Providing Information About Late Effects During Routine Follow-Up Consultations Between Pediatric Oncologists and Adolescent Survivors: A Video-Based, Observational Study

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Purpose: Information about late effects is a prerequisite for survivors of childhood cancers to engage in self-management of their health. Yet, many lack such knowledge. This study investigated to what extent: (1) potential late effects were discussed with adolescent and young adult (AYA)-aged survivors (of pediatric cancer), and (2) information about late effects was provided by the pediatric oncologists (POs) during routine follow-up consultations.

Methods: Consultations were recorded with 10 POs and 66 adolescents, aged 12–20 years, treated for leukemia (72.7%) or lymphoma (21.2%), or who had received hematopoietic stem-cell transplantation for a benign disease (7.6%). Discussions of potential late effects were identified and coded, and then the amount of information about late effects provided was categorized into three levels: none, basic, and extended information.

Results: Potential late effects were discussed in 85% of the consultations. Of these, 71% were PO initiated, and 60% concerned existing health problems. The POs provided none, basic, and extended information about late effects in 41%, 30%, and 29% of these discussions. Patients' age, time since treatment, and risk of late effects were not associated with amount of potential late effects discussed, but the type of potential late effect (physical vs. psychosocial and current vs. future risk) and PO were.

Conclusion: Potential late effects were frequently discussed, thus providing ample opportunity to provide information about late effects to adolescent cancer survivors. The observed PO variability in providing such information indicates a need for standardization of information practices.

Keywords: late effects, follow-up care, information provisioning, clinical communication, survivorship

Introduction

ON AVERAGE, MORE THAN 80% of those treated for childhood cancers are expected to become long-term survivors.¹ Depending on a range of treatment- and patient-related factors, many of these survivors face continuous risks of treatment-related morbidity in terms of late effects, and early mortality.^{2–7} Late effects—health problems caused by the cancer disease or its treatment—include secondary malignancies, cardiovascular complications, endocrinopathy, fatigue, and cognitive problems.^{3,6} Late effects can appear during treatment, but the majority appear years to decades beyond treatment completion.³

Given these health risks, survivors of childhood cancer are generally recommended to attend long-term follow-up care for prevention, early detection, and treatment of late effects.^{6,8} Several guidelines for such care exist.^{9–13} A general consensus regarding the content and organization of such care is lacking, but efforts are made to harmonize all guidelines to ensure consistency of care.¹⁴ Providing survivors with adequate information about their risks of late effects and to advocate health promotion is generally recommended.¹⁵

Studies from several countries, however, report that survivors of childhood cancer are largely unaware of their risk for late effects.^{16–18} Furthermore, information about late effects is frequently reported as an unmet need amongst young

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survivors.^{19,20} To what extent this apparent knowledge gap reflects clinical practice is uncertain.

Information about late effects enables survivors to take responsibility for their own health.^{8,21} Such information will also help survivors communicate their health risks and care needs to non-cancer healthcare personnel who often lack such knowledge.^{6,22} This is perhaps especially relevant for adolescent and young adult (AYA) survivors, as they often move away to study or work. Additionally, information about late effects may help survivors to adjust better to life after cancer,^{23,24} reduce uncertainty and anxiety about “what comes next,” and allow survivors to make beneficial life-style choices.²⁵ Conversely, lack of such knowledge may be a barrier to long-term follow-up care attendance.²⁶

For pediatric oncologists (POs), balancing providing sufficient information about late effects without causing unnecessary anxiety is challenging. Communicating risks of late effects to AYA survivors is especially challenging because routine follow-up consultations typically coincide with puberty—a time marked by physical, cognitive, emotional, behavioral, and social change.²⁷ Future health may not be their main priority.²⁸ If asymptomatic, AYA survivors may not experience a need for, or may even actively avoid, information about late effects.²⁹ Even if they want information, AYA survivors may not ask for it.²⁵ Thus, it is up to the POs to provide such information.^{25,30} To explore current information practices, routine follow-up consultations were video recorded at a large, pediatric outpatient clinic serving about half the Norwegian population of AYA survivors of pediatric cancer. The specific research questions were:

RQ1: To what extent are potential late effects discussed during consultations?

RQ2: Who initiates these discussions?

RQ3: To what extent do the POs provide information about late effects during these discussions?

RQ4: What factors are associated with the amount of information the POs provide?

Methods

Participants

Routine follow-up consultations between AYA survivors of pediatric cancer and POs were video recorded at an outpatient clinic at the largest university-affiliated pediatric cancer center in Norway—Oslo University Hospital—between 2010 and 2012. The center serves about a half of the Norwegian population of children with cancer.¹⁷ One PO (E.R.) identified 129 eligible patients from hospital records. Inclusion criteria were: currently 12 years of age or older; diagnosed with and completed treatment for lymphoma, leukemia, or a hematological disease treated by hematopoietic stem-cell transplantation ($n=5$); and in remission. The transplant recipients were included because their treatment and risks of late effects are similar to those of patients treated for lymphoma or leukemia.

Of the 129 eligible patients, 41 were unable to participate due to their appointment being rescheduled or the unavailability of researchers. Of the remaining 88 patients, 18 declined participation, and four were later excluded (technical

difficulties), yielding a sample of 66 patients (for details, see Mellblom et al.³¹). All POs at the center consented verbally to participation.

Setting and procedures

At the time of the study, survivors attended follow-ups for at least 10 years post-treatment, or until 18 years of age. The frequency of consultations decreases from several per year to annually, depending on the treatment received and the risk for recurrence. Consultations were scheduled for 30 minutes.

Patients were recruited consecutively. Invitations to participate were mailed out with consultation appointments from the hospital. Eligible patients were greeted upon arrival by one of the researchers. A small video camera was placed in the consultation room. The patients were told they could turn the camera off at any time. The researcher was not present during the consultation. There were no other alterations to the consultations.

Patients, parents, and doctors were informed that the purpose of the study was to explore communication between POs and adolescent patients. At the time of planning the study, the POs were also informed that the study aimed to explore communication about late effects. This information was not repeated over the 2 year period of data collection. They were instructed to conduct the consultations as per normal.

Patients received a sports-store gift voucher (100NOK/16USD) for their participation. The video recordings were transcribed verbatim, with person-identifying information removed. Analyses were based on transcriptions and video recordings, using Excel and HyperResearch 3.5.1TM to manage and code the data.

Qualitative analyses

Unable to identify a suitable tool to code communication about late effect, a coding tool was developed consisting of two components: (1) a list of late effects to identify when potential late effects were discussed (Table 1), and (2) a simple system to code the amount of information provided (Fig. 1).

The list of potential late effects (i.e., conversation topics that could indicate a late effect, hence called a potential late effect) was constructed prior to coding the data through several meetings with two clinicians (E.R. and J.H.L.). Adding potential late effects not already on the list was done in consultations with E.R. The final list included late effects (physical and psychosocial), advice about life-style, and routine screening procedures (Table 1). Who initiated the discussions about potential late effects and whether the discussion concerned a present problem/symptom (e.g., pain) or future risk of late effects (e.g., fertility) was also coded.

The scale for coding the amount of information provided was developed through preliminary analysis based on principles of thematic analysis of five consultations by A.V.M. and H.C.L. and extended discussions between clinicians (E.R. and J.H.L.) and communication researchers (A.V.M., H.C.L., L.K., and A.F.). The coding process is depicted in Figure 1, and examples of the three levels of information provided are presented in Table 2. The three levels reflect the amount of information provided—none, basic, and extended—based on Shepherd et al.’s tool designed to assess treatment-related information and each patient’s preferences.³³

TABLE 1. THE LIST OF POTENTIAL LATE EFFECTS DISCUSSED, WITH NUMBER OF CONSULTATIONS CONTAINING DISCUSSION OF EACH POTENTIAL LATE EFFECT, NUMBER OF EACH POTENTIAL LATE EFFECT DISCUSSED ACROSS CONSULTATIONS, AND WHO INITIATED THE DISCUSSIONS

<i>Potential late effects</i>	<i>Number of consultations topic raised</i>	<i>Number of times topic raised</i>	<i>Initiated by</i>		
			<i>Pediatric oncologist</i>	<i>Patient</i>	<i>Parent</i>
<i>Physical</i>					
Endocrinopathy	16	21	14	2	5
Fertility	15	18	15	3	0
Neuropathy, epilepsy	14	18	11	4	3
Cardiovascular complications	12	13	9	2	2
Dental problems	10	10	8	2	0
Secondary cancer	7	9	9	0	0
Neurocognitive problems	6	8	3	0	5
Other—physical ^a	4	4	2	1	1
Pulmonary complications	2	2	0	1	1
Loss of hearing	1	1	1	0	0
Skin problems	1	1	1	0	0
Kidney/urinary tract	0	0	0	0	0
Orthopedic problems	0	0	0	0	0
Total	88	105	73	15	17
<i>Psychosocial</i>					
Fatigue	20	27	15	6	6
Psychosocial distress ^b	11	13	5	5	3
Pain	10	13	5	6	2
School-related difficulties	6	7	5	2	0
Learning difficulties	5	6	4	0	2
Body image	5	5	2	2	1
Sleep problems	4	4	3	1	0
Problems concentrating	3	3	1	0	2
Problems with peers	1	1	1	0	0
problems with parents	0	0	0	0	0
Total	65	79	41	22	16
<i>Routine screening tests^c</i>					
Heart screening	22	26	26	0	0
Pulmonary screening	2	3	2	1	0
MRI screening	3	3	3	0	0
Hormone levels screening	0	0	0	0	0
Total	27	32	31	1	0
<i>Life-style advice</i>					
Smoking	17	18	15	2	1
Diet	16	17	16	0	1
Exercise	8	9	9	0	0
Self-examination—lymph	3	3	3	0	0
Sunscreen—sun behavior	1	1	0	0	1
Alcohol consumption	0	0	0	0	0
Total	45	48	43	2	3
Total all		264	188	40	36

^aThese four are: muscles in fingers get stuck, elevated iron levels due to blood transfusions, often nauseous, the patient is often fainting.

^bThe other patient-reported category includes bothersome thoughts about the cancer disease, fear for recurrence, depression, anxiety.

^cRecommended screening tests for early detection of late effects.

MRI, magnetic resonance imaging.

Any passage containing discussions about a potential late effect was coded for both topic (e.g., type of late effect) and amount of information provided. A passage could receive multiple codes if containing multiple topics (e.g., “I am so tired all the time [fatigue] that I struggle to concentrate at school” [concentration difficulties]).

Reliability of the list of potential late effects was assessed by dual coding of nine consultations by A.V.M. and L.K., and nine excerpts of discussions of potential late effects by A.V.M. and E.R. Inter-rater agreement ratings of A.V.M.

and L.K. was excellent, Cohen’s Kappa=0.91, and 100% agreement between A.V.M. and E.R. Because each consultation generally contained few discussions of late effects, inter-rater reliability calculations included sections of the consultation where no late effects were discussed. Inter-rater reliability for coding of the three levels of information across nine dually coded consultations by A.V.M. and L.K. was satisfactory ($\kappa=0.77$). Triple coding of the nine excerpts for level of information by A.V.M., E.R., and a second pediatrician (K.R.) achieved acceptable agreement:

FIG. 1. The process of coding information about late effects provided by the pediatric oncologist.

66% (K.R.–E.R.), 78% (E.R.–A.V.M.), and 89% (K.R.–A.V.M.).

Statistical analyses

For analytical purposes, the nature of potential late effects was categorized into four categories: physical late effects, psychosocial late effects, health advice, and routine screening tests. Differences between participants and non-participants, between the categories of potential late effects, and between category and information level were examined using Pearson's chi-square and Mann-Whitney *U*-tests. Associations between variables were assessed using Spearman's rho correlations. All analyses were conducted using SPSS Statistics for Windows v22 (IBM Corp., Armonk, NY).

Ethical considerations

All participants provided informed consent. Parental consent was obtained for participants younger than 18 years old. The POs consented verbally. The study was approved by the Regional Committee for Medical and Health Research Ethics of South-Eastern Norway.

Results

Sample characteristics

Sample characteristics are provided in Table 3. In brief, the patients were on average 15 years old, and diagnosed at 7 years of age. The majority was female and treated for leukemia. All had received intensive chemotherapy, either as the protocol-based treatment for leukemia/lymphoma only, or as the conditioning regimen before a hematopoietic stem-cell transplantation. Twelve patients received additional irradiation: tumor field ($n=5$) or as prophylactic irradiation of the central nervous system ($n=7$). Risk of late effects was stratified according to Oeffinger et al.'s criteria (see Table 3).³² Compared with non-participants, participants were more often female and had shorter observation times.

Characteristics of the consultations

The consultations reflected different stages in follow-up care ranging from fewer than 1 to 16 years since treatment completion. Four were the final follow-up consultation. Providing information about late effects is an explicit aim of the final consultation only. The average consultation time was 24 minutes (range 5–49 minutes). In 87% of the consultations, the patient was accompanied by the mother (39%),

father (28%), both parents (15%), or a friend/sibling (5%). Of the 10 POs, three were male, and the mean age was 54 years (range 35–68 years). Nine were consultants or senior consultants; one was a junior physician.

Discussions of potential late effects during follow-up consultations

The frequency of the potential late effects discussed and who initiated the discussions are presented in Table 1. Potential late effects were discussed in 56 (85%) of the consultations (264 discussions in total), with an average of four discussions per consultation (range 0–13). Fourteen (21%) consultations contained seven or more such discussions. Most discussions concerned physical potential late effects. The four final consultations contained on average seven discussions about potential late effects (range 3–13).

The majority (60%) of the potential late effects discussed were in the context of present problems/symptoms, rather than future concerns or risks. The number of potential late effects discussed was positively associated with the length of consultation ($r=0.45$, $p<0.001$) but not who initiated the discussion, patient's age at consultation, age at diagnosis, years since treatment, or patient's risk of late effects.

Initiation of discussions of potential late effects

The POs initiated 71%, the patients 15%, and the parents 14% of all the discussions about potential late effects (Table 2). The POs initiated 70% of the physical, 51% of the psychosocial, 97% of the routine screening tests, and 90% of the life-style discussions. In all four final consultations, the patients initiated one potential late effect, and the POs the rest.

Level of information provided by the PO

The POs provided no information about late effects in 41%, basic information in 30%, and extended information in 29% of the discussions of potential late effects. In the four final consultations, none, basic, and extended information was provided in 27%, 35%, and 38% of the discussions of potential late effects, respectively.

Factors associated with level of information provided

POs provided significantly more information when discussing potential late effects concerning future risks compared with present problems/symptoms ($\chi^2=43.2$, $p<0.001$). To examine whether the type of potential late effects was associated with level of information provided, levels

TABLE 2. THE THREE LEVELS OF AMOUNT OF INFORMATION ABOUT LATE EFFECTS PROVIDED BY THE PEDIATRIC ONCOLOGIST, WITH EXAMPLES FROM THE CONSULTATIONS

<i>Level</i>	<i>Observed frequency</i>	<i>Explanation</i>	<i>Examples</i>
None	41%	The problem discussed could be a potential late effect, but it is not referred to as a late effect or as a consequence of the treatment or disease.	(15-year-old boy) Dr.: And you felt tired, still? Patient: Yes. Dr.: How does that feel? Patient: Tired, it kind of puts a strain on me. Dr.: The school day is more than enough, right? Patient: Yes. Dr.: You become tired and then you need to rest when you come home from school? Patient: Yes. Dr.: But you can get through the school day, though? Patient: Yeah, yeah, I guess I survive.
Basic	30%	The potential late effect is related to the treatment, disease, and/or is called a late effect; no additional information or advice is provided.	(16-year-old girl) Dr.: So now we are going to send you to that heart examination, because then we can see if the medicine you have received has had any effect on your heart. (14-year-old girl) Dr.: If you had in mind to start smoking in the future, it is more harmful for you to start smoking than for others who haven't received chemotherapy. Patient: Yes [nods].
Extended	29%	The potential late effect is related to the treatment, disease, and/or is called a late effect AND additional information or advice is provided.	(15-year-old girl) Dr.: Your legs are still a bit weak then? Mother: Asked her to lift one leg and swing it back and forth and she went straight into the wall, the balance was not there, nor the strength. Dr.: Do you still go to physiotherapy? Mother: Yes, on a regular basis. Dr.: These are things we assume are caused by the chemotherapy, and we have probably said that several times before. Mother: Yes. Dr.: And we know, yes you have received a lot of leukemia treatment. Patient: A lot. Dr.: Eh, and, especially that one medicine named vincristin can give a lot of these effects. But usually it gets better, but often it takes a lot of time. Before we said that all will be well over 6 months to a year, and now we know that what they said was not true. (13-year-old boy) Dr.: You have received chemotherapy (in Norwegian: cell poison) and it is named this because it is poison ... so we are going to do a heart examination next time, an ultrasound ... to have a look at the heart muscle because your heart can be affected by one of these types of [cell poison], and this does not appear at once, but it comes creeping after 10 years or something like that. Those who have received large amounts of this chemo, the orange one—do you remember it?—are the most vulnerable. Patient: Okay, did I get a lot of it? Dr.: Nah, just about average (describes dosage). So if everything looks fine now after 10 years, then maybe later you should have a heart examination every 5 years or so).

were compared across the four categories of potential late effects: physical, psychosocial, routine screening tests, and life-style advice (Table 4). Providing no information about late effects was associated with discussing psychosocial potential late effects (e.g., fatigue, pain, psychosocial problems) and life-style advice, while providing extended information was associated with discussing physical potential late effects and routine screening tests (Table 4).

There were marked individual differences between the POs regarding the frequency at which potential late effects were discussed during their consultations and the levels of information provided. Average numbers of consultations per PO was 7.1 (range 1–22). The uneven distribution of consultations across the POs made analyzing inter-individual differences difficult. Three POs had 65% of the consultations in which 73% of the discussions about potential late effects

TABLE 3. SAMPLE CHARACTERISTICS INCLUDING COMPARISONS BETWEEN PARTICIPATING AND NON-PARTICIPATING PATIENTS

<i>Patients characteristics</i>	<i>Patients included (n=66)</i>	<i>Patient declined participation (n=18)</i>	<i>Patients not included for other reasons (n=45)^a</i>
Current age, <i>M</i> (SD, range)	15.3 (2.3, 12–20)	16.1 (12–20)	16.0 (11–22)
Age at diagnosis, <i>M</i> (SD, range)	6.7 (4.0, 0–16)	7.7 (0–15)	7.9 (1–16)
Years since treatment, <i>M</i> (SD, range)	6.3 (3.4, 0–16)	9.0 (1–15)*	9.0 (0–17)*
Sex, <i>n</i> (%)			
Female	45 (68.2)	6 (37.5)**	14 (31.8)**
Diagnoses, <i>n</i> (%)			
Leukemia	48 (72.7)	11 (61.1)	26 (59.0)
ALL	41 (85.4)	9 (50.0)	19 (43.2)
AML	6 (12.5)	2 (11.1)	6 (13.6)
CML	1 (2.1)		1 (2.3)
Lymphoma	14 (21.20)	7 (38.9)	18 (40.9)
Hodgkin lymphoma	6 (50.0)	5 (27.8)	10 (22.7)
Non-Hodgkin lymphoma	6 (50.0)	2 (11.1)	8 (18.2)
Aplastic anemia	3 (4.55)		
β -Thalassemia major	2 (3.0)		
Recurrence of malignancy	9 (13.6)	1 (5.6)	6 (13.6)
Treatment, <i>n</i> (%)			
Chemotherapy	66 (100)		
Radiation therapy	12 (18.0)		
Stem-cell transplantation	14 (21.0)		
Late effect risk level 2	44 (66.7)		
Late effect risk level 3	22 (33.3)		

Patients' risk of late effects was calculated according to criteria outlined in Oeffinger et al.³² Level 2: low to moderate doses of alkylating agent, anthracycline, bleomycin, or epipodophyllotoxin and no radiation. Level 3: high doses, radiation, and/or stem-cell transplant. Mann-Whitney *U*-tests were used to compare differences between patients included and patients who declined participation, and between patients included and patients not participating for other reasons.

^aPatients not included for other reasons include four patients who participated in the study but who were later excluded due to not meeting inclusion criteria or technical difficulties.

p* < 0.05; *p* < 0.01.

ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; CML, chronic myelogenous leukemia.

occurred. The PO with the most consultations (33%) discussed 20% of the potential late effects (mean of 2.5 per consultation) and provided 22% of all extended information. The PO with the most discussions of potential late effects (36%, mean of 7.2 per consultation) also provided almost 50% of the extended information despite having 20% of the consultations. Six of the 10 POs provided extended information at least once.

Discussion

Sixty-six consecutive routine follow-up consultations were video recorded of AYA survivors treated for pediatric leukemia or lymphoma, or those who received hematopoietic

stem-cell transplantations for a benign blood disorder. The consultations cover all stages of follow-up care and thus provide a "snap-shot" of the routine follow-up care provided at the largest pediatric cancer center in Norway.

To the best of the authors' knowledge, this is the first time actual communication about late effects during routine follow-up consultations has been studied. Most of the consultations contained discussions of potential late effects, with extended information about late effects provided in approximately one-third of these discussions. More information was provided in longer consultations, when discussing future versus current potential late effects, and potential late effects of a physical versus psychosocial nature. Physical late effects and routine screening tests were discussed most frequently.

TABLE 4. LEVEL OF INFORMATION ABOUT LATE EFFECTS PROVIDED BY THE PEDIATRIC ONCOLOGIST VERSUS TYPE OF POTENTIAL LATE EFFECTS

<i>Information level</i>	<i>Type of potential late effect</i>				<i>Total</i>
	<i>Physical</i>	<i>Psychosocial</i>	<i>Routine screening</i>	<i>Life-style advice</i>	
None	30 (27%)	38 (52%)	10 (31%)	29 (60.5%)	107 (41%)
Basic	32 (29%)	23 (32%)	10 (31%)	14 (29%)	79 (30%)
Extended	48 (44%)	12 (16%)	12 (38%)	5 (10.5%)	77 (29%)
Total	111 (100%)	73 (100%)	32 (100%)	48 (100%)	264 (100%)

Pearson $\chi^2 = 31.02$; *df* = 6; *p* < 0.01.

This biomedical focus is not surprising given the clinical setting, and is consistent with the medical focus of discussions of survivorship issues at treatment completion.³⁴

In contrast, patients typically initiated discussions about psychosocial potential late effects. This is consistent with reported patient preferences for a greater focus on psychosocial issues during follow-up care,^{25,35} and reports of elevated levels of psychological distress, chronic pain, and fatigue amongst childhood cancer survivors.^{36–38} Thus, attention to potential late effects initiated by the patient could help to tailor the consultation to meet the patient's needs.

It is not advocated that any discussion of any potential late effect should elicit information provisioning. Rather, the PO can help to establish whether health concerns are “normal” or potential late effects. However, the low proportion of extended information provided is consistent with childhood cancer survivors' perceptions of the information about late effects provided being vague and difficult to act upon,²⁴ as well as their lack of knowledge of late effects^{16,17,39} and their unmet needs for information about late effects.^{19,20,40,41}

Providing information that meets patients' needs is central in models of patient-centered care,⁴² and a European initiative has been made—PanCare—to structure how long-term care after childhood cancer could be conducted.⁴³ A challenge for the POs is that AYA survivors may not want such information, especially when feeling healthy.^{25,29} Additionally, AYA survivors may not have progressed from concrete to abstract thinking, making abstract information about future health risks difficult to appreciate.^{44–46} Concrete levels of thinking necessitate information exemplified in the “here and now,” not abstract “if..., then...” concepts.⁴⁶ Thus, providing information that is understood and perceived as relevant to AYA survivors is challenging and requires sensitivity, flexibility, and time on the behalf of the PO.⁴⁶

Although providing information should ideally be tailored to the individual survivor, the notable individual differences between the POs in information provisioning suggest that more standardized procedures for educating survivors about their medical history and (future) health risks might be beneficial. Including more detailed recommendations for providing information about late effects in guidelines for follow-up care, especially how and when, may be useful in this regard.

Strengths and limitations

The main strength of this study is the naturalistic design, including video recordings of actual follow-up consultations. Second, the consecutive recruitment reduces systematic bias in the sample and therefore enhances the generalizability of the findings. Third, the sample was drawn from approximately half of the Norwegian population of these survivors, although the sample was somewhat younger and had shorter observation times compared with non-participants.

Noteworthy limitations are, first, that this study represents a snapshot only of routine follow-up consultations. It did not include a measure of how much information the patients had received prior to the consultations or their understanding of the information provided. Including patient interviews would strengthen the study. Second, POs' knowledge of the purpose of the study may have affected their behavior in the consultations. However, if so, they should be more likely to discuss

late effects than usual. Third, five patients were included who were not treated for cancer, but who had undergone similar treatment protocols and thus had comparable risks of late effects as the cancer survivors. Fourth, given the lack of existing tools to code information about late effects, a new measure was developed. Its inter-rater reliability was satisfactory, but further testing of external reliability and validity is needed. Lastly, factors potentially limiting the generalizability of the findings were: the uneven distribution of consultations between the POs, which reflect if the POs were full-time staff; the moderate sample size, 41 eligible patients were not able to participate due to rescheduled appointment or unavailability of researchers, large variation in observation time, and consultation length. However, the sample is currently the largest of its kind,^{24,34} and represents the whole continuum of routine survivorship care provided in Norway. In Norway, everybody has equal access to government-provided healthcare services. Whether this could have influenced the results is uncertain.

Conclusions

Despite recommendations to inform survivors of childhood cancer about late effects,¹⁵ there are significant knowledge gaps regarding how such information is provided in clinical practice. Existing guidelines provide no specific advice for how and when to do so. Thus, these findings represent a first step toward developing an evidence base for communication at the survivorship stage of cancer care.⁴⁷ A clear biomedical focus was identified in the POs' provision of information about late effects. The observed variability in providing information about late effects indicates a need for further research into the standardization of such practices to ensure adequate communication and provision of essential information for long-term survivors of pediatric cancer.

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References

1. Ward E, DeSantis C, Robbins A, et al. Childhood and adolescent cancer statistics, 2014. *CA Cancer J Clin.* 2014;64:83–103.
2. Robison LL, Hudson MM. Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nat Rev Cancer.* 2014;14:61–70.
3. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med.* 2006;355:1572–82.
4. Reulen RC, Frobisher C, Winter DL, et al. Long-term risks of subsequent primary neoplasms among survivors of childhood cancer. *J Am Med Assoc.* 2011;305:2311–19.
5. Reulen RC, Winter DL, Frobisher C, et al. Long-term cause-specific mortality among survivors of childhood cancer. *J Am Med Assoc.* 2010;304:172–9.

6. Hudson MM, Ness KK, Gurney JG, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *J Am Med Assoc.* 2013;309:2371–81.
7. Kero AE, Järvelä LS, Arola M, et al. Late mortality among 5-year survivors of early onset cancer: a population-based register study. *Int J Cancer.* 2014; 134: 664–73.
8. Earle C, Ganz P. Cancer survivorship care: don't let the perfect be the enemy of the good. *J Clin Oncol.* 2012; 30:3764–68.
9. Children's Oncology Group. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers, Version 4. 2014. Accessed January 15, 2015 from: www.survivorshipguidelines.org
10. Dutch Childhood Oncology Group. Richtlijn follow-up na kinderkanker meer dan 5 jaar na diagnose. SKION, Den Haag/Amsterdam 2010. Accessed January 15, 2015 from: www.skion.nl
11. Skinner R, Wallace WHB, Levitt GA, et al. Long-term follow-up of people who have survived cancer during childhood. *Lancet Oncol.* 2006;7:489–98.
12. Hewitt ME, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academy Press; 2006.
13. Swedish Working Group for Long-Term Follow-Up After Childhood Cancer. Follow-up after childhood cancer. 2010: Version 5.0. Accessed January 15, 2015 from: www.blf.net/onko/page6/page14/files/Salub_5_2010_Eng.pdf
14. Kremer LC, Mulder RL, Oeffinger KC, et al. A worldwide collaboration to harmonize guidelines for the long-term follow-up of childhood and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Ped Blood Cancer.* 2013;60:543–9.
15. Adolescent Young Adult Oncology Progress Review Group. Closing the gap: research and care imperatives for adolescents and young adults with cancer (NIH Publication No. 06-6067). Bethesda, MD: Department of Health and Human Services, National Institutes of Health, National Cancer Institute, and the LIVESTRONG Young Adult Alliance; 2006.
16. Hess SL, Jóhannsdóttir IM, Hamre H, et al. Adult survivors of childhood malignant lymphoma are not aware of their risk of late effects. *Acta Oncol.* 2011;50:653–59.
17. Ruud E, Kanellopoulos A, Zeller B, et al. Patient knowledge of late effects of acute lymphoblastic leukaemia. *Tidsskrift for den Norske laegeforening.* 2012;132: 2052–5.
18. Bashore L. Childhood and adolescent cancer survivors' knowledge of their disease and effects of treatment. *J Ped Oncol Nurs.* 2004;21:98–102.
19. Zebrack B. Information and service needs for young adult cancer survivors. *Support Care Cancer.* 2009;17:349–57.
20. Gianinazzi ME, Essig S, Rueegg CS, et al. Information provision and information needs in adult survivors of childhood cancer. *Pediatr Blood Cancer.* 2014;61: 312–18.
21. Knijnenburg SL, Kremer LC, Versluys AB, et al. Evaluation of a patient information website for childhood cancer survivors. *Support Care Cancer.* 2013;21:919–26.
22. Landier W, Wallace WHB, Hudson MM. Long-term follow-up of pediatric cancer survivors: education, surveillance, and screening. *Pediatr Blood Cancer.* 2006;46: 149–58.
23. Husson O, Mols F, Van de Poll-Franse L. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol.* 2011;22:761–72.
24. Hauken MA, Larsen TMB, Holsen I. Meeting reality: young adult cancer survivors' experiences of reentering everyday life after cancer treatment. *Cancer Nurs.* 2013; 36:17–26.
25. Lie HC, Loge JH, Fosså SD, et al. Providing information about late effects after childhood cancer: lymphoma survivors' preferences for what, how and when. *Patient Edu Couns.* 2015;98:604–11.
26. Mitka M. Young adult cancer survivors face barriers to receiving primary care. *J Am Med Assoc.* 2012;308: 1618–19.
27. Arnett JJ. Adolescence and emerging adulthood. Upper Saddle River, NJ: Prentice Hall; 2000.
28. McClellan W, Klemp JR, Krebill H, et al. Understanding the functional late effects and informational needs of adult survivors of childhood cancer. *Onc Nurs Forum.* 2013; 40:254–62.
29. Nathan PC, Hayes-Lattin B, Sisler JJ, et al. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer.* 2011;117:2335–41.
30. Stanton AL. Psychosocial concerns and interventions for cancer survivors. *J Clin Oncol.* 2006;24:5132–7.
31. Mellblom AV, Finset A, Korsvold L, et al. Emotional concerns in follow-up consultations between pediatric oncologists and adolescent survivors: a video-based observational study. *Psychooncology.* 2014;23:1365–72.
32. Oeffinger KC, Nathan PC, Kremer LCM. Challenges after curative treatment for childhood cancer and long-term follow up of survivors. *Pediatr Clin North Am.* 2008;55: 251–73.
33. Shepherd HL, Barratt A, Trevena LJ, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. *Patient Edu Couns.* 2011;84:379–85.
34. Lamanna J, Trapp S, Russell C, et al. Preparing for the future: an examination of healthcare provider and patient communication regarding childhood cancer survivorship. *Child Care Health Dev.* 2014 Oct 22. DOI: 10.1111/cch.12210. [Epub ahead of print].
35. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *J Clin Oncol.* 2012;30:1221–6.
36. Hudson MM, Mertens AC, Yasui Y, et al. Health status of adult long-term survivors of childhood cancer. *J Am Med Assoc.* 2003;290:1583–92.
37. Schwartz L, Drotar D. Posttraumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *J Pediatr Psychol.* 2006;31:356–66.
38. Rourke MT, Hobbie WL, Schwartz L, et al. Posttraumatic stress disorder (PTSD) in young adult survivors of childhood cancer. *Pediatr Blood Cancer.* 2007;49:177–82.
39. Kadan-Lottick NS, Robison LL, Gurney JG, et al. Childhood cancer survivors' knowledge about their past diagnosis and treatment: Childhood Cancer Survivor Study. *J Am Med Assoc.* 2002;287:1832–9.
40. Knijnenburg SL, Kremer LC, van den Bos C, et al. Health information needs of childhood cancer survivors and their family. *Pediatr Blood Cancer.* 2010;54:123–7.

41. Wakefield CE, Butow P, Fleming CAK, et al. Family information needs at childhood cancer treatment completion. *Pediatr Blood Cancer*. 2012;58:621–6.
42. Butow PN. Giving and using information: what we know and don't know. *Patient Educ Couns*. 2009;77:149–50.
43. Hjorth L, Haupt R, Skinner R, et al. Survivorship after childhood cancer: PanCare: a European network to promote optimal long-term care. *Eur J Cancer*. 2015;51:1203–11.
44. Piaget J. The language and thought of the child. London: Routledge and Kegan Paul; 1959.
45. White B, Viner RM. Improving communication with adolescents. *Arch Dis Child Educ Pract Ed*. 2012;97:93–7.
46. Christie D, Viner R. Adolescent development. *Br Med J*. 2005;330:301–4.
47. Thorne SE, Stajduhar KI. Patient perceptions of communications on the threshold of cancer survivorship: implications for provider responses. *J Cancer Surviv*. 2012; 6:229–37.

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