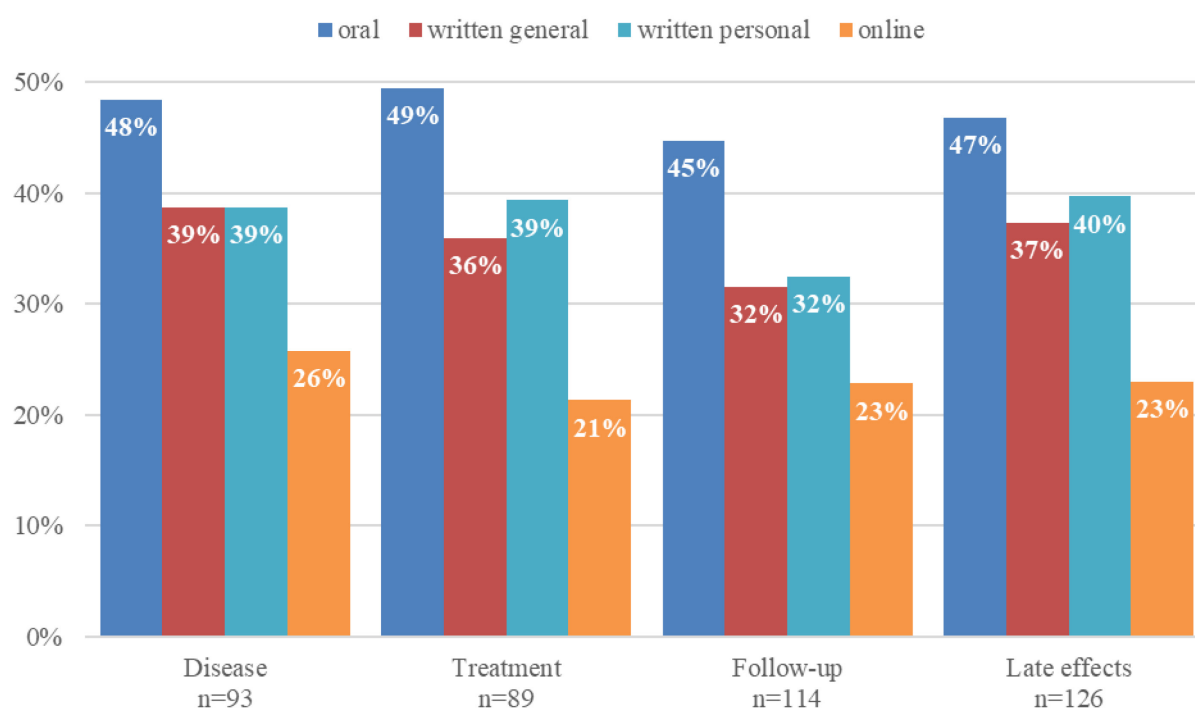


Figure 4. Preferred format of communication for information provision regarding disease, treatment, follow-up and late effects in adolescent and young adult cancer survivors with information needs.

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

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: First, especially in younger AYA cancer patients, comprehensive information about their disease and treatment is often provided to parents (Palmer et al., 2007), and AYACS may not have received all the information personally. Second, it has been shown that the more information presented to the patient, the smaller the proportion of correctly recalled information (McGuire, 1996). Third, the memory for medical information may be affected by the perceived importance of the information (Kessels, 2003). At the time of diagnosis and treatment, information on late effects might not be relevant as the primary focus lies on surviving the cancer. Further, survivorship, late effects, and information on these topics has only become an important part in the care of AYACS in the last decades. It is therefore possible, that AYACS with more time since diagnosis had not received detailed information about late effects as the information was not available then.

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 and understand the need to focus on this information. This is also in line with the survivors' desire that information was continuously provided (Lie et al., 2015).

Our study found a considerable information need among AYACS. This finding is supported by four studies from the USA (DeRouen et al., 2015; Keegan et al., 2012; Shay et al., 2017; Zebrack, 2009). 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). Being unmarried, unemployed, not being a college graduate, male, older at study and younger at diagnosis, having more health problems and a poorer health status were found to be associated with reporting unmet information needs about cancer (Keegan et al., 2012; Zebrack, 2009). This is in contrast with our study, where we found no associations between information needs and sociodemographic and clinical characteristics. This is

reassuring, as it indicates that among Swiss AYACS there is no specific subgroup at risk for unmet information needs.

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. However, oral advice only is not very successful, and should be complemented with written information (Kessels, 2003). The survivorship passport complies with this and with AYACS preferences. It will contribute to improving survivors' knowledge about their diagnosis and treatment, fulfil basic information needs on follow-up care and late effects, and empower 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). Providing information regularly might, therefore, be a possibility to improve mental health outcomes in cancer survivors.

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. A reason for this might be that 90% of the participants of our study were born before 1985 and, therefore, are not digital natives. It is possible that survivors born after that time have a

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>	<i>56.1</i>	<i>1.00</i>			<i>57.9</i>	<i>1.00</i>			<i>70.2</i>	<i>1.00</i>			<i>73.7</i>	<i>1.00</i>		
Chemotherapy ^c	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 ^c	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>	<i>58.1</i>	<i>1.00</i>			<i>55.2</i>	<i>1.00</i>			<i>69.1</i>	<i>1.00</i>			<i>77.9</i>	<i>1.00</i>		
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>	<i>58.6</i>	<i>1.00</i>			<i>55.0</i>	<i>1.00</i>			<i>72.2</i>	<i>1.00</i>			<i>77.5</i>	<i>1.00</i>		
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>	<i>58.6</i>	<i>1.00</i>			<i>57.1</i>	<i>1.00</i>			<i>75.7</i>	<i>1.00</i>			<i>81.4</i>	<i>1.00</i>		
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>	<i>61.0</i>	<i>1.00</i>			<i>59.3</i>	<i>1.00</i>			<i>78.0</i>	<i>1.00</i>			<i>81.4</i>	<i>1.00</i>		
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

higher preference for online information, as for them the internet and digital media are omnipresent. This hypothesis is supported by the results of a recent study from the UK, which showed that teenage and young adult cancer patients and survivors wish to receive and share clinical information from professionals online (Abrol et al., 2017). It was also suggested that a website with specific and age-appropriate information could 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 CCS 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, such as exploring the most pressing topics AYACS want to be informed about or understanding the reason for a low desire of online information. 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. Before completing the questionnaire of our study, survivors might not have felt a need for information. However, even if our questionnaire made participants aware of information needs, these needs have to be taken seriously.

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.

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 informed personally, continuously and proactively about their disease, treatment, follow-up care and late effects.

CONFLICT OF INTEREST STATEMENT

No conflict of interest for any of the authors.

ACKNOWLEDGMENTS

We thank all survivors for participating in our survey and the members of the study team (Philip Laeuppi, Anna Hohn, Zina Heg-Bachar). This article is based on a revised version of the master thesis "Information needs in adolescent and young adult cancer survivors" that has been submitted to the Faculty of Humanities and Social Sciences at the University of Lucerne in 2015. The master thesis has been prepared by Esther Weishaupt under the supervision of Gisela Michel and Corina S. Rueegg.

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