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Development and psychometric evaluation of the Symptom Self-Management Behaviors Tool for adolescents/young adults with cancer

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Abstract

Objectives. Adolescents and Young Adults (AYAs) with cancer experience symptoms related to disease and treatment. To manage these symptoms, they need to develop self-management behaviors, yet no tool exists to assess these behaviors. The Symptom Self-Management Behaviors Tool (SSMBT) was developed to meet this need.

Methods. The study consisted of 2 phases. Phase 1 evaluated content validity, and Phase 2 evaluated reliability and validity. The SSMBT initially contained 14 items with 2 dimensions: (1) behaviors used to Manage Symptoms and (2) behaviors used to communicate with providers regarding symptoms. Four oncology professionals and 5 AYAs with cancer assessed the content validity. Evaluation of reliability and validity involved 61 AYAs with cancer. Reliability was evaluated using Cronbach's alpha. Construct validity was assessed with factor analysis. Discriminant validity was assessed using associations with symptom severity and distress.

Results. Content validity evaluation supported the importance of the items. Factor analysis supported a two-factor structure: Manage Symptoms (8 items) and Communicate with Healthcare Providers (4 items) subscales. Internal consistency reliability for the total SSMBT was acceptable with Cronbach's alpha = 0.74. Cronbach's alpha value for the Manage Symptoms subscale was $\alpha = 0.69$ and for the Communicate with Healthcare Providers subscale was $\alpha = 0.78$. The SSMBT total and the Manage Symptoms subscale scores were moderately correlated with symptom severity (r = 0.35, p = 0.014; r = 0.44, p = 0.002, respectively), partially supporting discriminant validity.

Significance of results. Systematic assessment of behaviors AYAs use is critical for clinical practice and evaluate interventions to improve self-management. The SSMBT demonstrates initial reliability and validity but requires further evaluation for clinical interpretation and future use.

Introduction

Adolescents and young adults (AYAs) with cancer experience multiple symptoms from their disease and its treatment, and management of these symptoms is important for optimal quality of life. Common symptoms include lack of energy, nausea, hair loss, feeling drowsy, and difficulty sleeping (Erickson et al. 2019). Most symptoms subside once treatment is completed; however, some, such as fatigue, worry, and sexual dysfunction, may persist for months or years (Galán et al. 2018; Lea et al. 2020).

AYAs with cancer benefit from learning self-management strategies to cope with their symptoms across the disease trajectory. Self-management is the process by which individuals and families use knowledge, beliefs, skills, and abilities to achieve health-related outcomes (Ryan and Sawin 2009). As set forth in the Individual and Family Self-Management Theory (IFSMT) by Ryan and Sawin (2009), developmental stage is an individual factor that can enhance or diminish engagement in self-management behaviors. In the IFSMT, self-management behavior is an outcome of this process. Distinct from processes, behaviors are actions or activities that can be observed or measured (https://psychologydictionary.org/behavior/).

Symptom self-management is one aspect of self-management, where efforts are specifically directed toward recognizing, preventing, and relieving symptoms (Hoffman 2013). Per the IFSMT, better symptom self-management is hypothesized to improve symptoms.



While there is little research specifically for AYAs, research with adults has demonstrated an association between symptom selfmanagement behaviors and reduced symptom severity (Berry et al. 2014) and symptom distress (Mooney et al. 2017).

Symptom self-management research involving adults with cancer tends to focus on single symptoms (Chan et al. 2016; Hoffman et al. 2013) or interventions to mitigate individual symptoms. Study outcomes commonly examine related self-management variables of self-efficacy, patient activation, or multidimensional aspects of individual symptoms, such as with the Patient Reported Outcomes Measurement Information System (Crafoord et al. 2020; Knoerl et al. 2019; Mooney et al. 2017). No instrument exists to measure symptom self-management behaviors as a proximal outcome in symptom management for a population of cancer patients.

Self-management has been studied in AYAs with cancer (Jibb et al. 2017; Linder et al. 2017; Stinson et al. 2015), but no instruments are available to measure symptom self-management behaviors. Generic instruments measure adolescents' independence in performing health behaviors to manage chronic illness as they transition to independent living (Ferris et al. 2012; Sawin et al. 2018); however, these instruments emphasize disease and life management, rather than symptom management. Development of an instrument to measure symptom self-management behaviors is important to advance research to improve symptom self-management among AYAs with cancer.

This paper outlines the development and psychometric evaluation of a new instrument to assess symptom self-management behaviors in AYAs with cancer: the Symptom Self-Management Behavior Tool (SSMBT). The psychometric evaluation of the SSMBT consisted of 2 phases: Phase 1 was evaluation of content validity, and Phase 2 was evaluation of the psychometric properties including internal consistency reliability and construct validity, assessed via factor analysis and discriminant validity.

Phase 1: content validity evaluation

Methods

Conceptualization and preliminary development

The SSMBT was developed based on a review of the literature (Galassi et al. 1992; Heidrich et al. 2009; Hibbard et al. 2005; Maly et al. 1998) and our previous work (Linder et al. 2017, 2019a). We conceptualized symptom self-management behaviors as having 2 dimensions: (1) behaviors to Manage Symptoms and (2) behaviors to Communicate with Health-care Providers (HCP) regarding symptoms. Eight items addressed the managing symptoms dimension, and 6 items addressed the communicating with HCP dimension. Response options are on a scale from 0 (*never/rarely*) to 4 (*always*). We conceptualized that a higher score would indicate more frequent engagement in self-management behaviors.

Design, sample, and setting

Content validity was evaluated via a content review survey (CRS) and qualitative interviews. Both oncology professionals and AYAs with cancer completed the CRS. AYAs with cancer also completed qualitative interviews.

AYA oncology professionals who provide care to AYAs with cancer at 5 United States-based institutions were invited to participate. AYAs were recruited from a Children's Oncology Group affiliated children's hospital in the Midwest. Eligible AYAs were (1) 15–29 years of age, (2) currently receiving or completed cancer treatment, and (3) able to speak and understand English. We planned to exclude AYAs with cognitive or developmental disabilities if that limited their ability to understand instrument items or participate in study-related procedures. However, this did not occur.

Institutional review board approval was granted for the study. AYA oncology professionals received an electronic cover letter, indicating that returning a completed CRS implied informed consent. Potential AYA participants were screened for eligibility by research staff. Then, parents of minors provided written permission for their adolescent's participation, and minors provided written assent. Adult AYAs provided written informed consent.

Measures

Content review survey. The CRS assessed both the importance and clarity of each item of the SSMBT using 2 separate 4-point scales (1 = not important/not clear at all to 4 = extremely important/very clear) The survey also solicits suggestions to improve the clarity of items and to propose additional symptom self-management behaviors for inclusion.

Semi-structured interview. Interviews with AYAs consisted of open-ended questions exploring their CRS ratings of importance and clarity.

Procedures

Five AYA oncology professionals were sent an email requesting their participation in the study. Those who agreed received study materials via email. Materials included the SSMBT and the CRS, along with instructions on how to complete the CRS.

Recruitment of AYAs was restricted due to the SARS-CoV pandemic. AYAs received a study flyer from their oncology team and were asked if they could be contacted by study staff. Consent/permission/assent was obtained by telephone. Then AYAs were interviewed to learn about their self-management strategies. Upon completion of the interview, the CRS was emailed to the AYA. AYAs completed the CRS while on the call to allow the researcher and respondent to ask clarifying questions and avoid missing data. The telephone call was recorded.

Analytic approach

For the CRS, mean scores on importance and clarity ratings from the AYA oncology professionals were calculated for each item. Items with mean scores of 3.0 or higher on importance would be retained. For clarity, items with mean scores of 3.0 would be considered acceptable; however, suggestions for improvement would be considered (Polit and Beck 2006). Prior to having the AYAs complete their CRS, the SSMBT was edited based on the oncology professionals' assessment. Data from the AYA-completed CRS were evaluated in the same way.

Results

Participants

Four of the 5 AYA oncology professionals returned completed CRS forms. All were female, based in academic settings, and 3 also held clinical practice positions. Five AYAs, ages 15–21 years of age, completed Phase 1. Three were female, 3 were Hispanic or Latino, and 3 were currently receiving treatment.

CRS results from oncology professionals

All 14 items had mean scores greater than 3.0 for both importance and clarity, so no items were deleted based on CRS scores. Several items were modified to improve clarity (such as rewording "I try a NEW activity" to "I try an activity that I have never tried before" as AYAs felt that was clearer).

CRS results from AYAs

All 14 items had mean scores higher than 3.0 for both importance and clarity. Based on feedback, 2 items were deleted from the "communicate with HCPs regarding symptoms" dimension because the AYAs perceived redundancy. The final SSMBT contained 12 items.

Phase 2: psychometric evaluation

Design, setting, and sample

This phase used a cross-sectional, correlational design to evaluate the factor structure, internal consistency reliability, and discriminant validity of the SSMBT. Recruitment occurred at the same site as Phase 1. Eligibility requirements were the same as Phase 1, and AYAs who participated in Phase 1 could participate in Phase 2. The target sample size was 60 AYAs based on a sample size of 5 participants per item recommended for factor analysis (Guadagnoli and Velicer 1988).

Measures

Symptom Self-Management Behaviors Tool

The SSMBT consists of 2 dimensions: (1) behaviors used to Manage Symptoms (8 items), and (2) behaviors used to Communicate with HCPs regarding symptoms (4 items). Items are scored using a 5-point scale (0 = never/rarely to 4 = always). Scores are summed across items. Higher scores indicate more frequent engagement in symptom self-management behaviors.

Memorial Symptom Assessment Scale

Based on the IFSMT's proposed relationships between symptom self-management and the symptom experience, measures of symptom severity and distress were used to assess discriminant validity. The Memorial Symptom Assessment Scale (MSAS) is a self-report 32-item instrument that assesses the severity and distress of each of the cancer symptoms that the individual is experiencing (Portenoy et al. 1994). Participants rate severity on a 4-point scale (1 = slightly to $4 = very \ severe$) and distress on a 5-point scale (0 = none to $4 = very \ much$). Mean scores for severity and distress were used in the analyses.

Procedures

AYA participants completed the SSMBT, MSAS, and a demographic form. Participants could complete study measures inperson on a tablet computer or later through a secure link sent via email. Data were collected in Research Electronic Data Capture (REDCap) hosted at Children's Mercy, Kansas City (Harris et al. 2019). Periodic reminders were sent via REDCap to those AYAs who had not completed study measures.

Analytic approach

Internal consistency reliability of the SSMBT was estimated using Cronbach's alpha, which is an adequate approach to estimating reliability for a single test with a single administration (Sijtsma and van der Ark 2015). Construct validity was evaluated using factor analysis and discriminant validity. For factor analysis, a principal component factor analysis with oblique rotation was used. First, a scree plot was used to confirm the number of factors. Next, the factor analysis was run on the 12 items.

We examined discriminant validity using Pearson's correlation between the SSMBT and MSAS symptom severity and MSAS symptom distress. Discriminant validity assesses the distinctiveness of related constructs; thus, the constructs are expected to have low to moderate correlations (Jensen 2003). Because symptom distress and severity should be constructs that are distinct from but related to symptom self-management behaviors, we expect correlations between the constructs to be low to moderate. Data from participants who reported at least 2 symptoms using the MSAS were included in the discriminant validity test to be able to calculate mean symptom severity and distress scores. Analyses were completed using JMP Statistical software 16.0. (JMP*^{FEOF} 2021).

Results

Participants

Eighty-three AYAs were approached, 11 declined, 72 enrolled, and 61 completed study measures. Reasons for non-completion included 1 death, 1 who was no longer interested, and 9 who did not respond despite repeated contact. Feedback from participants who did complete indicated that they often forgot about the surveys and appreciated the reminder emails. Mean age of participants was 17 years (SD = 1.5; range 15–21 years); 56% were receiving treatment, 49% were female, 23% were Latino, and 10% were Black/African American (Table 1).

Validity

Factor analysis. Construct validity of the SSMBT was first examined via principal component factor analysis with oblique rotation. Because the SSMBT intended to assess 2 dimensions of self-management, a 2-factor solution was pursued to confirm the conceptual structure. The scree plot supported the 2-factor solution, with the first 2 factors explaining 17% and 22% of the variance for a total of 39% of the variance explained and the leveling of eigenvalues on the scree plot after 2 factors. Based on the factor analysis and conceptual underpinnings, the scale appears to have 2 subscales: Manage Symptoms and Communicate with HCP. All items that loaded on factor 1 were from the Manage Symptoms subscale, and all had factor loadings greater than the recommended minimum of 0.30 (Guadagnoli and Velicer 1988). All items that loaded on factor 2 were from the Communicate with HCP subscale and had factor loadings greater than 0.30 (Table 2). One item from the Manage Symptoms subscale, "change/skip medicine" did not load on either factor. However, this item was retained because of recommendations from HCPs and AYAs during the content validity phase.

One item (talk to HCP about the symptom) loaded nearly equally on both factor 1 and factor 2 (0.45 and 0.43, respectively). Because it loaded similarly on both factors, we performed a maximum likelihood estimation and compared the 2 solutions and then repeated the calculation with a different number of factors. This process did not lead to a clearer computational solution as to which factor the item belonged. Therefore, we opted to place this item in factor 1 due to its conceptual fit.

Reliability

The Cronbach's alpha reliability coefficient for the SSMBT total scale was 0.74, for the Manage Symptom subscale was 0.69, and for the Communicate with HCP subscale was 0.78 (Table 3). For the

Table 1. Phase 1 and 2 sample characteristics

| | Pha | ise 1 | Pha | se 2 |
|--------------------------------|-----|-------|-----|------|
| Characteristic | n | % | n | % |
| Gender | | | | |
| Male | 2 | 40 | 30 | 49 |
| Female | 3 | 60 | 31 | 51 |
| Race | | | | |
| American Indian/Alaskan Native | | | 1 | 2 |
| Asian | | | 1 | 2 |
| Black/African American | | | 6 | 10 |
| White | 4 | 80 | 53 | 86 |
| More than one race | 1 | 20 | | |
| Ethnicity | | | | |
| Hispanic | 3 | 60 | 14 | 23 |
| Non-Hispanic | 2 | 40 | 46 | 77 |
| Diagnosis | | | | |
| Leukemia | 2 | 40 | 17 | 28 |
| Lymphoma | 1 | 20 | 16 | 26 |
| Solid tumor | 1 | 20 | 10 | 16 |
| Brain tumor | | | 6 | 10 |
| Bone tumor | 1 | 20 | 7 | 12 |
| Cancer, type not specified | | | 5 | 8 |
| Treatment status | | | | |
| Completed treatment | 3 | 60 | 27 | 44 |
| Receiving treatment | 2 | 40 | 34 | 56 |

Note. Phase 1: N = 5. Participants were on average 18.0 years old (SD = 2.4). Phase 2: N = 61. Participants were on average 17.2 years old (SD = 1.5).

Manage Symptoms subscale, the Cronbach's alpha value decreased if any of the items were excluded except for the "change/skip medicine" item, in which case it increased to $\alpha = 0.71$ (from 0.69). For the Communicate with Provider subscale, the Cronbach's alpha value decreased if any of the items were excluded except for the "participation in decisions" item, in which case it increased to $\alpha = 0.79$ (from 0.78). All items were retained for 2 primary reasons: these items were endorsed by the content validity experts, and the alpha values were not affected greatly by deleting these items.

Discriminant validity. Participants reported a mean of 8 (SD = 6.2; range 0–25) symptoms using the MSAS. A total of 48 of the 61 participants reported 2 or more symptoms. Because at least 2 symptom scores are required to generate mean severity and mean distress scores, data from those 48 participants were used to evaluate discriminant validity of the SSMBT. The SSMBT total and the Manage Symptoms subscale scores both had moderate, positive correlations with the MSAS symptom severity scores (r = 0.35, p = 0.014; r = 0.44, p = 0.002, respectively). The correlations between the SSMBT total and Manage Symptoms subscale scores and the MSAS distress scores were low and positive (r = 0.19, p = 0.19; r = 0.25, p = 0.09; respectively). These low to moderate correlations between the SSMBT scores and MSAS severity and distress

| Table 2. Means, standard deviations, rotated factor loadings, and communali | - |
|---|---|
| ties for the SSMBT items | |

| | | | Factor loading | | |
|--|------|------|----------------|-------|-------------|
| SSMBT item | М | SD | 1 | 2 | Communality |
| 1. Change daily habits | 1.97 | 1.08 | 0.71 | -0.05 | 0.48 |
| 2. Do activity that has helped before | 2.67 | 1.15 | 0.55 | -0.05 | 0.29 |
| 3. Try a new activity | 1.41 | 1.20 | 0.32 | 0.04 | 0.16 |
| 4. Change something about myself | 1.67 | 1.29 | 0.39 | 0.04 | 0.23 |
| 5. Take scheduled medication | 2.69 | 1.41 | 0.50 | 0.07 | 0.28 |
| 6. Change/skip a medication | 0.67 | 1.09 | 0.06 | 0.20 | 0.05 |
| 7. Talk to HCP about symptom | 2.77 | 1.19 | 0.45 | 0.43 | 0.50 |
| 8. Talk to family/friends about symptom | 2.74 | 1.15 | 0.33 | 0.18 | 0.18 |
| 9. Give HCP information about symptom | 3.48 | 0.81 | -0.06 | 0.71 | 0.49 |
| 10. Ask HCP ques- tions about symptom management | 3.10 | 1.01 | -0.13 | 1.03 | 1.00 |
| 11. Listen carefully to HCP's explanation | 3.61 | 0.76 | -0.06 | 0.61 | 0.35 |
| 12. Participate in mak- ing decisions about symptom management | 3.49 | 0.70 | 0.13 | 0.41 | 0.21 |

Note. N = 61. HCP = health-care provider. The extraction method was a principal components analysis with an oblique rotation. italics denote which factor the item loaded on most strongly.

Table 3. Descriptives and reliabilities for the Symptom Self-Management Behaviors Tool

| SSMBT | No. of items | М | SD | Cronbach's α |
|---|--------------|------|------|---------------------|
| Subscale | | | | |
| Manage Symptoms | 8 | 16.6 | 5.37 | 0.69 |
| Communicate with Health-care Provider | 4 | 13.7 | 2.57 | 0.78 |
| Total | 12 | 30.3 | 6.69 | 0.74 |

Note. *N* = 61.

scores support discriminant validity of these constructs. However, the correlations between the Communicate with Health-care Providers subscale scores and the MSAS distress scores (r = -0.01, p = 0.97) and MSAS Severity scores (r = 0.02, p = 0.91) were nearly 0.

Discussion

This psychometric evaluation of the SSMBT provides initial evidence of its reliability and validity to assess the frequency of symptom self-management behaviors among AYAs with cancer. While our sample consisted mostly of adolescents, participants completed the SSMBT in about 5–10 minutes, suggesting that it was not unduly time-consuming to complete.

The factor analysis preliminarily confirmed the 2-factor structure of the SSMBT with 11 of 12 items loading on the hypothesized dimensions with factor loadings greater than 0.30. Discriminant validity was supported by the low to moderate correlations between the SSMBT total and both subscales' scores and the MSAS symptom severity scores, and the low correlations between the SSMBT total and Manage Symptoms subscale scores and the MSAS distress scores. The lack of association between SSMBT total and subscale scores and symptom distress warrants further investigation. It is important to note that perceived severity of a symptom is usually but not always related to distress. These attributes may need to be studied separately in future work.

Item 7, talk to HCP, loaded nearly equally on both factors. It is important to realize that talking to an HCP is an important symptom self-management behavior. However, the literature and interviews led us to consider the many aspects of communication with the HCP as a separate subscale. The Communicate with HCP subscale explores more about the type of communication the AYA has with the HCP; thus, we chose to keep Item 7 on the Manage Symptoms subscale.

Despite the performance of Item 6, which pertains to changing or skipping medications, retaining this item is responsive to a person-centered approach to supporting symptom selfmanagement behaviors for AYAs with cancer. The relatively low frequency with which AYAs endorsed this item may reflect social desirability and AYAs' concerns about disclosing what might have been perceived as nonadherence, especially for this group of AYAs consisting mostly of adolescents. Our prior work identified taking or choosing not to take a medication as AYAs' most frequent response to common symptoms such as pain, nausea, and difficulty sleeping (Linder et al. 2019a). Their responses suggest that their reasons for changing or skipping a given medication are complex and can be based on the context of a given situation and may reflect a willingness to endure a given symptom over another, e.g., choosing not to take an antiemetic to avoid the associated drowsiness or avoiding opioids despite the experience of moderate to severe pain to manage constipation (Linder et al. 2019a). AYAs may also choose to skip or delay taking disease-directed medications that cause nausea to avoid experiencing the associated risk of nausea and vomiting in a public setting (Linder et al. 2019b). Even though AYAs frequently use medications to manage their symptoms, they may be less knowledgeable and confident about weighing the benefits of a medication to alleviate one symptom against the risks of the same medication making another symptom worse. This is an area where AYAs may need additional guidance from clinicians about self-managing their medication regimens.

The internal consistency reliability of the total SSMBT (0.74) was acceptable for a newly developed instrument (Nunnally and Bernstein 1994). Although the item pertaining to changing or skipping medications slightly decreased the overall internal consistency of the Manage Symptoms subscale, we elected to retain the item as part of this subscale, given that AYAs disclosed skipping medications as a strategy to alleviate symptoms in our prior research (Linder et al. 2017, 2019a). In addition, AYAs endorsed the relevance of this item during the first phase of this project.

Clinical implications

The SSMBT assesses general symptom self-management behaviors; however, it could also be used to assess behaviors in response to a specific symptom. While this sample of AYAs reported a wide range of symptoms, how they considered their symptoms while completing the SSMBT is not known. Although higher individual item scores reflect more frequent use of symptom self-management behaviors, higher scores may or may not represent more effective symptom management. Individual responses could serve as a prompt to the clinician to ask what specific symptom selfmanagement behaviors AYAs have tried and whether they are effective. Likewise, clinicians could suggest adoption of different strategies or ask about reasons for not choosing other strategies. Further research is needed to explore how the SSMBT can best be used to guide discussions about symptom self-management interventions.

Within this study sample, items that scored higher in the Manage Symptoms subscale, indicating more frequent use, aligned with themes of self-management strategies reported by AYAs in our prior work, specifically taking medications, e.g., antiemetics and analgesics, and physical care strategies, e.g., engaging in/avoiding specific activities or adjusting dietary habits (Linder et al. 2017, 2019a). AYAs' responses to individual items on the Manage Symptoms subscale suggests a wide range of variability in the frequency with which they are engaging in self-management behaviors, which may reflect the context in which symptoms are occurring or opportunities to support AYAs in initiating self-management behaviors.

Limitations

Recruitment of the study sample occurred at a single site with a predominantly adolescent sample. Although most participants were White, racial and ethnic minority groups were represented in both phases of the study. Participants were heterogenous regarding their treatment status, and the study sample included those in extended survivorship as well as those receiving disease-directed therapy. All were initially screened for some evidence of ongoing symptoms.

Participant recruitment and accrual began during the early stages of the COVID-19 pandemic when in-person researchrelated activities were restricted. Despite these challenges, the data collection process was consistent across participants, with Phase 1 participants completing the CRS during the context of a telephone interview. Although Phase 2 participants had the option of completing study measures during the context of a clinic visit or at home, all measures were delivered electronically via REDCap.

Additionally, the SSMBT was developed to assess the frequency of behaviors initiated in response to symptoms in general, rather than in response to any one specific symptom. Although the frequency of symptom self-management behaviors was assessed, the perceived efficacy of these behaviors was not.

Next steps

Further evaluation and refinement of the SSMBT with different and larger samples of AYAs with cancer is needed to provide additional evidence of its reliability and validity to support use in future studies. Specifically, we need to further assess the item exploring AYAs' choice to change or skip a medication to better understand this response item. It is likely that the item may need to be rephrased. Additionally, further refinement of Item 7, talking to health-care providers about my symptom(s), is warranted to clarify the factor structure of the SSMBT and delineate where this item best resides in the tool. Research is needed to better understand how AYAs considered their symptoms when completing the SSMBT to guide interpretation of scores. Additional refinement of the SSMBT could include response options that explore AYAs' perceived efficacy for self-management behaviors. Further psychometric evaluation is warranted to determine the SSMBT's responsiveness to change in support of intervention-based studies that seek to improve symptom outcomes by increasing engagement in symptom self-management.

The 2 subscales, "Manage Symptoms" and "Communicate with Health-care Provider" align with theoretical outcomes of selfmanagement interventions and provide a basis for theory-based intervention studies. For example, the IFSMT (Ryan and Sawin 2009) depicts negotiated collaboration, which includes communication with the health-care team as a process-related outcome resulting from a patient-centered intervention. Engagement in self-management behaviors, i.e., initiating actions to manage one's symptoms, is depicted as a proximal outcome. Although the IFSMT posits that engaging in self-management behaviors leads to distal outcomes of improved health status and quality of life, more research is needed to evaluate the efficacy of given symptom selfmanagement behaviors.

The SSMBT's utility in routine clinical care to guide symptom management also warrants evaluation. Because symptoms are complex and may occur as clusters, a tool to assess selfmanagement behaviors aimed at the totality of the symptom experience, rather than individual symptoms, may be beneficial. The SSMBT was developed specifically for AYAs with cancer, but the symptom self-management behaviors represented also have potential relevance to other AYA and adult populations with complex symptoms due to their disease, e.g., sickle cell disease or asthma (Forrest et al. 2022), or underlying health state, e.g., pregnancy or menopause (Bai et al. 2016; Coslov et al. 2021). This tool focuses on symptom self-management behaviors. Therefore, it is plausible to propose that the SSMBT could be extended to studies with other groups in the future.

Conclusion

The newly developed SSMBT supports the assessment of AYAs' self-reported symptom self-management behaviors. The SSMBT demonstrated acceptable internal consistency and construct validity to support its continued development in future studies measuring symptom self-management among AYAs with cancer. The SSMBT has the potential to support a person-centered assessment of the behaviors AYAs undertake to self-manage their symptoms and how they engage with members of the clinical team to further support their symptom self-management efforts.

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