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RESEARCH ARTICLE

Beyond presence of symptoms: Self-reported psychosocial distress interference among outpatient youth with cancer and other life-limiting conditions

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Abstract

Background: Youth with life-limiting conditions face significant psychosocial challenges (e.g., symptoms of anxiety, depression, and pain) throughout illness and treatment. Without appropriate intervention, this can negatively affect long-term outcomes (e.g., disease management, health-related quality of life). Prompt identification and appropriate attention to distress can mitigate these effects. We aimed to determine the prevalence and severity of distress interference among outpatient youth with cancer and other life-limiting conditions, using the *Checking IN* screener.

Procedure: Within a larger study across four hospital centers, English-speaking pediatric outpatients aged 8–21, and a caregiver-proxy-reporter, completed a brief distress screener. Descriptive analyses were used to characterize the sample and evaluate reported distress symptoms.

Results: *Checking IN* was completed by 100 participants, aged 8–21 (M = 14.27, SD = 3.81); caregivers completed an equivalent proxy screener. Youth most frequently endorsed *fatigue* (moderate: $n = 50$, 50.0%; high: $n = 21$, 21.0%), *paying attention* (moderate: $n = 45$, 45.0%; high: $n = 16$, 16.0%), and *sleep difficulty* (moderate: $n = 46$, 46.0%; high: n = 13; 13.0%) as problematic. Caregivers proxy reported *fatigue* (moderate: $n = 46$, 46.0%; high: $n = 32$, 32.0%), *worry* (moderate: $n = 56$, 56.0%; high: $n = 10$, 10.0%), and *sleep difficulty* (moderate: $n = 47$, 47.0%; high: $n = 14$; 14.0%) as most problematic. Group differences between youth and caregiver responses were not significant.

Conclusions: Youth self-report via *Checking IN* can detect psychosocial distress interference. By directing resources based on real-time assessment of symptom interference, there is potential to simplify outpatient psychosocial screening and improve referral timeliness and specificity, thus allowing for more effective attention to evolving symptoms of distress.

KEYWORDS
adolescents, children, chronic illness, outpatient care, psychosocial distress

Abbreviations: ASQ, Ask-Suicide Screening Questions; IRB, Institutional Review Board.

1 INTRODUCTION

The rates of survival for children and adolescents diagnosed with cancer and other life-limiting conditions have benefitted dramatically from continued advances in prevention, control, and treatment. However, these youth still face significant psychosocial challenges throughout their disease trajectory and treatment. Some of the challenges prevalent in this population include symptoms of anxiety and depression, social isolation and difficulty maintaining peer relationships, limited academic progress, and poor body image.[1–3] Pain and fatigue can also interfere with psychosocial functioning. When not appropriately addressed, the distress that youth experience secondary to these challenges can lead to negative long-term outcomes, including poor disease management and health-related quality of life.[4–6] Nevertheless, many healthcare providers tend to underestimate the enormous impact of emotional and behavioral stressors on their young patients.[7,8]

In the outpatient setting, psychosocial screening tools exist to quickly assess for symptoms of emotional and behavioral distress, specifically identifying those patients who may benefit from additional support.[9–12] Unfortunately, routine psychosocial screening is not always considered a priority, and as a result, opportunities to engage in such screening are often missed.[13–15] Even when routine screening occurs and referrals and other resources are subsequently directed, studies indicate that there is little guarantee of patient uptake.[16–19] This may be related, in part, to whether the screening data accurately represent the patient's direct experience. For example, many existing pediatric psychosocial screeners rely solely on caregiver-proxy-report, which can be significantly discrepant from youth self-report, particularly regarding psychosocial distress.[3,20–25] Such limitations can be misleading to healthcare providers, thereby restricting the intended reach of available referrals and resources, while simultaneously perpetuating inaccuracies related to the psychosocial needs and concerns of these youth.[6,16,26–28]

Checking IN is an electronic screening tool designed to assess psychosocial distress in youth ages 8–21 years who have cancer or another life-limiting condition, for use in the outpatient setting.[29] The screener is intended to supplement time-limited outpatient visits, promptly provide access to necessary resources, and address issues that may interfere with quality of life. Moreover, *Checking IN* documents patients' reported symptom interference as a matter of course, such that providers can track and assess their patients' distress and identified needs over time.[29,30] Notably, *Checking IN* is designed to achieve these goals using both youth and caregiver-proxy-report, independently assessed. This paper focuses on the psychosocial symptoms that youth and their caregivers endorse as interfering with their current (i.e., the past week) quality of life using the *Checking IN* screener. A second objective was to compare responses to *Checking IN* between groups: youths with life-limiting conditions and caregiver-proxies. Finally, the study aimed to explore whether youth responses related to domains of psychosocial distress reflected any gender- or age-based differences.

2 MATERIALS AND METHODS

As part of a larger study assessing the feasibility of *Checking IN*,[29] pediatric outpatients aged 8–21 years were asked to complete an age-specific, web-based version of the *Checking IN* screener via tablet or laptop. All patients had a caregiver complete the equivalent age-appropriate proxy-report of *Checking IN*. A study investigator was present to help ensure that patients and caregivers completed the screen independently. Eligible patients were English-speaking and receiving active outpatient treatment for cancer or another life-limiting condition at one of four hospital centers. Data were collected using convenience sampling between 2020 and 2021. All caregivers and patients ≥18 years of age provided written informed consent, and children and adolescents less than 18 years provided assent. No compensation was provided. The study was approved by the Institutional Review Board (IRB) of the National Institute of Mental Health and the IRB at each of the participating sites.

2.1 Measures

Checking IN is a brief and interactive e-screening measure designed to assess psychosocial symptom interference across 15 domains (i.e., anxiety, depression, self-harm, suicidality, anger, attention, body image, sleep disturbance, fatigue, pain, medication adherence, family relationships, peer relationships, faith, and school). As previously reported,[29] by focusing the screening questions on those symptoms that are actively interfering with the youth's quality of life, *Checking IN* facilitates better identification of the domains that require clinical attention. Each domain is evaluated by asking "How much has [domain] been a problem for you in the past week." Within the caregiver-proxy report, domains are evaluated by asking "How much has [domain] been a problem for your child in the past week?" Response options include "Not at all," "A little bit," "Sometimes," "Often," and "Almost Always." If "Not at all" is endorsed, branching logic skips to the next domain. For all other responses, participants are prompted to characterize how the domain has been problematic for them over the past week, using three to seven checkbox items.

Given the significant potential impact of pain on psychosocial functioning, *Checking IN* also assesses the youth's experience of pain severity over the past week. This is measured on a pain scale ranging from 0 to 10, with 0 being "no pain" and 10 being "the worst pain I could imagine." Furthermore, embedded within the screener for youth ages 10 and up is the Ask-Suicide Screening Questions (ASQ),[31] a validated four-item suicide risk screen. Responses to the ASQ and questions regarding self-harm were analyzed and reported separately.[32]

Due to the electronic nature of the screener, *Checking IN* can be administered to patients and caregivers by anyone in the clinical setting. However, following completion of *Checking IN*, healthcare providers receive a summary report in real-time, with recommendations for triage as necessary. For those domains reported as "Not at all" a problem (i.e., No Interference), no specific intervention is suggested.

Domains endorsed as “A little” or “Sometimes” a problem (i.e., Moderate Interference) are flagged in the report, with the recommendation that of provider follow-up via further inquiry and discussion with the youth. For responses of “Often” or “Almost always” (i.e., High Interference), providers are advised to offer a suggested referral for specialized care (e.g., mental health provider, chaplain). Additionally, when available, *Checking IN* has the capability to include data from up to five of the youth’s past visits within the summary report, which allows providers to monitor a patient’s experience of symptom interference over time and make better-informed decisions regarding triage, discussion, and referrals.

2.2 | Data analysis

Descriptive analyses were calculated to characterize the demographic variability of the sample. Similarly, responses regarding the impact of distress were also analyzed using descriptive statistics. Group differences, including those between youth and caregivers, as well as those based on gender, were analyzed using independent samples *t*-tests. Bivariate correlations were used to assess relationships between impact of distress per domain and age. All analyses in the current study are descriptive in nature and report the aggregate results of participant and/or caregiver responses from the original parent study.[29] Analyses were conducted using SPSS 28 software.[33]

3 | RESULTS

Data were derived from the larger study,[29] and included only those participants who completed the final version of the *Checking IN* screening measure. Thus, for the current analysis, the sample comprised 100 participants aged 8–21 (*M* = 14.27, SD = 3.81; see Table 1) who completed the *Checking IN* screening measure, as well as the proxy screener completed by their caregiver. Participating youth were mostly White (*n* = 74, 74.0%) and non-Hispanic (*n* = 89, 89.0%), and were equally representative of gender (female: *n* = 50, 50.0%, and male: *n* = 50, 50.0%). Additionally, most had a cancer diagnosis (*N* = 81, 81.0%). See Table 1 for additional detail.

For the purposes of analyses, the impact of distress domains was categorized as none (i.e., “Not at all”), moderate (i.e., “A little bit” or “Sometimes”) and meriting discussion with the youth, or high (i.e., “Often” or “Almost always”) and warranting referral. These categorizations match those seen in the *Checking IN* summary report. The symptoms most frequently endorsed as interfering with quality of life by youth were *fatigue* (moderate: *n* = 50, 50.0%; high: *n* = 21, 21.0%), *paying attention* (moderate: *n* = 45, 45.0%; high: *n* = 16, 16.0%), *sleep difficulty* (moderate: *n* = 46, 46.0%; high: *n* = 13; 13.0%), and *worry* (moderate: *n* = 46, 46.0%; high: *n* = 8, 8.0%). In contrast, the domains youth endorsed least often were *family* (moderate: *n* = 26, 26.0%; high: *n* = 3, 3.0%), *friends* (moderate: *n* = 12, 12.0%; high: *n* = 2, 2.0%), and *faith* (moderate: *n* = 5, 5.0%; high: *n* = 3, 3.0%). See Figure 1 for further details. Among youth who rated *fatigue* as a problem, they most frequently identified that fatigue made it “hard to keep up with regular activities or tasks” (*n* = 28, 37.3%) when presented with a checklist to characterize their symptoms. Those who rated *paying attention* as problematic tended to endorse “problems remembering information” (*n* = 56, 37.1%). For those who rated *sleep* as a problem, difficulty “falling asleep” was endorsed most often (*n* = 35, 53.8%). Youth who

TABLE 1 Participant demographics.

Youth participants	***n* (%)**
Gender	
Female	50 (50.0)
Male	50 (50.0)
Age	
8–9 years	15 (15.0)
10–12 years	21 (21.0)
13–17 years	42 (42.0)
18–21 years	22 (22.0)
Race	
White	74 (74.0)
Black/African American	12 (12.0)
Biracial	6 (6.0)
Asian	5 (5.0)
American Indian or Alaska Native	3 (3.0)
Ethnicity	
Not Hispanic/Latino/a	89 (89.0)
Hispanic/Latino/a	9 (9.0)
Unknown	2 (2.0)
Medical diagnosis	
Cancer	81 (81.0)
Acute lymphoblastic leukemia	29
Sarcoma	15
Brain tumor/central nervous system cancer	10
Acute myeloid leukemia	4
Hodgkins	4
Non-Hodgkins	4
Other	15
Neurofibromatosis type 1	11 (11.0)
Hematologic disease	5 (5.0)
Primary immune deficiency	3 (3.0)
Caregiver participants	***n* (%)**
Relationship to child	
Mother	83 (83.0)
Father	14 (14.0)
Aunt/uncle	1 (1.0)
Grandparent	1 (1.0)
Other	1 (1.0)

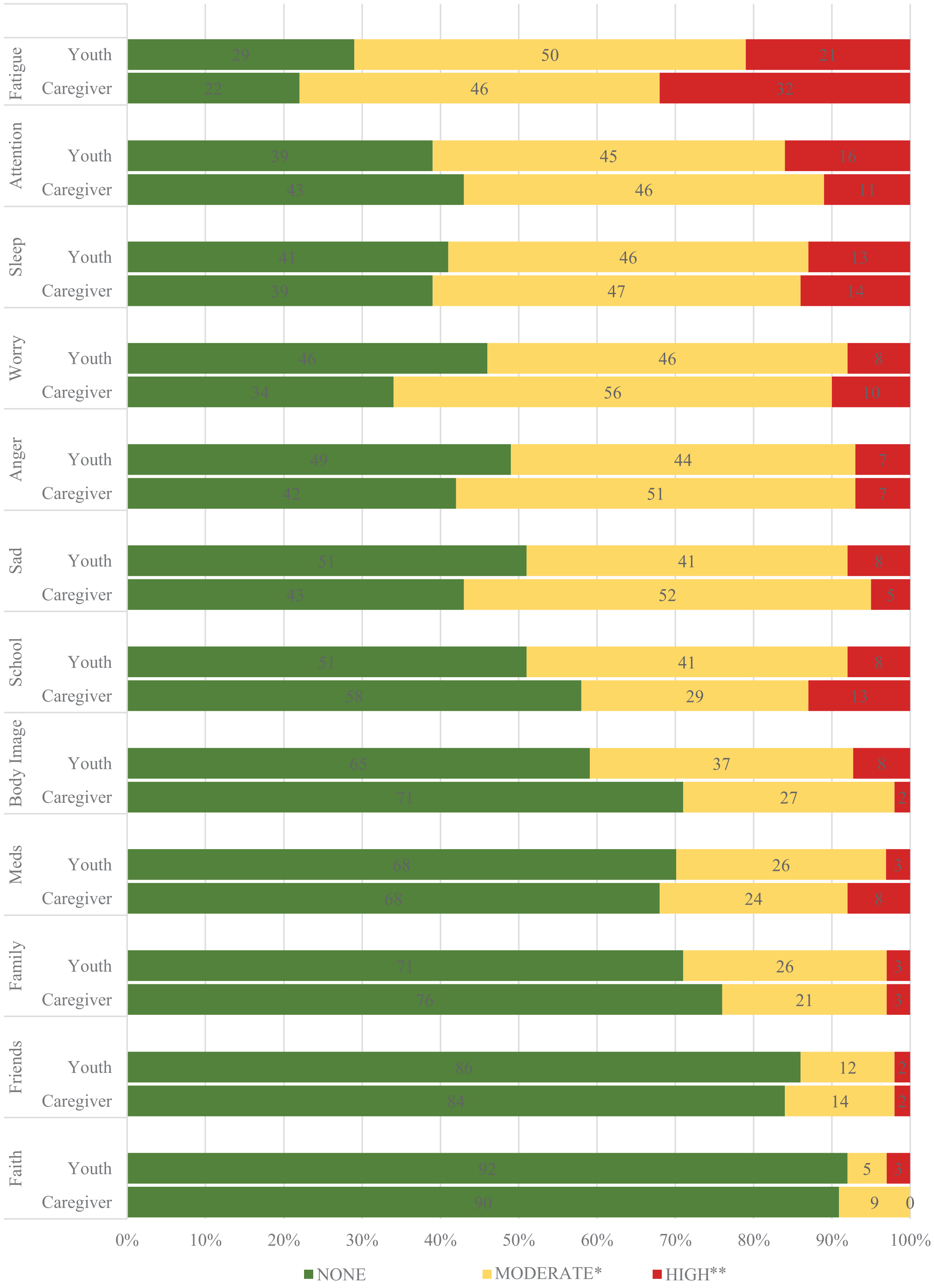

FIGURE 1 Level of endorsement by symptom domain. *Moderate includes responses of “A little bit” or “Sometimes”; **high includes responses of “Often” or “Almost.”

rated *worry* as a problem selected “worrying about what could happen to me” most frequently ($n = 30$, 49.2%) (see Table 2).

Caregiver-proxy responses tended to endorse *fatigue* (moderate: $n = 46$, 46.0%; high: $n = 32$, 32.0%), *worry* (moderate: $n = 56$, 56.0%; high: $n = 10$, 10.0%), and *sleep difficulty* (moderate: $n = 47$, 47.0%; high: $n = 14$; 14.0%) as most problematic for the youth (see Figure 1). Like the youths, caregivers who rated *fatigue* as a problem for the youth also endorsed that fatigue made it “hard to keep up with regular activities or tasks” most frequently ($n = 34$, 41.0%). Similarly, regarding *paying attention* and *sleep difficulty*, caregivers’ most frequently endorsed responses matched those of the youths (i.e., “problems remembering information” ($n = 33$, 56.9%) and difficulty “falling asleep” ($n = 32$,

TABLE 2 Endorsement of symptom interference using checkbox descriptors.

Domain	Youth N (%)	Caregiver N (%)
Sleep		
Difficulty falling asleep	35 (53.8)	32 (51.6)
Difficulty staying asleep	25 (38.5)	29 (46.8)
Thoughts keep me awake	12 (23.1)	14 (22.6)
Fatigue		
Too tired to do the things I want	18 (24.0)	23 (27.7)
Difficulty staying awake	13 (17.3)	10 (12.0)
Difficulty keeping up with daily tasks	28 (37.3)	34 (41.0)
Worry		
Worried/scared about doctor/hospital visits	13 (21.3)	15 (21.7)
Worried/scared about tests or procedures	15 (24.6)	28 (40.6)
Worried/scared about what could happen to me	30 (49.2)	24 (34.8)
Anger		
Felt cranky or irritable	22 (40.7)	34 (58.6)
Felt mad or angry about inability to do what I like due to illness	26 (48.1)	25 (43.1)
Sadness/depression		
Felt angry	12 (22.6)	26 (44.8)
Felt cranky or irritable	22 (41.5)	39 (67.2)
Do not enjoy the things I used to like to do	17 (32.1)	12 (20.7)
Paying attention		
Must work really hard to pay attention	22 (33.3)	17 (29.3)
Problems remembering things	37 (56.1)	33 (56.9)
Takes longer to understand things than others my age	12 (18.2)	21 (36.2)
School/work		
Too much schoolwork or work	21 (38.3)	5 (11.4)
School/work feels too difficult	12 (21.8)	12 (29.5)
I have been absent from school/work	18 (32.7)	8 (18.2)

51.6%), respectively. However, not all items endorsed by caregiver-proxy matched those endorsed by youth. Regarding *worry*, caregivers endorsed “worrying about tests or procedures” much more frequently (n = 28, 40.6%) than youths (N = 15, 24.6%). Similarly discrepant responses were noted in other symptoms, such as *anger* and *sadness* (see Table 2). Domains that caregiver-proxies endorsed with the least frequency were *family* (moderate: n = 21, 21.0%; high: n = 3, 3.0%), *friends* (moderate: n = 14, 14.0%; high: n = 2, 2.0%), and *faith* (moderate: n = 9, 9.0%) (see Figure 1).

In comparing youth and caregiver responses on each domain using independent samples t-tests, no significant differences between groups were found. However, the finding that caregivers tended to rate more interference due to *fatigue* than did youth was approaching significance [$t(198) = -1.94$, $p = .05$]. Separately, youth reported experiencing mild pain on average ($M = 1.76$, SD = 1.96, range: 0–8) over the past week. Caregiver-proxy reported similarly low pain scores on average (M = 1.91, SD = 2.48, range: 0–10). Testing the mean differences between youth and caregiver-proxy responses on the pain thermometer showed no significant difference between these groups. Finally, assessment of symptom interference based on demographic variables, including gender and age, revealed few differences. Younger youths endorsed significantly more interference due to *medication difficulties* than their older counterparts ($r = -.32$, $p < .01$). No other significant correlations were found.

4 | DISCUSSION

Living with a medical illness has been associated with acute, chronic, and long-term psychosocial stressors in youth,[34] which can negatively impact health-related outcomes,[4,5] and points to the importance of routine screening. However, the extant literature highlights the limitations of current pediatric self-report screening and resource distribution practices,[7,14,15,24,26,27] thereby emphasizing the need for innovative methods of investigating and screening for psychosocial stressors to ultimately reduce barriers to care. The aim of the current study was to elucidate the domains of psychosocial distress that youth with a life-limiting condition such as cancer report as interfering most with their quality of life. Notably, these youth most frequently endorsed distress related to symptoms of *fatigue*, *sleep difficulty*, *attention*, and *worry*.

Our findings suggest that use of *Checking IN* in the outpatient setting has great potential to facilitate targeted triaging and resource allocation most relevant to those youths being screened for distress, as well as facilitate the implementation of systematic psychosocial assessment, as per the recommendations for the standards of care.[10] By assessing the severity of youths’ endorsed concerns, *Checking IN* can simplify the triaging process, pinpointing those who demonstrate severe and/or persistent distress and therefore require immediate intervention, while also detecting those with elevated distress who require further discussion and monitoring. Moreover, because *Checking IN* has longitudinal tracking capability, there is additional potential for identifying progression and/or patterns in youth reports of distress and symptom interference over time, including those who had been provided with resources in the past. This approach aligns closely with the framework of the Pediatric Psychosocial Preventative Health Model, which has been used extensively within the pediatric cancer and chronic illness literature, and demonstrates an effective approach to triaging issues of psychosocial distress.[35,36] Of note, while the current study surveyed youth with cancer and other life-limiting conditions on active treatment, *Checking IN* is designed in such a way that it can be easily adapted for and used in other clinical settings to screen for psychosocial distress, monitor changes over time, and successfully triage concerns.

Findings from the current study also suggest modest agreement between youth and caregiver-proxy groups’ reports regarding psychosocial interference across several domains. The domains of distress that caregivers endorsed most frequently (i.e., *fatigue*, *worry*, and *sleep difficulty*) overlapped with those most frequently reported by youth. Indeed, the greatest discrepancy between youth and caregiver-proxy responses was in rating the extent of interference related to *fatigue*, though this remained the most highly endorsed domain of distress interference among both groups. These findings diverge from the extensive literature that demonstrates discordant symptom reporting between similar youth and caregiver samples.[20,21,23,37] We believe that this difference is likely attributable to the design of the screener. *Checking IN* specifically assesses the interference, rather than merely the presence, of a symptom. Thus, we hypothesize that caregivers may detect symptom interference more easily than symptom presence.[20–22,28,38] Indeed, our findings suggest that, even in assessing interference rather than presence, caregivers may have more difficulty gauging the interference of internal symptoms of distress[28,38] (e.g., symptoms of *anger*, *sadness*, and *worry*; see Table 2) than others, as there was appreciable discrepancy between caregiver-proxy and youth ratings on these symptoms.

It is worth noting the several important limitations to this study. *Checking IN* was only administered in English, thus limiting its availability across our patient population, and therefore limiting the generalizability of our findings to more language diverse populations. Similarly, while a broad range of life-limiting conditions were included, most of the youth in our sample had a cancer diagnosis, such that we were unable to compare findings based on diagnosis. Moreover, the sample was too small to properly examine group differences based on age, despite the wide developmental age range identified for screening. Additionally, data regarding level of functioning (e.g., school enrollment and/or performance, social engagement) were not collected. Consequently, the study findings are likely not equally representative of the breadth of neurodevelopmental, functional, and diagnostic presentations in the sample. Further, most caregivers who participated in this study identified as mothers, which limits the generalizability of our findings regarding agreement between youth and other caregiver-proxy reports of psychosocial distress interference. Finally, because the study was cross-sectional in nature, we are limited in the conclusions that we can draw from our findings.

With these limitations in mind, the current study sets the stage for future research that will focus on collecting data from a larger and more diverse sample over a longer period.[10,29] Including a larger, more clinically diverse sample will allow for a more robust investigation of potential differences in reports of symptom interference across diagnoses. Moreover, longitudinal sampling would allow for the collection of symptom interference data over time, facilitating full use of the response tracking functionality of *Checking IN* and thus, creating opportunities to identify optimal conditions for resource and referral uptake.[8,11,16,19,29] To that end, keeping track of how and when resources and referrals are provided, as well as the frequency with which participants engage them, would be a useful addition to the data. Furthermore, this longitudinal work may help identify the ideal timing for engaging participants in repeat screening. Expanding the study sample and data in this way would also allow for deeper investigation of reports of moderate- as well as high-level symptom interference, potentially helping to clarify the apparent discrepancies between interference severity ratings and number of symptoms reported, as seen in the current study. Moreover, continued use of *Checking IN* in a clinical and research capacity lays the foundation for incorporating systematic psychosocial assessments for youth with cancer across the treatment trajectory, as is recommended by the standards of care in pediatric cancer.[10]

Study findings indicate that youth self-report on the e-screening tool *Checking IN* is useful in detecting symptom interference leading to psychosocial distress. Moreover, current findings support the existing research identifying the significant distress and symptom interference youths experience, particularly related to fatigue, sleep difficulties, and attention.[6,39–43] Bolstering available resources and support around these common symptom domains (e.g., sleep medicine and/or neuropsychology consults) are likely to have wide-reaching benefits. By directing resources based on a real-time assessment of symptom interference and documentation over time, this approach to screening has the potential to improve referral specificity and relevance, as well as streamline appropriate, timely resource allocation; all of which may serve to improve youth referral uptake. Ongoing research efforts, as well as more extensive implementation of psychosocial screening tools like *Checking IN*, have the potential to uncover additional patterns in symptoms of distress among youths, which may be used to optimize resource benefit in the outpatient setting, and thus, enhance overall patient care.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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