Adolescents and Young Adults with Cancer Using a Symptom Heuristics App: Provider Perceptions and Actions

Catherine Fiona Macpherson, PhD, RN, CPON,¹ Kristin Stegenga, PhD, RN, CPON,²
Jeanne M. Erickson, PhD, RN,³ Lauri A. Linder, PhD, APRN, CPON,⁴
Amy R. Newman, PhD, RN, CPNP-PC, CPHON,⁵ Ronald K. Elswick, Jr., PhD,⁶ John Charlson, MD,⁷
Stefanie Thomas, MD, MS,⁸ and Suzanne Ameringer, PhD, RN, FAAN⁶

Purpose: This study examined health care providers' perceptions of the usefulness and ease of use of a symptom heuristics app delivered via a tablet computer as a resource for understanding symptom experiences of adolescents and young adults (AYAs) with cancer. AYAs' app-generated symptom reports were compared with providers' documentation of AYAs' symptoms.

Methods: This multisite study included responses from 86 AYAs 15–29 years of age who completed the Computerized Symptom Capture Tool (C-SCAT) before two scheduled visits for chemotherapy. After each visit, their providers completed a survey addressing their perspective of: (1) the usefulness of data provided by the C-SCAT to understand the AYAs' symptom experience, and (2) the nature of the discussion of symptoms with the AYA. An electronic health record review compared symptoms that AYAs identified by using the C-SCAT with providers' documentation of symptoms.

Results: One hundred forty-four complete surveys were returned after 162 visits. Fifty percent ($n=72$) of responses reported that the C-SCAT helped identify the patient's symptoms, and 53% ($n=76$) reported that it helped identify the patient's priority symptoms. Providers also reported higher patient engagement and more focused discussions regarding symptoms. They reported that use of the C-SCAT facilitated the development of symptom management plans. Priority symptoms were documented more frequently than nonpriority symptoms (54% vs. 32.7%; $p<0.01$) as was a plan for managing priority symptoms (33.7% vs. 17.9%; $p<0.01$).

Conclusion: Use of the C-SCAT enhanced providers' understanding of AYAs' symptom experiences. Further research is needed to demonstrate the effectiveness of the C-SCAT as a resource to improve symptom management among AYAs with cancer.

Keywords: heuristics, technology, communication, symptom assessment

Introduction

ADOLESCENTS AND YOUNG ADULT (AYA) patients with cancer experience multiple co-occurring and related symptoms from their disease and treatment that negatively impact quality of life and interfere with achieving developmental tasks.^{1,2} Provision of optimal care to AYAs includes symptom management. However, addressing the manage-

ment of multiple symptoms may be challenging for providers, such as attending physicians, physician fellows, nurse practitioners, and physician assistants, due to the time constraints surrounding patient visits; limited provider expertise in discussing symptoms with patients, especially with patients who may have a limited ability to clearly and concisely articulate salient details of their symptom experience to the provider; and the complexity of the symptom experience for

¹Inpatient Cancer Care Unit, Seattle Children's Hospital, Seattle, Washington, USA.

²Division of Pediatric Hematology/Oncology/BMT, Children's Mercy Hospital, Kansas City, Missouri, USA.

³College of Nursing, University of Wisconsin, Milwaukee, Wisconsin, USA.

⁴College of Nursing and Center for Cancer and Blood Disorders, University of Utah, Primary Children's Hospital, Salt Lake City, Utah, USA.

⁵College of Nursing, Marquette University and Department of Nursing Research and Evidence-Based Practice, Children's Hospital of Wisconsin, Milwaukee, Wisconsin, USA.

⁶Department of Family and Community Health, School of Nursing Virginia Commonwealth University, Richmond, Virginia, USA.

⁷Department of Medicine Division of Hematology/Oncology, Medical College of Wisconsin, Milwaukee, Wisconsin, USA.

⁸Department of Pediatric Hematology, Oncology, and BMT, Cleveland Clinic Children's, Cleveland, Ohio, USA.

many AYAs. The purpose of this study was to examine the perspectives and actions of providers by using a heuristics-based symptom assessment tool, the Computerized Symptom Capture Tool (C-SCAT), designed for AYAs. The study aimed at: (1) examining health care providers' perceptions of the usefulness and ease of use of the C-SCAT as a resource for understanding the symptom experience of AYAs with cancer, and (2) comparing AYAs' symptom reports from the C-SCAT to health care providers' documentation of AYAs' symptoms.

Methods

Computerized symptom assessment tool

An alternative to traditional symptom assessment instruments that are delivered as checklists, the C-SCAT uses an innovative inductive heuristic-based approach to shift the dominant quantitatively derived paradigm to explore symptoms and symptom clusters from the perspective of the AYA. Heuristics are conscious or unconscious "mental models" that are used in decision making and problem solving. Symptom heuristics are those "mental models" that individuals use in relation to their symptom experience. Based on a symptom cluster heuristics interview developed by Dr. Nancy Woods,³ the C-SCAT was created by the Consortium to Study Symptoms in Adolescents and Young Adults with Cancer. The C-SCAT is delivered via a tablet computer and serves as a resource for AYAs to understand and communicate their symptom experience.⁴ The C-SCAT features the 32 symptoms from the Memorial Symptom Assessment Scale⁵ and uses a novel approach to symptom assessment that combines graphical images and free text responses. AYAs are guided through a series of screens that ask them to identify symptoms experienced during the past 24 hours and identify causal relationships between symptoms and group of symptoms that occur together (i.e., symptom clusters). Finally, they give names to their identified symptom clusters and identify priority symptoms. The final graphical image shows symptoms/symptom clusters, priority symptoms, and relationships among symptoms from the perspective of the AYA.⁴ The C-SCAT's initial feasibility and acceptability was demonstrated among 72 AYAs receiving chemotherapy at five sites in the United States, who endorsed its ease of use and its ability to represent their individual symptom experiences. This study also demonstrated the C-SCAT's ability to generate rich data about AYAs' symptom experiences.^{6,7}

The C-SCAT has potential to empower AYAs to share their symptom experiences and partner with providers in their symptom management.⁸ Its potential use in fostering patient-provider communication was captured by one participant in the feasibility and acceptability study who commented, "...the doctors don't always know how we feel."⁴ The AYA completes the C-SCAT just before a provider encounter, and the final graphical image can be shared by the AYA to furnish the provider with rich data in a format convenient for rapid review and immediate use.⁴ Electronic self-report systems that patients complete before health care encounters have resulted in improved discussion and documentation of troublesome symptoms.⁹⁻¹¹ Less is known about providers' perspectives on the usefulness of these systems and their impact on workflow. Acceptance of a given technology-

based resource depends, in part, on key attributes, including its perceived usefulness, the extent to which it can enhance job performance, and its perceived ease of use.¹² Incorporating the C-SCAT-generated image in the context of the clinic visit may assist providers to conduct focused conversations that emphasize the symptoms the AYA is experiencing, how she or he perceives them to be related, and what she or he perceives to be the priority symptoms, thus facilitating the collaborative development of a symptom management plan.⁴

Study design

This article presents the secondary aims of a larger study investigating the efficacy of the C-SCAT to support AYAs' self-efficacy for symptom self-management. The study's primary AYA-focused aim was investigated by using a single-group pretest-posttest mixed-methods design with baseline data collection occurring at the time of enrollment followed by use of the C-SCAT and data collection during each of two subsequent scheduled visits (outpatient or inpatient) for myelosuppressive chemotherapy.⁸ These secondary provider-focused aims were investigated with an exploratory descriptive design. AYA oncologists, both pediatric and adult, were consulted during the development of study procedures and instruments to maximize provider response rates.

Setting and sample

After institutional review board approval at each site, AYAs, 15-29 years of age receiving myelosuppressive chemotherapy for any diagnosis of cancer in an outpatient or inpatient setting were enrolled at five academic medical centers in the United States; representing the West Coast, Intermountain West, Midwest, and Southeast. Inclusion criteria were: (1) completion of at least one cycle of therapy for cancer with at least two additional anticipated cycles of myelosuppressive chemotherapy; (2) ability to read, write, and speak English; and (3) physical and cognitive capacity to complete the C-SCAT and study measures. Attending physicians, physician fellows, nurse practitioners, and physician assistants who conducted and documented the history and physical exam associated with the visit when the C-SCAT was completed were considered eligible provider participants. Eligible provider participants were invited to participate with a cover letter explaining the study and that return of the questionnaire implied consent along with the questionnaire. Because the unit of analysis was the patient-provider encounter, an individual provider could participate more than once for one or more AYA participants.

Procedures

Before meeting with their provider at the two scheduled visits, AYAs completed the C-SCAT and received a copy of the image to use during their patient-provider encounter to discuss their symptom experience. After the clinical encounter, the provider completed the paper-based questionnaire. After the provider completed the clinic note, a research team member completed a chart review with attention to the provider's documentation of symptoms identified by the AYA and any plans to manage those symptoms.

Instruments

The Provider Questionnaire (PQ) is an investigator-developed 7-item questionnaire assessing the provider's perspective of: (1) the usefulness of the data provided by the C-SCAT for understanding the AYA participant's symptom experience, and (2) the nature of the discussion of symptoms with the AYA participant. PQ items were adapted from items developed by Lai et al.¹¹ to elicit providers' perceptions of the usefulness and acceptability of their electronic symptom monitoring system for reporting fatigue in children, adolescents, and young adults with cancer. Three items are measured by using a 5-point Likert-type scale, and 4 items are measured by using a semantic differential scale (100-mm visual analog scale).

The electronic health record (EHR) review form was developed to compare symptoms AYAs identified by using the C-SCAT with provider documentation of symptoms and plans for managing identified symptoms. Demographic variables were collected from providers to characterize the provider cohort.

Data analysis

Providers' responses to the PQ were summarized descriptively across both visits. Free text comments from providers were analyzed by using inductive content analysis. Each comment was analyzed and divided into meaning units. These were subsequently grouped into categories reflecting the providers' thoughts about using the C-SCAT with the AYA during a visit.^{13,14} Documentation of AYAs' symptoms in the EHR was summarized with attention to overall documentation of symptoms reported by the AYA; documentation of priority symptoms; and documentation of management strategies for reported symptoms. Documentation was then compared with AYAs' C-SCAT reports. The Fisher's exact test was used to analyze 2×2 tables of the frequency of documentation of symptoms and plan to manage the symptoms by priority, severity, and distress.

Results

Sample characteristics

AYA participants. Eighty-eight AYAs from the five sites were enrolled in the study, and two withdrew after enrollment. Eighty-six AYAs completed the C-SCAT at visit 1, and 85 AYAs completed the C-SCAT at visit 2. Eighty-three AYAs (97%; 83/86) reported at least one symptom at visit 1, and 79 of 85 AYAs (93%) reported at least one symptom at visit 2. In total, AYAs reported symptoms at 162 of 171 visits. The majority of these 86 participants were White (71%) and male (55%), with a mean age of 20.9 years [standard deviation (SD)=4.92]. Ninety-five percent were receiving treatment for a primary cancer. The most common cancer diagnoses were acute and chronic leukemia (43%) followed by lymphoma [Hodgkin lymphoma (15%) and non-Hodgkin lymphoma (8%)]. A more detailed description of the sample has been previously published.⁸

Provider participants. PQs were returned for 149 of the 162 visits in which AYAs reported at least one symptom. Five providers completed the demographic portion of the questionnaire, but they did not answer the seven items about

usefulness of the C-SCAT. These five incomplete PQs were excluded from the analysis, resulting in 144 evaluable surveys. Providers were not assigned unique identifiers; therefore, they are described as a cohort. Seventy-one of these 144 responses (49%) were provided by attending physicians and 44 (30%) by nurse practitioners ($n=44$). Additional responses were submitted by fellows ($n=18$, 13%) and physician assistants ($n=10$, 7%). The majority of responses were submitted by females ($n=91$, 66%). Ninety-eight (70%) of responses were from providers between the ages of 30 and 49 years. Practice locations were split nearly evenly between pediatric and adult medical oncology (Table 1).

Provider questionnaire

Quantitative. The first 3 items on the PQ addressed the perceived usefulness of the C-SCAT for identifying the patient's symptoms, relationships among symptoms, and the patient's priority symptoms. Seventy-two (50%) of provider responses indicated that the C-SCAT helped identify the patient's symptoms, 59 (42%) of responses indicated it helped identify relationships among symptoms, and 76 (54%) of responses reported it helped identify the patient's priority symptoms.

Items 4–7 on the PQ addressed how the C-SCAT affected patient engagement in discussing symptoms, the focus of discussions, the length of discussion about symptoms, and the development of a symptom management

TABLE 1. PROVIDER DEMOGRAPHICS

Demographics	Total, n (%)
Role	
Attending physician	71 (49.7)
Nurse practitioner	44 (30.8)
Fellow	18 (12.6)
Physician assistant	10 (7.0)
Total	143
Gender	
Female	91 (65.5)
Male	48 (34.5)
Total	139
Age, years	
29 and under	3 (2.1)
30–39	58 (41.1)
40–49	40 (28.6)
50–59	27 (19.3)
60–69	12 (8.6)
Total	140
Race	
White	112 (80.6)
Asian	24 (17.3)
>1	3 (2.2)
Total	139
Ethnicity	
Non-Hispanic	137 (97.2)
Hispanic	4 (2.8)
Total	139
Practice area	
Pediatric oncology	72 (50.7)
Adult oncology	70 (49.3)
Total	142

plan. These four items were measured with a semantic differential scale ranging from 0 to 100 mm. Providers reported that after using the C-SCAT: (1) patient levels of engagement in discussions regarding symptom experiences were higher (mean=69.2, SD=27.5); (2) symptom discussions were more focused (mean=72.7, SD=25.2); (3) use of the C-SCAT did not increase the typical amount of time spent in symptom discussions with patients (mean=48.7, SD=26.1); and (4) use of the C-SCAT facilitated the development of symptom management plans with patients (mean=65.8, SD=24.5).

Qualitative. Of the 144 completed surveys, 43 (30%) included free text comments from providers. Providers' responses on 12 of these surveys indicated that the C-SCAT image was not used. Comments from the remaining 31 surveys were grouped into 5 categories (Table 2), indicating: (1)

C-SCAT was helpful (22 comments); (2) C-SCAT was not helpful (6 comments); (3) more education of patients on the use of C-SCAT is needed (2 comments); (4) desire for more information about the C-SCAT (6 comments); and (5) C-SCAT is not a fit for all patients (4 comments).

Electronic health record documentation

Table 3 summarizes the frequencies with which (1) AYAs' symptoms reported by using the C-SCAT at both visits were documented in the provider note, and (2) a plan for managing the symptom was documented based on priority and non-priority designation within the C-SCAT. Providers documented priority symptoms more frequently than nonpriority symptoms [54% (88/163) vs. 32.7% (217/664); $p < 0.01$] in their clinical notes summarizing the visit. They also more frequently documented a plan for managing AYA's reported priority symptoms compared with nonpriority symptoms

TABLE 2. EXAMPLES OF PROVIDER COMMENTS ABOUT THE COMPUTERIZED SYMPTOM CAPTURE TOOL

<i>Category</i>	<i>Setting</i>	<i>Provider comment</i>	<i>Provider role and gender</i>	<i>AYA participant</i>
C-SCAT was helpful	Pediatric	I liked that it brought up symptoms I wouldn't usually ask about/worry, but they are a big deal to them—i.e., hair loss, dry skin, etc.	Physician (fellow) Female	16-year-old male with ALL
	Adult	I would not have known about his sleep difficulty	Nurse practitioner Female	25-year-old male with sarcoma
	Pediatric	For this patient who does not volunteer symptoms, it facilitated our discussion	Nurse practitioner Female	19-year-old male with ALL
	Pediatric	My patient identified two symptoms that have been bothering him but he was hesitant to bring up in regular discussions. It was very fruitful to focus on these symptoms	Nurse practitioner Female	18-year-old male with ALL
	Adult	I think this application helps me visualize the patients' concerns. Easy for me to manage and even to dictate. I am more visual on apps great for me	Physician (attending) Female	28-year-old female with breast cancer
C-SCAT was not helpful	Adult	My first experience with this. I already have a systemic way to review symptoms/issues so it felt a little awkward/redundant... Since we have very limited time-does prolong discussion	Physician assistant Female	29-year-old female with adenocarcinoma
	Pediatric	This visit was essentially the same as prior visit. I could not see an impact from this	Physician (attending) (no gender reported)	17-year-old male with brain cancer
More education of patients is needed	Pediatric	My patient was confused and did the C-SCAT for all the symptoms in history	Physician (fellow) Female	19-year-old male with ALL
Desire for more information	Pediatric	I would have liked to have more details on his symptoms	Nurse practitioner Female	19-year-old male with ALL
	Adult	May be useful to see if symptoms are increasing or decreasing	Physician (attending) Male	26-year-old male with sarcoma
Not a fit for all patients	Pediatric	He is an introverted guy who doesn't love talking. He was lukewarm to writing out thoughts	Physician (fellow) Male	17-year-old male with CML
	Pediatric	Would be more helpful for a patient who has difficulty communicating	Physician (attending) Female	15-year-old female with ALL

ALL, acute lymphoblastic leukemia; AYA, adolescent and young adult; CML, chronic myelocytic leukemia; C-SCAT, Computerized Symptom Capture Tool.

TABLE 3. PROVIDER DOCUMENTATION OF SYMPTOMS REPORTED BY ADOLESCENTS AND YOUNG ADULTS USING THE COMPUTERIZED SYMPTOM CAPTURE TOOL BASED ON PRIORITY DESIGNATION

<i>Symptom</i>	<i>Priority</i>			<i>Nonpriority</i>		
	<i>Frequency</i>	<i>Sx documented</i>	<i>Plan documented</i>	<i>Frequency</i>	<i>Sx documented</i>	<i>Plan documented</i>
Lack of energy	19	13	3	52	19	5
Nausea	18	13	10	30	24	18
Difficulty sleeping	15	7	5	37	13	4
Pain	15	8	8	36	23	16
Feeling irritable	9	0	0	28	0	0
Feeling drowsy	8	4	2	45	8	3
Lack of appetite	8	5	3	25	10	4
Hair loss	7	3	2	39	3	1
Tingling in hands/feet	7	5	3	26	14	8
Weight loss	6	3	2	14	6	6
Worrying	6	1	1	16	4	2
Difficulty concentrating	5	2	1	19	1	0
Changes in how food tastes	4	3	1	33	3	1
Mouth sores	4	3	2	14	3	1
Shortness of breath	4	2	1	10	1	0
Vomiting	4	2	1	14	5	2
Constipation	3	3	3	23	7	6
Cough	3	3	1	22	10	3
Feeling bloated	3	2	0	12	1	1
Feeling nervous	3	1	1	19	2	1
Feeling sad	3	1	0	20	8	4
Itching	3	2	2	12	3	2
Skin changes	3	0	0	16	11	6
Dizziness	2	1	1	23	8	4
Don't look like myself	2	0	0	13	2	1
Sweating	2	0	0	19	2	1
Diarrhea	1	1	1	19	7	5
Difficulty swallowing	1	0	0	5	1	1
Sexual dysfunction	1	1	1	5	3	3
Dry mouth	0	0	0	20	3	2
Problems with urination	0	0	0	4	0	0
Swelling in arms/legs	0	0	0	6	2	2

[33.7% (55/163) vs. 17.9% (119/664); $p < 0.01$]. Symptoms of moderate or greater severity were documented more frequently than those of slight severity [39.4% (235/597) vs. 29.7% (60/202); $p = 0.014$]; however, documentation of a plan for managing symptoms of moderate or greater severity did not differ from those of slight severity [22.4% (134/597) vs. 17.3% (35/202); $p = 0.14$]. Symptoms of moderate or greater distress were documented more frequently than those of slight or no distress [41.1% (184/448) vs. 31.2% (109/349); $p < 0.01$] as was a plan for managing symptoms of moderate or greater distress [24.1% (108/448) vs. 17.2% (60/349); $p = 0.02$].

Discussion

This sample of oncology providers from both adult and pediatric settings provided positive feedback about the potential to use the C-SCAT as a tool to guide discussions with AYAs about symptoms. From questionnaire data, providers indicated that the C-SCAT helped identify patient symptoms, including priority symptoms, helped AYAs be more engaged in discussions, and facilitated the development of symptom management plans. Their comments suggested that use of the C-SCAT might be especially helpful to generate discussion

around symptoms not typically discussed or volunteered by the patient. A few providers commented on the usefulness of identifying relationships between symptoms.

Previous research shows that AYAs' supportive care needs are often unmet and their distress is underestimated by providers.¹⁵ Challenges in communication between AYAs and their providers may be due to AYAs' developing cognitive and decision-making skills and varying preferences for involvement and information-sharing.¹⁶ AYAs may need more support to become engaged and motivated partners in health care and communicate about their needs for information and resources.¹⁷ A tool such as the C-SCAT, developed for AYAs, may promote their engagement in discussions about symptoms and facilitate collaboration on developing symptom management plans with their provider.

Providing the opportunity for AYAs to illustrate and share their personal symptom experience with their provider using the C-SCAT may also enhance "connectedness" in the AYA-provider relationship. AYAs value the feeling of "connectedness" with their provider, which they describe as having mutual feelings of empathy, caring, trust, and being respected as an individual. When AYAs feel connected with their provider, they are more likely to feel empowered and have confidence to express their needs.¹⁵

The C-SCAT was helpful to open communication between patient and provider, particularly regarding symptoms that the patient might not otherwise discuss. The C-SCAT image offered the provider a visual representation of the symptom experience, and the presence of symptoms in the image allowed the provider to ask questions about various symptoms. In addition, the app offered the AYA the opportunity to “collect thoughts” regarding the symptom experience in preparation for the discussion.⁸

Prior research in other clinical specialties indicates that symptoms reported by patients are not consistently documented by providers in the EHR.¹⁸ Although overall EHR documentation of symptoms and a plan to address these symptoms was low in this study, the frequency of documentation was greater for those symptoms that AYAs designated as priority symptoms. Our previous work indicates that priority symptoms were of greater distress and severity than nonpriority symptoms,¹⁹ providing clinical relevance for designation of priority symptoms within the C-SCAT. Supporting AYAs to designate priority symptoms in advance of a provider visit may facilitate bringing those priority symptoms to the attention of providers and developing a plan to address them.

Limitations

A nonrandomized design without a control group precluded a comparison of AYA–provider encounters with and without use of the C-SCAT. Not all AYAs shared the copy of their C-SCAT image with their provider, and the reasons for this were not explored. The PQ was investigator-developed and used for the first time in this study. Not all eligible providers completed the PQ in part or in full, and reasons for noncompletion were not documented. In addition, AYAs may not have had the same provider at each visit, and the strategy for obtaining PQ responses did not evaluate whether provider perceptions of the C-SCAT changed over time with repeated exposure to use by multiple patients. As our intent was not to analyze data at the level of individual provider–patient dyads, any one provider could have participated in the study multiple times if more than one of their patients were study participants. Therefore, identification of each unique provider who participated is not germane to this discussion. Also, the limited provider documentation does not necessarily imply lack of provider attention to AYAs’ reported symptoms. Because the study did not seek to capture the discussion between AYA participants and providers regarding the symptom experience, the actual dialogue that occurred is unknown. The study also did not seek to account for individual and system-level factors that could have further affected symptom-related discussion and documentation.

Implications for further research and practice

Study results provide preliminary support for the C-SCAT’s ability to enhance communication among AYAs and their providers regarding their symptom experience. Further research is needed within the context of a randomized controlled trial to demonstrate the effectiveness of the C-SCAT as a tool to enhance attention to priority symptoms to improve symptom management among AYAs with cancer.

Perceptions from both AYAs and providers suggest opportunity for greater attention and discussion around the

patient symptom experience, specifically AYA identification of priority symptoms. Providers are encouraged to elicit the AYA’s perspective about her/his symptoms, specifically which symptoms are the most bothersome or distressing and in need of better management. Without pointed questions prompting focused attention, an AYA may struggle to articulate which symptoms are most distressing.

Conclusion

Optimizing symptom management for AYAs receiving chemotherapy requires a patient-centric approach. This study provides preliminary evidence for a heuristics-based symptom assessment tool, the C-SCAT, to enhance symptom-related communication among AYAs and providers. Although the study demonstrated the perceived usefulness and ease of use of the C-SCAT, additional research is needed to evaluate its effectiveness to improve symptom management, including symptom outcomes.

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References

1. Smith AW, Belizzi KM, Keegan TH, et al. Health-related quality of life of adolescent and young adult patients with cancer in the United States: The adolescent and young adult health outcomes and patient experience study. *J Clin Oncol*. 2013;31(17):2136–45.
2. Linder LA, Ameringer S, Baggott C, et al. Measures and methods for symptom and symptom cluster assessment in adolescents and young adults with cancer. *Semin Oncol Nurs*. 2015;31(3):206–215.
3. Woods NF, Cray L. Symptom clusters and quality of life. *Menopause*. 2013;20(1):5–7.
4. Macpherson CF, Linder LA, Ameringer S, et al. Feasibility and acceptability of an iPad application to explore symptom clusters in adolescents and young adults with cancer. *Pediatr Blood Cancer*. 2014;61(11):1996–2003.
5. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer*. 1994;30A(9):1326–36.
6. Ameringer S, Erickson JM, Macpherson CF, et al. Symptoms and symptom clusters identified by adolescents and young adults with cancer using a symptom heuristics app. *Res Nurs Health*. 2015;38(6):436–48.

7. Linder LA, Erickson JM, Stegenga K, et al. Symptom self-management strategies reported by adolescents and young adults with cancer receiving chemotherapy. *Support Care Cancer*. 2017;25(12):3793–3806.
8. Erickson JM, Ameringer S, Linder L, et al. Using a heuristic app to improve symptom self-management in adolescents and young adults with cancer. *J Adolesc Young Adult Oncol*. 2019;8(2):131–40.
9. Berry DL, Blumenstein BA, Halpenny B, et al. Enhancing patient-provider communication with the electronic self-report assessment for cancer: A randomized trial. *J Clin Oncol*. 2011;29(8):1029–35.
10. Hilarius DL, Kloeg PH, Gundy CM, Aaronson NK. Use of health-related quality-of-life assessments in daily clinical oncology nursing practice: A community hospital-based intervention study. *Cancer*, 2008;113(3):628–37.
11. Lai JS, Yount S, Beaumont JL, et al. (2015). A patient-centered symptom monitoring and reporting system for children and young adults with cancer (SyMonSAYS). *Pediatr Blood Cancer*. 2015;62(10):1813–8.
12. Venkatesh V, Bala H. Technology acceptance model 3 and a research agenda on interventions. *Decis Sci*. 2008;39(2): 273–315.
13. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2007;62(1):107–115.
14. Krippendorff, K. *Content analysis: An introduction to its methodology* (2nd ed.). Thousand Oaks, CA: Sage; 2004.
15. Phillips CR, Haase JE. A connectedness primer for healthcare providers: Adolescents/young adult cancer survivors' perspectives on behaviors that foster connectedness during cancer treatment and the resulting positive outcomes. *J Adolesc Young Adult Oncol*. 2018;7(2):174–80.
16. Siembida EJ, Bellizi KM. The doctor-patient relationship in the adolescent cancer setting: A developmentally focused literature review. *J Adolesc Young Adult Oncol*. 2015;4(3): 108–117.
17. McCarthy MC, McNeil R, Drew S, et al. Information needs of adolescent and young adult cancer patients and their parent-carers. *Support Care Cancer*. 2018;26(5):1655–64.
18. Pakhomov SV, Jacobsen SJ, Chute CG, Roger VL. Agreement between patient-reported symptoms and their documentation in the medical record. *Am J Manag Care*. 2008; 14(8):530–39.
19. Linder LA, Stegenga K, Erickson J, et al. Priority symptoms, causes, and self-management strategies reported by AYAs with cancer. *J Pain Symptom Manage*. 2019; 58(5): 774–83.

Address correspondence to:

Catherine Fiona Macpherson, PhD, RN, CPON
Inpatient Cancer Care Unit
Seattle Children's Hospital
4800 Sand Point Way NE
Seattle, WA 98105
USA

E-mail: catherine.macpherson@seattlechildrens.org