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Priority Symptoms, Causes, and Self-Management Strategies Reported by AYAs With Cancer

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Abstract

Context

Cancer and symptom experiences of adolescents and young adults (AYAs) with cancer can be highly variable, creating challenges for clinicians and researchers who seek to optimize AYAs' health outcomes. Understanding the heuristics AYAs use to designate priority symptoms can provide insight into the meaning they assign to their symptoms and self-management behaviors.

Objectives

This study described the frequency and characteristics of priority symptoms. It qualitatively explored reasons for a symptom's designation as a priority symptom, perceived causes of priority symptoms, and strategies AYAs use to manage priority symptoms.

Methods

Participants in this single-group, longitudinal study reported symptoms using a heuristics-based symptom reporting tool, the Computerized Symptom Capture Tool, at two scheduled visits for chemotherapy. AYAs designated priority symptoms and responded to three short answer questions: What makes this a priority symptom?, What do you think causes it?, and What do you do to make it better?

Results

Eighty-six AYAs, 15–29 years of age (median 19 years), identified 189 priority symptoms. Priority symptoms were of greater severity ($t = 3.43$; $P < 0.01$) and distress ($t = 4.02$; $P < 0.01$) compared with nonpriority symptoms. Lack of energy, nausea, difficulty sleeping, and pain comprised 39% of priority symptoms. Reasons for priority designation included the impact of the symptom and the attributes of the symptom. Categories of self-management strategies included “Physical Care Strategies,” “Things I take (or not),” and “Psychosocial Care Strategies.”

Conclusion

Supporting AYAs to identify their priority symptoms may facilitate a more personalized approach to care. Seeking the patient's perspective regarding priority symptoms could enhance patient-clinician collaboration in symptom management.

Key Words

Symptoms, symptom self-management, adolescents and young adults, cancer, technology

Introduction

The National Cancer Institute (NCI) defines adolescents and young adults (AYAs) as patients between the ages of 15 and 39 years based on types of cancers AYAs are more likely to acquire and evidence that indicates some of these cancers may have unique genetic and biological characteristics.¹ During the transition from adolescent, to emerging adult, to young adult, AYAs' attainment of physiological maturity, independence, and assumption of traditional adult roles in society is multidimensional and

very individual.² As a result, AYAs' cancer and symptom experiences are highly variable and dynamic, creating challenges for clinicians and researchers who seek to optimize AYAs' health outcomes.

These developmental factors have important implications for the health-related behaviors of AYAs with cancer, including how they interpret their symptoms and make self-management decisions. The heuristics, or mental rules, AYAs use to interpret their illness and symptoms are based on cognitive processing, prior experiences, cultural beliefs, and social comparisons.³ Understanding AYAs' symptom heuristics can provide insight into their self-management behaviors and the meaning they assign to their symptoms.

To partner with AYAs in managing their symptoms, providers need a consistent approach to elicit the symptoms AYAs are experiencing, including those which are of priority to them. Standard approaches to symptom assessment with AYAs with cancer do not exist. Measures and indices of symptoms and symptom burden have been developed for adults with varying types of cancer.^{4, 5, 6, 7, 8, 9} The development of many of these measures included patient perspectives around the most bothersome and most important symptoms. Although the measures were developed around the concept of priority symptoms, many of these measures are intended to provide an overall assessment, or score, of the patient's overall symptom burden, health-related quality of life, and response to treatment. Although patient perceptions and priorities in symptom assessment and management are encouraged,^{10, 11} reports soliciting patient priorities at the individual level within a clinical encounter are lacking.

A recent study asked women with recurrent ovarian cancer to identify the top three symptoms for which they would like to get better control, that is, what are their priority symptoms.¹² Provider documentation and management of priority symptoms were then examined. Although the top four priority symptoms (fatigue, peripheral neuropathy, sleep disturbances, and pain) reported by women were also most frequently documented by providers, 53% of all priority symptoms were not documented by the provider. This lack of documentation suggests that providers may not specifically ask patients to assign priority to their symptoms.

Having AYAs identify their own priority symptoms, the symptoms that are most important to them, is consistent with the concept of personalized health care. Personalized medicine is defined by the National Institutes of Health as “an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.”¹³ Personalized health care is the broader term and is defined as “the tailoring of medical management and patient care to the individual characteristics of each patient”¹⁴ and includes, for example, identification of patients' priorities to be used as guiding principles for collaborative care.¹⁵ In addition to medical management, the concept of personalized health care includes the self-management of symptoms. Thus, symptom self-management calls for a patient-centered approach, demonstrating the need for patients to be able to identify and voice their priority symptoms. The desire for this individualized approach has been expressed by individuals with cancer in other symptom management studies.¹⁶ The Computerized Symptom Capture Tool (C-SCAT) developed by the investigators¹⁷ allows AYAs to efficiently and precisely identify not only all symptoms they are experiencing, but more importantly, symptoms that are priorities to them.

Purpose

This study explored priority symptoms identified by AYAs receiving chemotherapy and the heuristics they use in relation to those symptoms. Specifically, this study described and compared the frequency and characteristics of priority and nonpriority symptoms. The study also qualitatively explored reasons why a given symptom was identified as a priority symptom, perceived causes of priority symptoms, and strategies AYAs use to manage priority symptoms.

Methods

Design

This study used a single-group, longitudinal, mixed-methods design in which participants reported symptoms at two scheduled visits for receipt of chemotherapy. Participants used the C-SCAT, a heuristics-based symptom reporting tool, to relate their symptom experiences during the previous 24 hours.

Sample and Setting

Eligible participants were AYAs 15–29 years of age receiving myelosuppressive chemotherapy as treatment for cancer. An age range narrower than that designated by the NCI was selected to recruit a study sample more likely to have similar life experiences compared with AYAs 30 years of age and older.^{18, 19} Participants were required to have completed at least one cycle of chemotherapy and anticipated to receive at least two additional cycles to be able to complete all study visits. Additional inclusion criteria were the ability to read, speak, and understand English and be physically and cognitively capable of completing study procedures. Participants were recruited from five academic medical centers in the Southeast, Midwest, Intermountain West, and Southwest United States treating AYAs with cancer.

Study Measure

The study measure was the C-SCAT, an investigator-developed, heuristic-based symptom reporting tool that is administered via a tablet computer.¹⁷ Users create a graphical image of their symptom experiences by selecting symptoms from a menu of 32 symptoms included in the Memorial Symptom Assessment Scale (MSAS)²⁰ that they have experienced during the previous 24 hours. They identify the perceived cause of each symptom and rate each symptom's severity and distress using the scales from the MSAS. Severity is measured on a 1–4 scale with 1 = slight to 4 = very severe. Distress is measured on a 0–4 scale with 0 = none to 4 = very much, recognizing that the presence of a symptom may or may not be perceived as distressing. Users then identify temporal and causal relationships between symptoms and have the option to designate clusters, or groups, of symptoms that they perceive to occur together. Finally, users identify priority symptoms within each cluster, “Tap the most important symptom in each group. If you did not draw any groups, tap the symptom that is most important to you.” As users designate priority symptoms, they are asked: 1) What makes this a priority symptom? and 2) What do you do to make it better? Output includes a final image ([Fig. 1](#)) and an .xml file containing text-based data.

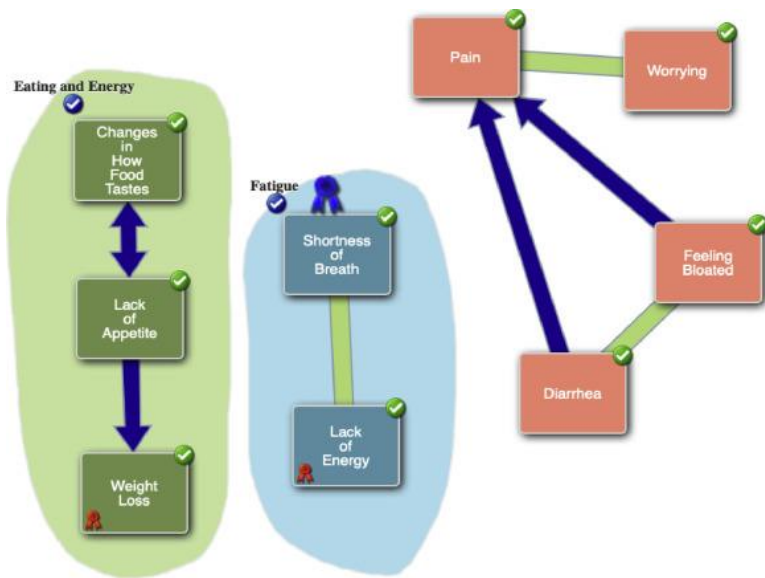


Fig. 1. C-SCAT image from a 16-year-old boy with acute lymphoblastic leukemia. The participant identified a total of nine symptoms. Green lines between symptoms indicate a perceived relationship between the symptoms. Blue arrows indicate perceived causal relationships. Five symptoms were grouped into two clusters, designated and named by the AYA, “Eating and Energy” and “Fatigue.” Priority symptoms, those perceived by the AYA as most important within each cluster, are designated with red ribbons and are “weight loss” and “lack of energy.” The priority cluster, or group of symptoms, perceived as being the most important group, “Fatigue,” is designated with a blue ribbon. AYA = adolescent and young adult; C-SCAT = Computerized Symptom Capture Tool. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

Study Procedures

Institutional review board approval was granted from each study site. Study team members routinely screened clinic and inpatient admission schedules for potentially eligible participants. Among AYAs who met preliminary screening criteria, reasons for ineligibility were most frequently related to the patient's treatment plan, specifically uncertainty about the exact number of additional chemotherapy cycles. Written assent and written parental permission were obtained for patients aged 15 to 17 years. Patients aged 18 years and older provided written informed consent. At the enrollment visit, AYAs provided baseline demographic information about themselves using Research Electronic Data Capture (REDCap).²¹ Clinical data, including diagnosis, months since initial diagnosis, and disease status, were identified through medical record review.

A study team member met with the AYA before each of the next two scheduled visits for chemotherapy administration (Visits 1 and 2) to review study procedures and be available as a resource while AYAs completed the C-SCAT. AYAs received a copy of their C-SCAT-generated image to review with their provider. They also received a gift card after each visit.

Data Management and Analysis

Quantitative Data

Demographic data from REDCap and quantitative C-SCAT-generated data were imported into SPSS files for analyses. Descriptive statistics and measures of central tendency characterized the study sample

and the frequencies of symptoms, priority symptoms, and their associated characteristics. Independent-sample t-tests compared the severity and associated distress of priority versus nonpriority symptoms. Chi-square analyses compared differences in frequencies of categories of AYAs' responses.

Qualitative Data

Qualitative data from C-SCAT files were organized into Excel files to support coding procedures. Qualitative content analysis procedures^{22, 23} were used to analyze AYAs reported: 1) reasons for designating a given symptom as a priority symptom, 2) perceived causes of the priority symptom, and 3) strategies used to alleviate the symptom. Authors reviewed responses across questions to gain a sense of the data as a whole and perspective of how responses to one question may have also been reflected in responses to the other two questions. Each question was then analyzed independently with individual responses treated as the unit of analysis.^{22, 23} Four investigators (L. A. L., C. F. M., A. R. N., K. S.) reviewed data independently and assigned preliminary codes. They then met together to review codes. Discrepancies were infrequent and were resolved through discussion to reach consensus for all coded responses. Codes were further organized into categories and subcategories.

Results

Participants

Eighty-eight AYAs enrolled in the study, and 86 completed at least one C-SCAT visit. Recruitment rates averaged 76% across sites. The most frequent reason for declining was lack of interest. Reasons for withdrawal included completion of therapy before C-SCAT visits could be completed and a parent's decision to withdraw his son after further reviewing the parental permission and participant assent documents. Participants were a median of 19 years of age (range 15–29), and a median of five months (range 1–48) since initial diagnosis. Demographic characteristics of AYAs who completed at least one C-SCAT visit are included in [Table 1](#).

Table 1. Participant Characteristics

Characteristic	N	%	Mean (SD)	Median	Range
Gender					
Male	45	52.3			
Female	41	47.7			
Age (yrs)			21 (5.0)	19	15–29
Age group					
Adolescent (15–18 yrs)	40	46.5			
Young Adult (19–29 yrs)	46	53.5			
Race					
White	61	70.9			
Other/more than one race	12	14			
African-American	10	11.6			
Native American/Alaska Native	2	2.3			
Asian	1	1.2			
Ethnicity					
Non-Hispanic	67	77.9			

Hispanic	19	22.1			
Diagnosis					
Acute lymphoblastic leukemia	27	31.3			
Hodgkin lymphoma	13	15.1			
Sarcoma	10	11.6			
Brain tumor	8	9.3			
Breast cancer	7	8.1			
Non-Hodgkin lymphoma	7	8.1			
Acute promyelocytic leukemia	4	4.7			
Other	4	4.7			
Acute myelogenous leukemia	3	3.5			
Chronic myelogenous leukemia	3	3.5			
Disease status					
Initial diagnosis	82	95.3			
Relapsed/refractory disease	3	3.5			
Secondary	1	1.2			
Months since initial diagnosis			11.7 (13.1)	5	1–48

Symptoms

At Visit 1, AYAs reported a total of 468 symptoms (mean = 5.44; SD = 4; range = 0–15). Eighty-nine of these symptoms were designated as priority symptoms (median = 1; range = 0–3). At Visit 2, AYAs reported a total of 377 symptoms (mean 4.44; SD = 3.8; range 0–18). Eighty of these symptoms were designated as priority symptoms (median = 1; range = 0–3). [Table 2](#) reports the most frequently reported symptoms.

Table 2. Most Frequently Reported Symptoms Across Visits

Symptom	<i>n</i>
Lack of energy	71
Feeling drowsy	53
Difficulty sleeping	52
Pain	51
Nausea	48
Hair loss	46
Feeling irritable	38
Changes in how food tastes	37
Lack of appetite	33
Tingling in hands/feet	33

Twenty-nine of the 32 symptoms included in the C-SCAT were designated as a priority symptom at least once. Priority symptoms were reported as more severe ($t = 3.43$; $P < 0.01$) and distressing ($t = 4.02$; $P < 0.01$) compared with nonpriority symptoms. Priority symptoms were of moderate or greater severity on 83% of occasions and of somewhat or greater distress on 68% of occasions. [Fig. 2](#) summarizes the 11 most frequent priority symptoms across visits along with the occasions each

priority symptom was rated as of moderate or greater severity and distress. Three symptoms were never named as priority symptoms: dry mouth, problems with urination, and swelling in arms and legs.

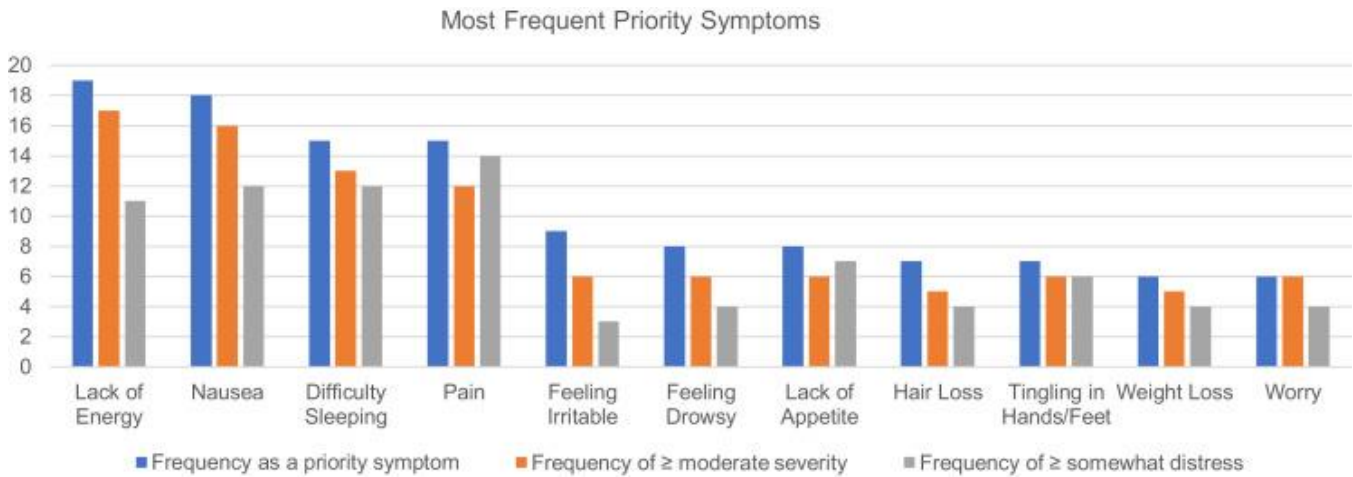


Fig. 2. Summary of most frequent priority symptoms and frequency with which these symptoms were of moderate or greater severity and somewhat or greater distress.

Lack of energy, nausea, difficulty sleeping, and pain comprised 39% of all reported priority symptoms. For these four symptoms, severity and distress did not differ based on priority designation (Table 3). These symptoms were also of moderate or greater severity on more than 80% of reported occasions regardless of priority designation.

Table 3. Comparison of Symptom Severity and Distress for Four Most Frequent Priority Symptoms

Priority Symptom	Mean Severity (SD) ^a		Mean Distress (SD) ^b	
	Priority	Nonpriority	Priority	Nonpriority
Lack of energy	2.3 (0.7)	2.1 (0.7)	1.8 (0.8)	1.9 (1.2)
Nausea	2.2 (0.71)	2.2 (0.8)	2.4 (1.3)	2.0 (1.1)
Difficulty sleeping	2.2 (0.8)	2.0 (0.7)	2.2 (0.9)	1.9 (1.2)
Pain	2.6 (1.0)	2.3 (0.7)	2.7 (0.8)	2.4 (1.2)

^aDifferences in severity not statistically significant based on priority/nonpriority designation.

^bDifferences in distress not statistically significant based on priority/nonpriority designation.

Reasons for Designating a Symptom as Priority

Participants provided 153 responses to the question, “What makes this a priority symptom?” These responses were organized into 158 codes that were organized into three categories (Impact of Symptoms, Attributes of Symptoms, Don't Know) and seven subcategories (Table 4). Definitions of categories and subcategories arose from the AYAs' responses. Post hoc comparisons indicated that AYAs' reasons for designating a symptom as priority did not differ based on the visit (Visit 1 vs. Visit 2) ($X^2 = 2.66$; $P = 0.85$). Reasons for designating a symptom as priority also did not differ based on whether the symptom was one of the four most frequently reported priority symptoms versus the other priority symptoms ($X^2 = 8.94$; $P = 0.18$).

Table 4. Categories and Subcategories of Reasons for a Symptom's Designation as Priority

Categories and Subcategories	Frequency (%)	Example
Impact of the symptom	101 (63.9)	
Physical impact	36	<p>"Nausea makes me feel sick and it decreases my appetite" (Nausea, 16 y/o F with Hodgkin lymphoma [HL])</p> <p>"It makes the rest of my body weaker" (Lack of energy, 19 y/o M with rhabdomyosarcoma [RMS])</p> <p>"It makes me feel bloated and nauseous" (Constipation, 19 y/o M with RMS)</p>
Well-being	34	<p>"I need sleep and energy to get better" (Difficulty sleeping, 15 y/o M with acute lymphoblastic leukemia [ALL])</p> <p>"Interferes with interpersonal interactions, not as even-tempered as usual" (Feeling irritable, 29 y/o F with breast cancer)</p>
Functional status	16	<p>"Because I can't do basic daily activities such as cooking" (Lack of energy, 28 y/o F with breast cancer)</p> <p>"I need to think clearly, focus, and be concentrated in day-to-day life" (Difficulty concentrating, 16 y/o M with ALL)</p>
Emotional impact	15	<p>"Anxious about appointments" (Difficulty sleeping, 29 y/o F with metastatic adenocarcinoma)</p> <p>"This was my biggest fear" (Hair loss, 23 y/o M with ALL)</p>
Attributes of the symptom	56 (35.4)	
Severity/distress	34	<p>"It makes me feel the worst" (Nausea and constipation, 17 y/o F with HL)</p> <p>"Pain is the most noticeable" (Pain, 23 y/o F with non-Hodgkin lymphoma [NHL])</p> <p>"It bothers me the most" (Feeling bloated, 17 y/o F with HL)</p>
Causes the others	11	<p>"Causes the rest of the symptoms" (Difficulty sleeping, 29 y/o F with ALL)</p> <p>"I believe it leads to the rest" (Worrying, 28 y/o F with breast cancer)</p> <p>"It causes the other symptoms" (Changes in how food tastes, 16 y/o F with sarcoma)</p>
Temporality	11	<p>"Most prevalent" (Feeling bloated and lack of energy, 24 y/o male with HL)</p> <p>"Constant symptom" (Vomiting, 25 y/o F with acute promyelocytic leukemia)</p> <p>"I have felt this during the whole cancer process" (Feeling sad, 26 y/o F with NHL)</p>
Don't know	1 (1.0)	

The Impact of Symptoms category ($n = 101$) included four subcategories. Physical impact ($n = 36$) was most frequently named and reflected the immediate physical consequences of the symptom such as, “If nauseous then that causes me to throw up,” (15-year-old boy with acute lymphoblastic leukemia [ALL]). Well-being ($n = 34$) encompassed AYAs' awareness of what they perceived to be healthy behaviors and how the given symptom affected these behaviors, “I need good sleep,” (29-year-old woman with adenocarcinoma).

Priority symptoms adversely impacted AYAs' functional status ($n = 16$), that is, their ability to perform expected day-to-day roles, such as “Makes doing daily activities difficult,” (26-year-old man with ALL). The emotional impact of the symptom ($n = 15$), such as “I miss my hair” (23-year-old man with ALL), also resulted in its designation as a priority symptom.

The Attributes of Symptoms category ($n = 56$) contained three subcategories. The severity and/or distress associated with a given symptom ($n = 34$), as in “It bothers me the most” (17-year-old girl with Hodgkin lymphoma), was the most frequently reported attribute. Other named attributes of a symptom that resulted in its designation as a priority symptom included its perception as a symptom that caused other symptoms ($n = 11$), “I believe it leads to [the] rest,” (28-year-old woman with breast cancer) or its temporality, that is, its persistence or frequency over time ($n = 11$), “It happens every day” (26-year-old woman with a brain tumor).

Perceived Causes of Priority Symptoms

AYAs provided 123 responses to the question, “What do you think caused it [the priority symptom]?” These responses were organized into 135 codes that were further organized into four categories: chemotherapy/treatment ($n = 91$), other health conditions ($n = 22$), psychosocial factors ($n = 11$), and don't know ([Table 5](#)). Post hoc comparison of frequencies of perceived causes did not differ based on the visit ($X^2 = 4.64$; $P = 0.20$) or whether a symptom was one of the four most frequently reported priority symptoms versus the other priority symptoms ($X^2 = 1.40$; $P = 0.71$).

Table 5. Categories and Subcategories of Perceived Causes of Priority Symptoms

Categories/Subcategories	Frequency (%)	Example
Chemotherapy/Treatment	91 (67.4)	
Medications	71	“Chemo” or “chemotherapy” (multiple patients with various diagnoses) “My medicine” (Lack of energy, 17 y/o M with brain cancer) “Meranol” (Difficulty sleeping, 15 y/o M with acute lymphoblastic leukemia [ALL])
Cancer and treatment-related symptoms	11	“Feet pain possibly caused by vincristine” (Pain, 16 y/o F with non-Hodgkin lymphoma [NHL]) “Hair loss” (Don't look like myself, 16 y/o F with NHL)
Experience of going through treatment	9	“Tough scheduling appointments every day ...” (Difficulty sleeping, 19 y/o M with

		rhabdomyosarcoma [RMS]) "Surgery ..." (Tingling in hands, 20 y/o M with RMS)
Other physical condition	22 (16.3)	"Dizziness" (Nausea, 17 y/o M with NHL) "Back problems" (Pain, 28 y/o F with ALL)
Psychosocial cause	11 (8.1)	"Anxiety" (Nausea, 23 y/o F with NHL) "Mixed emotions from chemotherapy" (Worrying, 16 y/o F with NHL)
Don't know	11 (8.1)	

The medications that AYAs were receiving as part of their cancer treatment, such as "chemo," "vincristine," and "going off prednisone," predominated as perceived causes. AYAs also identified other cancer-related symptoms as causing priority symptoms such as "lack of sleep" as causing fatigue and "lack of appetite" causing weight loss. The larger cancer and treatment experience was also reflected in perceived causes such as "The whole process I have to go through" and "Tough scheduling for appointments everyday."

Although less frequently reported, AYAs' responses included other health conditions that were not specific to their cancer. These included perceived causes such as "allergies," "Crohn's disease," and "back problems." Psychosocial factors perceived as causes of priority symptoms included "stress," "anxiety," "scary thoughts," and "circumstances." Eleven responses included "don't know" as the perceived cause.

Strategies for Self-Managing Priority Symptoms

AYAs provided 140 responses to the question "What do you do to make it [the priority symptom] better? These responses were organized into 174 codes that were further organized into five categories: "Physical Care Strategies," "Something I Take (or not)," "Psychosocial care Strategies," "Nothing," and "Don't Know" (Table 6). Post hoc comparison of frequencies of self-management strategies did not differ based on the visit ($X^2 = 2.39$; $P = 0.79$). Self-management strategy frequencies differed based on whether a symptom was one of the four most frequently reported priority symptoms ($X^2 = 19.44$; $P < 0.01$). AYAs more frequently reported taking medications (or not) to manage nausea, pain, and difficulty sleeping. Psychosocial strategies were more frequently reported to manage the less prevalent priority symptoms, particularly those with a psychological component, such as feeling irritable, worrying, and feeling nervous.

Table 6. Categories of Strategies for Self-Managing Priority Symptoms

Categories	Frequency (%)	Example
Physical care strategies	101 (59.4)	"Try to relax or sit down" (Pain, 16 y/o F with non-Hodgkin lymphoma [NHL]) "Ice, rest, massage, acupuncture" (Pain, 29 y/o F with acute lymphoblastic leukemia [ALL]) "Just eat the foods I can" (Changes in how food tastes, 16 y/o F with sarcoma)

		“Shorter activity or more recovery, take it easier when exercising” (Shortness of breath, 29 y/o F with breast cancer)
Things I take (or not)	42 (24.7)	“Take medicine” (Nausea, 15 y/o M with ALL) “Sometimes not taking my pills” (Difficulty sleeping, 19 y/o M with ALL) “Take Miralax or another laxative” (Constipation, 17 y/o F with NHL)
Psychosocial care strategies	19 (11.2)	“Distract myself with music” (Worrying, 28 y/o F with breast cancer) “Try to relax and think” (Difficulty concentrating, 16 y/o M with ALL) “Reframe angry thoughts” (Feeling irritable, 29 y/o female with breast cancer)
Nothing	10 (4.1)	“Nothing” “Can't do much right now” (Don't look like myself, 17 y/o F with NHL)
Don't know	2 (1.0)	“No idea” (Difficulty concentrating, 16 y/o M with rhabdomyosarcoma)

Physical care strategies were most frequently reported ($n = 101$) and reflected a variety of efforts including managing rest and activity, adjusting eating habits, and the use of integrative therapies. “Something I take (or not)” ($n = 42$) included both prescribed and over-the-counter medications, particularly for managing pain and nausea. Responses also reflected AYAs' choices in relation to their medications. These choices included intentional nonadherence to prescribed treatment-related medications, for example, one AYA reported, “Sometimes not taking my medicine,” to alleviate difficulty sleeping. Another AYA related how she made choices with a prescribed pain medication in an effort to alleviate constipation, “Reduce Oxy intake and take Miralax.”

Psychosocial care strategies ($n = 19$) included both intrapersonal efforts, such as “Reframe angry thoughts,” and interpersonal strategies, “Being with family.” Ten responses indicated a lack of an effective self-management strategy either as “nothing” or ineffective past efforts such as, “I've try some thing (sic) but nothing seems to work.”

Discussion

This study explored symptoms reported by AYAs with cancer before receiving a cycle of chemotherapy and specifically sought insight into the symptoms the AYAs identified as “priority symptoms.” Consistent with previous reports, AYAs reported multiple symptoms during treatment, with some participants reporting over 15 concurrent symptoms.^{24, 25, 26} This high number is especially concerning because symptom self-reports were collected before the administration of chemotherapy, a time when the presence of symptoms is expected to be low.

Fatigue, difficulty sleeping, nausea, and pain were the most frequent priority symptoms and among the most frequently reported symptoms overall. Given that these symptoms contribute to a higher symptom burden^{27, 28, 29} and that they were of moderate or greater severity more than 80% of

reported occasions, a report of these symptoms warrants clinician attention regardless of priority designation.

Not expected was the finding that all but three symptoms included in the C-SCAT were identified by AYAs as priority symptoms at least once. These symptoms included other physical symptoms, such as lack of appetite, hair loss, and tingling in hands and feet, as well as psychological symptoms and responses, such as worry and feeling irritable. Furthermore, this research indicates that the priority symptoms AYAs identified were not always apparent.²⁴ For example, one cluster of symptoms that an AYA identified included dizziness, dry mouth, and feeling drowsy. The priority symptom was feeling drowsy, which is not obvious and would require further assessment. Although symptoms such as hair loss may not have a present remedy, acknowledging their presence and significance to the AYA may be a “solution” in and of itself. In addition, the clinician could recommend resources to help alleviate distress associated with the symptom.

Study findings also emphasize the relevance of inquiring about the reason for a symptom's designation of priority, a feature lacking in most measures that include ratings of severity and distress.^{30, 31} Most of the reasons for symptoms' priority designations were not their severity or distress but rather their effects on the body. These effects included function, as well as general physical and emotional well-being.

Consistent with results from the initial study using the C-SCAT,²⁴ priority symptoms were most frequently ascribed to cancer and cancer treatment. These findings also align with reports examining symptom experiences of adults with cancer, who largely associate their symptoms with cancer-related morbidity and treatment.³² AYAs' frequent attribution of their priority symptoms to cancer and cancer treatment underscores the need to engage and encourage them to discuss their symptom experiences. If AYAs believe their symptoms are expected or unavoidable aspects of the cancer experience, they may hesitate to address them with providers and struggle to manage them independently. As AYAs consider symptoms within the context of their illness and the medications they are required to take, they may decide not to take medications, including oral chemotherapy or other prescribed medications, as a means to manage symptoms.^{33, 34} Viewing nonadherence behaviors in the context of symptom self-management rather than regarding them as irrational acts of noncompliance may support clinicians in gaining a greater understanding of the AYA's perspective. Exploring with AYAs not only the symptoms they are experiencing, but also what they believe is causing them, is an integral part of patient-centered symptom assessment and management and supporting patients in symptom self-management.

AYAs' self-management strategies for priority symptoms were also consistent with those reported in the initial study using the C-SCAT³⁵ and reflect AYAs' individual preferences and approaches. Although medications were frequently reported, particularly for nausea, pain, and difficulty sleeping, most strategies were ones that do not require a prescription. Many also align with evidence-based guidelines such as balancing activity and rest. Strategies also reflected some AYAs' interest in incorporating integrative therapies for symptom self-management. Clinicians need to be aware of the range of AYAs' symptom self-management strategies and to ask about perceived efficacy.

Study results suggest value in clinicians using a structured approach to symptom assessment and management and add to the literature addressing the role of electronically administered patient-reported outcome measures.^{36, 37} These resources may improve efficiency with regards to collecting patient-reported measures to support a more patient-centric approach to care. Adopting a patient-centered approach that acknowledges the priority symptom/s of the AYA, rather than the clinician, as well as the AYA's current self-management strategies and their perceived efficacy supports a more personalized approach to symptom assessment and may enhance patient-clinician collaboration in symptom management.

A limitation of this study is the manner in which AYAs designated priority symptoms. The C-SCAT allowed users to designate only one priority symptom within each identified cluster. As a consequence, priority symptoms may not have been based on rank order. Users who reported more than one symptom but did not identify a cluster could designate only one priority symptom.

Although the C-SCAT has not undergone psychometric evaluation, it includes symptoms and rating scales included in the MSAS, a tool with established reliability and validity.²⁰ In addition, the C-SCAT's larger focus is not to measure a distinct construct but rather to identify the individual AYA's distinct perspective of his/her symptom experience including perceived relationships between symptoms.

This study demonstrates the C-SCAT's potential to support a personalized approach to symptom management through the identification of priority symptoms and the heuristics AYAs use in designating priority symptoms. Emphasizing priority symptoms will guide clinicians to a greater understanding of the negative impact of symptoms on AYAs' daily lives and foster more meaningful personalized interventions to enhance their quality of life. Future studies should evaluate the efficacy of the C-SCAT to facilitate improved symptom outcomes.

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