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Feasibility And Acceptability of a Game-Based Symptom-Reporting App for Children with Cancer: Perspectives of Children And Parents

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Abstract

Background: Children with cancer have difficulty identifying and describing the multiple symptoms they experience during hospitalization and between clinical encounters. Mobile health resources, including apps, are potential solutions to support child-centric symptom reporting. This study evaluated the feasibility and acceptability of a newly developed game-based symptom-reporting app for school-age children with cancer. Procedure: Nineteen school-age children (6–12 years of age) receiving treatment for cancer at a COG institution in the Intermountain West of the United States used a game-based symptom-reporting app between clinical visits. Feasibility was evaluated through a summary of actual days of app use and interaction with each of the app's features. Children and their parents participated in interviews regarding the app's acceptability. Results: Children used the app a median of 4 days (range 1–12) and interacted most frequently with the symptom reporting and the drawing features. Children enjoyed aspects of the app that supported their creativity and provided choices. Parents endorsed the interactive nature of the app and the value of the child providing his/her own report. Both children and parents identified additional opportunities to enhance the child's user experience. Conclusion: Study results support the preliminary feasibility and acceptability of the app. Children's and parents' responses supported the developmental relevance of the app and its role in enhancing the child's autonomy and serving as an outlet for creativity. Future directions include optimizing the child user's experience and investigating the app's role as a resource to enhance shared decision-making for symptom management.

Keywords

Introduction and background

Managing symptoms that children with cancer experience as a consequence of their disease and its treatment is essential to optimizing the child's quality of life [[1]]. The initial step to symptom management is assessment; however, standard approaches to symptom assessment in most clinical settings, including opportunities to track symptoms between visits, are lacking [[3]].

Although the prevalence and severity of symptoms typically decrease over the course of the child's treatment [[4]], children's symptom experiences and the trajectories of symptoms are highly individual [[6]]. While symptoms vary during a hospitalization [[7]], they also persist in the ambulatory setting [[9]]. Children may experience persistent physical and psychological symptoms, including nausea, pain, and difficulty sleeping, following discharge from the hospital but not report them to the clinical team

[[10]]. Children also relate the persistence of symptoms and strategies to manage these symptoms on days when they are feeling well [[11]].

School-age children (6–12 years of age) are developing reasoning abilities that allow them to represent experiences mentally and symbolically [[12]]. In contrast to adolescents and adults who recall information through verbal prompts, school-age children recall and communicate information through sensory activities. Many symptom-reporting resources for children, however, are largely derived from adult versions of tools that rely on verbal prompts to recall information. These tools typically emphasize assessment at a given point in time with a limited recall period which may not identify trends in symptoms over a longer period of time.

Mobile health (mHealth) resources, including gamified apps, are potential solutions to support child-centric symptom reporting and trend identification for symptoms between clinical encounters [[14]]. Mobile devices, including tablet computers, are familiar to most school-age children and provide a developmentally relevant platform for engaging children in that they are easy to manipulate and remove a level of abstraction [[15]]. Incorporating game-based features, i.e., "gamification" into apps engages children's senses and supports problem-solving and creativity to enhance their recall and report of symptoms and experiences [[16]]–[[19]]. Although symptom-reporting apps have been developed for older children and adolescents with cancer [[20]], fewer resources exist for younger children [[22]]. Examining the extent to which target users interact with a given technology and their attitudes toward that technology provides insights into its potential future use [[23]].

Purpose

This study evaluated the feasibility and acceptability of a newly developed, game-based symptom-reporting app, *Color Me Healthy*, for school-age children with cancer. The larger project guiding the app's development was grounded in developmental science, which recognizes the multiple aspects of the child's development [[24]], and symptom science, which recognizes the patient's self-report as the gold standard for symptom reporting [[26]]–[[28]].

Methods

Setting

The study setting was the Center for Cancer and Blood Disorders at a Children's Oncology Group—affiliated children's hospital in the Intermountain West of the United States. The center includes a 32-bed inpatient unit and an ambulatory clinic serving approximately 40 patients each day.

Sample

Participants included children and parents. Eligible children were 6 to 12 years of age and receiving chemotherapy as treatment for cancer in an inpatient or ambulatory setting. Children were required to have completed at least one cycle of chemotherapy, speak and understand English, and be physically and cognitively able to complete study procedures. Because the focus of the study was evaluation of the app, children were heterogenous with regard to diagnosis and stage of disease. Parent participants were the parent or legal guardian of a child participant. They were required to speak and understand English and be able to participate in the acceptability interview.

Color Me Healthy app

The *Color Me Healthy* app is a game-based symptom-reporting app delivered via a tablet computer that was co-designed with iterative input from school-age children with cancer and pediatric oncology clinicians [[29]]. Children and clinicians provided input regarding symptoms of priority for inclusion, preferences for communicating symptoms, and preferences for having data represented [[11], [30]].

Programming support was provided by graduate students working in the University of Utah's Therapeutic Games and Apps Lab (The GApp Lab) under the supervision of the principal investigator (LL) and lab director (RA) [[31]]. The interdisciplinary three-student team included the roles of a programmer, artist, and producer. Programming was guided by Design Box principles, an inductive, qualitative approach that supports analysis of the problem and considers perspectives of the end users from the beginning. The Design Box method is built on the assumption that a good design solves a problem [[32]] and considers the technology, aesthetics, audience, and the underlying play/question theory before proposing a design.

The app features a customizable avatar that guides children to identify their symptoms using drawing features, brief checklists, and short-answer responses (Fig. 1). The app supports the report of the prevalence, severity, and associated bother of eight general symptoms: pain, nausea, vomiting, fatigue, difficulty sleeping, appetite changes, coughing, and dizziness. It also supports children to localize additional symptoms, including pain, rash, itching, bruising, numbness/tingling, mouth sores, and difficulty swallowing to specific areas of the body including the head, mouth, chest, abdomen, and extremities.

1a. Customizable Home Page

1b. Avatar and About Me page

1c. Symptom checklist and daily questions

1d. Ability to localize symptoms

1e. Diary and Daily Goals page

1f. Sketch page

1g. Ability to review trends in symptom severity and distress
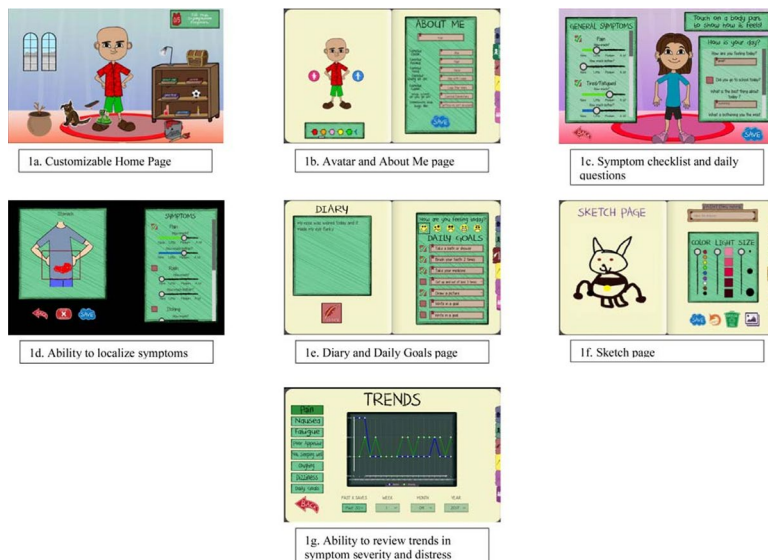
Fig. 1 Screen shots from the Color Me Healthy app

The app also includes a goals page emphasizing daily health promotion activities along with a sketch pad and diary to support personal creativity and reflection. Children receive up to two daily rewards: one for logging into the app and a second for completing key daily tasks within the app. Patient-entered data are encrypted and stored as JavaScript Object Notation (.json) files in the patient's account within the app.

Measures

Feasibility

The feasibility of the *Color Me Healthy* app was evaluated through review of children's actual use of the app. Children's actual days of use and days of interaction with each feature within the app were summarized using date and time-stamped data files that were generated as children interacted with the app.

Acceptability

Acceptability was evaluated from the perspectives of children and their parents through brief, semi-structured interviews at the close of the study period. Interviews were guided by three questions: "What three things did you like most about the app?"; "What three things did you not like about the app?"; and "What three things would you change about the app?" These questions have been used in previous work evaluating an exercise-empowerment mobile video game for children with cancer from the perspectives of children, parents, and clinicians [[33]]. Children were also asked about their willingness to use the app again and their preference for reporting symptoms using the app or a paper-based resource. Collectively, questions addressed the app's perceived ease of use and perceived usefulness, key determinants of technology adoption [[23]].

Procedure

Recruitment and enrollment

Institutional review board approval was granted for the study. A research team member screened patients scheduled for clinic visits or inpatient admissions for eligibility. A clinical team member approached eligible families with information about the study and to obtain permission for the research team member to meet with them to explain the study. Parents provided written permission for the child's participation and informed consent for their own participation. Children 7 to 12 years of age provided written assent. Children who were 6 years of age provided verbal assent.

Data collection

Children received a study-dedicated tablet computer for use during the study period. A research team member assisted the child to set up a user account and oriented the child and parent to the app and its features. Children were requested to use the app for 5 days between ambulatory clinic visits or inpatient admissions for chemotherapy. A 5-day trial period was selected to support consistent use-related expectations across settings and treatment schedules. Children who were anticipated to have more than 5 days between study-related visits were informed that they could use the app beyond the requested 5-day period if they wished.

A research team member met with children and parents at the conclusion of the study period, typically during the subsequent scheduled clinic visit for chemotherapy, to complete the child and parent acceptability interviews. Interviews were audio recorded and lasted 3.5 to 12 min. Child and parent participants received gift cards after completing the interviews.

Data management and analysis

Each participant's app-generated data were extracted from tablet computers as a password-protected zip file via an administrator account. Days of app use and its features were entered into an Excel sheet and summarized descriptively. Date and time stamps of files generated as children used the app were

reviewed to identify total days of app use as well as days of interaction with individual features within the app.

Interviews were transcribed verbatim. Responses to each question were analyzed using descriptive, qualitative content analysis procedures [[34]]. Single words or simple phrases were regarded as individual units of analysis. Key meanings were extracted from longer responses. Responses were reviewed by four authors (LL, AN, SW, KS) to assign codes and reach consensus. A given code was assigned only once to a child's or parent's response even if the individual may have repeated the larger meaning more than once in his or her response. Codes were further organized into categories and subcategories.

Results

Participants

Twenty children and nineteen parents enrolled in the study (Tables 1 and 2). One child withdrew after enrollment because the parent deemed study procedures too burdensome. Children and parents were predominantly White, non-Hispanic. Child participants were a median of 8 years of age (range 6–12 years) and a median of 4 months (range 1–74 months) from initial diagnosis. Parent participants were a median of 35 years of age (range 26–48 years).

Table 1 Demographic characteristics of child participants

Characteristic	n	%
Gender		
Male	13	65
Female	7	35
Race		
White	19	95
More than one race	1	5
Ethnicity		
Hispanic	3	15
Non-Hispanic	17	85
Diagnosis		
Acute lymphoblastic leukemia	9	45
Brain tumor	5	25
Hodgkin lymphoma	2	10
Non-Hodgkin lymphoma	2	10
Osteosarcoma	2	10
Disease state		
Initial diagnosis	17	85
Relapsed or progressive disease	3	15

Table 2 Demographic characteristics of parent participants

Characteristic	n	%
Gender		
Male	1	5

Female	18	95
Race		
White	17	95
Asian	1	5
Ethnicity		
Hispanic	1	5
Non-Hispanic	18	95

Six children (4 boys and 2 girls) who were approached about study participation declined to participate. One family declined to be contacted by the study team. Four children (2 boys and 2 girls) indicated that they were not interested. The sixth patient did not engage in the study discussion, and the study team member was unable to confirm an affirmative response of the child's interest in participation.

Feasibility

Collectively, children used the app for 102 days. Children's patterns of use reflected varied overall interaction and varied interest in individual app features (Table 3). All children used the app at least 1 day with total days of use ranging from 1 to 12 days (median 4 days). Nine children, 5 boys (6–11 years) and 4 girls (7–11 years), used the app 5 days or more. Another four children, 2 boys and 2 girls, used the app for 4 days. One boy and three parents related difficulty remembering to use the app and incorporating its use into their daily schedules. Other parents related their children initiating daily use of the app. Children most frequently used the symptom-reporting page and the drawing page. Of note, all children reported pain at least once (48 days total), and 11 reported nausea at least once (30 days total), providing support for the app's capacity to support collection of clinically relevant symptom data between clinical encounters.

Table 3 Days of app use: overall and by page/feature

	Overall days of interaction	Symptom report	Drawing page	Goal entry	Diary entry
Range	1–12	1–12	1–12	1–11	0–11
Median	4	4	4	3	2
Mean	5.4	4.5	4.5	3.8	3
Standard deviation	3.2	2.8	3.2	3.0	3.2

Acceptability

Children

Eighteen children participated in interviews at the close of the data collection period. One child declined to participate due to fatigue. Responses are summarized in Table 4.

Table 4 Categories and subcategories of children's acceptability interview responses

Category and Subcategory Names	*n*	Exemplars

What did you like most about the app?		
Choices and creativity	22	
Choices	10	"I liked the customizing the things," (12-year-old boy with ALL)
Drawing/creativity	10	"I like drawing pictures," (11-year-old boy with lymphoma)
Fun features within the app	2	"plant" (7-year-old girl with ALL)
Rewards and incentives	10	
Stickers/rewards	8	"daily prizes," (11-year-old girl with a brain tumor)
Goals	2	"the goal thing because it reminded you like to brush your teeth and take care of that," (12-year-old boy with ALL)
Individualization	8	
Avatar	5	"making your person (avatar)," (8-year-old girl with ALL)
"About me" page	3	"having a page with own stuff on it," (8-year-old boy with ALL)
Functionality	3	
Reporting symptoms	2	"the thing that you can draw...like where it hurt, yeah...um," (11-year-old boy with a brain tumor)
Easy to use	1	"it was easy to learn, yeah. It was easy to learn how to do it," (11-year-old boy with a brain tumor)
What did you not like about the app?		
No dislikes	10	"Um, none of it," (8-year-old boy with ALL)
Navigation issues	3	"after you push the button you have to wait for it to load," (10-year-old boy with Hodgkin lymphoma)
Specific features	2	"Uh, the background music," (12-year-old boy with ALL)
"Everything"	1	"Yeah, and everything," (6-year-old boy with ALL)
Remembering to use	1	"It was hard to keep track of remembering each day," (12-year-old boy with ALL)
What would you change about the app?		
Enhance the user engagement	15	
Increase choices within existing features	7	"Change the plant so that so like you could change it into a tree. So each day you could make it a different plant and then you could water it and see what happens." (10-year-old boy with Hodgkin lymphoma)
More activities/games to do	6	"Maybe you can do more stuff (other games) on it," (7-year-old girl with an optic glioma)
New feature (e.g., imaginary friend)	2	"Make an imaginary friend that you can design and tell that imaginary friend how you feel...," (11-year-old girl with a brain tumor)
Improve the usability	4	
Improve navigation	2	"scrolling on history page," (9-year-old boy with ALL)

Terminology/rating	2	"Word "bother"..."not sure how many other kids would understand that..." "I just read it like how much does this bug you." (11-year-old girl with a brain tumor)

All 18 children identified aspects of the app that they enjoyed. The most frequently identified aspects of the app were those that supported their creativity and provided choices (*n* = 22 responses). Children also reported enjoying the rewards and incentives in the app (*n* = 10 responses), and the personal aspects of the app (*n* = 8 responses). Three children's responses addressed clinical relevance including perceived ease of symptom reporting and specifying symptom location through drawing.

When asked to identify what they did not like about the app, 10 children actively denied anything that they disliked, e.g., "Um, none of it." Seven children related aspects of the app that they disliked. Of note, a 6-year-old boy with ALL reported disliking, "everything," about the app. During his mother's interview, however, this child interacted with features within the app and showed his creations to the interviewer. Five children described aspects of the app's navigation (*n* = 3 responses) and features of the app (*n* = 2 responses) that they disliked. One 12-year-old boy with ALL described difficulty remembering to use the app each day.

Fourteen children provided suggestions for improvement that were grouped into two larger categories related to different aspects of the user experience. These included enhancing user engagement (*n* = 15 responses), primarily through increasing choices in existing features or providing more activities within the app, and improving the usability of the app (*n* = 4 responses).

Sixteen of the 18 children who participated in the interviews affirmed willingness to use the app again. Fifteen indicated a preference for reporting symptoms using the app. Reasons addressed the potential clinical benefits of app-based reporting such as "easier to explain," and the ability to "... be more specific," as well as the multisensory experience, "... the different things you can do on it."

Parents
Nineteen parents participated in interviews at the close of the data collection period. Responses are summarized in Table 5.

Table 5 Categories and subcategories of parents' acceptability interview responses

Category and subcategory names	n	Exemplars
What did you like best about the app?		
Fun and interactive	19	
Element of "fun"	6	"It's just fun. I like how it's colorful," (mother of an 8-year-old girl with ALL)
Opportunity for the child to express self	5	"that it had a spot for him to write his thoughts," (mother of a 12-year-old boy with ALL)
Choices within the app (e.g., drawing)	4	"I liked the creative part of it. Letting them go and color and draw." (mother of a 6-year-old boy with osteosarcoma)

Parent/child interaction (e.g., showing what he/she did)	2	"...he'd show me the funny things that he said or did or whatever so it was fun." (mother of an 11-year-old boy with lymphoma)
Provides incentives	2	"liked that it had goals and made sure that he'd remember, kind [of] an extra incentive to remember to brush his teeth and remember to take his bath and all of those things," (mother of an 11-year-old boy with lymphoma)
Easy and enjoyable to use	18	
Easy for the child to use	6	"I just like that it was so easy for him to use." (mother of a 10-year-old boy with Hodgkin lymphoma)
Parent did not have to help or be the one providing the report	5	"she can put it down and I did not have to think about it," (mother of an 8-year-old girl with pilocytic astrocytoma)
Enjoyable for the child and/or parent to use	4	"She enjoyed, you know, playing on it and using it," (mother of an 11-year-old girl with a brain tumor
Creative approach to achieving the objective	3	"is just a fun way for her to talk about what's going on I guess," (mother of a 7-year-old girl with ALL)
Supports the child's own report	16	
Child is the one providing the report	8	"I liked that it basically he could tell us how he felt without having to answer questions like from us verbally." (mother of a 12-year-old boy with ALL)
Child is the one entering his/her own information	4	"I liked that she could put in how she's feeling," (mother of a 7-year-old girl with ALL)
Less intimidating for the child by not having to talk	4	"I think it's a good way for kids to express themselves because some kids do not like to talk or they do not share how they feel." (mother of a 10-year-old boy with Hodgkin lymphoma)
Consequences of the child's own report	14	
Facilitates awareness and recall of symptoms	5	"...liked that it reminded us of the little things that you think 'Oh she felt well today' but then you are like 'No she had a headache.'" (mother of an 8-year-old girl with ALL)
Supports more accurate/precise reporting	5	"... but she can write down on her thing, and kids know exactly where it was hurting which I think were good where she might not describe it to the doctor." (mother of an 8-year-old girl with ALL)
Facilitates parent/child discussion about symptoms	4	"then he was also more open with us, like this is what is going on and I can show you sort of thing." (mother of an 8-year-old boy with Hodgkin lymphoma)
What did you not like about the app?		
Denied dislikes	8	"I really cannot think of anything." (mother of an 11-year-old boy with lymphoma)
Child user engagement	6	
Not sufficiently engaging/interactive	4	"...it just wasn't engaging for him. I wish it would have like kept his attention better." (mother of an 8-year-old boy with ALL)

Stickers not a sufficient incentive	2	"like the stickers, I mean are OK. But I think sometimes they do not do anything." (mother of a 6-year-old boy with osteosarcoma)
Child user experience	3	"...I was watching and that's the only thing is we could not figure out how to get out of the diary, but that's it." (mother of a 10-year-old boy with Hodgkin lymphoma)
Additional parent burden	3	"...with all her homework and all her other stuff is one more thing to do." (mother of an 8-year-old girl with ALL)
What would you change about the app?		
Enhance user engagement	10	
Increase activities and interaction within the app	4	"games puzzles or something for them to kind of do different things" (mother of a 7-year-old girl with ALL)
Different activities for older children	3	"might have been better to have something a little bit a part of it that is more challenging maybe for a 12-year-old because it does have kind of a wide range." (mother of a 12-year-old boy with ALL)
Enhance incentivization/reward system	3	"Rewards, something for them to work toward, because every game they have is like they are trying to get there, reach a different level or something like that," (mother of a 7-year-old boy with Burkitt lymphoma)
Enhance usability	6	
Improve navigation (includes for children with sensory deficits)	4	"it says that it will save it, but if you go in and try and change it you have reenter all the symptoms again" (mother of an 8-year-old boy with Hodgkin lymphoma)
Enhance the presentation/appeal	2	"kind of like 3D," (mother of a 7-year-old boy with Burkitt lymphoma)
Facilitate parent access to the child's report	4	"what would be cool if ... it could like send it to like the parent like if the parent had an app," (mother of an 8-year-old boy with ALL)

All parents related at least one aspect of the app that they enjoyed. Parents endorsed the interactive nature of the app (n = 19 responses) and felt it provided an outlet to support the child's creativity, such as through drawing, in addition to reporting symptoms. Parents reported that the child could use the app easily (n = 18 responses) and that they did not have to be heavily involved.

Parents recognized the clinical relevance of a child-centric approach to symptom reporting (n = 16 responses). Specifically, they endorsed the value of the child giving his/her own report rather than their reporting on behalf of their child. Several parents related that their child did not like to talk with clinicians and/or was intimidated by having to respond verbally at clinic visits. They specifically endorsed the value of a resource that could support the child's report without being made to talk at visits. Four parents also addressed the perceived value of the app in allowing the child to be the one who entered the symptom report—not just relating the information but being the one who physically entered the information via the app. Parents related important perceived benefits of the child's report (n = 14 responses). These included a greater awareness and recall of symptoms, the potential for more

accurate and precise symptom reporting, and facilitation of parent and child discussion about symptoms. Three parents whose children had been receiving treatment for 6 months or longer reported the app would have been of greater benefit if it had been introduced earlier in the child's treatment.

Ten parents provided specific critiques of the app. Critiques related to limited user engagement were most frequent (*n* = 6 responses) and related to both opportunities for interaction and incentives beyond earning stickers. A parent of an older child commented on a desire for the app to be more challenging. Three parents also offered critiques related to the general user experience including the animation style, a navigation issue with the diary, and expressed confusion with the term "bother" as a means to express distress. Critiques also addressed potential burden for both parents and children associated with the app's use (*n* = 3 responses) including remembering to use the app and having an additional thing to do.

Thirteen parents offered suggestions for improving the app, and six denied having suggestions for improvement. Suggestions related to enhancing the child user's experience (*n* = 10 responses) centered around increasing activities and opportunities for interaction, including different activities for older children, and enhancing incentives. Parents provided suggestions to enhance the app's usability (*n* = 6 responses), primarily through improving specific aspects of navigation. Suggestions included needs of children with physical or sensory deficits occurring as a consequence of the child's cancer and/or its treatment. Parents also expressed a desire for access to the child's report (*n* = 4 responses), potentially through a parent portal or a separate parent log in process.

Discussion

The study advances investigation of the role of mHealth resources to support symptom tracking among children with cancer between clinical encounters with attention to users' interactions with a given technology and their attitudes toward that technology [[23]]. While mHealth resources, including apps, are not interventions themselves, they can support efforts to better understand the patient experience [[36]]. Because self-report is the gold standard for symptom reporting [[27]] and children have the capacity to provide self-report [[37]]–[[39]], child-centric approaches to facilitate their self-report are essential and are part of a personalized approach to symptom management.

Study results support the app's preliminary feasibility and provide insight into contextual factors to guide its future development [[40]]. Although children's patterns of app use varied, their overall median use of 80% of requested days was similar to previous feasibility reports of initial evaluations of symptom tracking resources for children and adolescents with cancer [[42]]. As with any mHealth technology, motivation for daily use varied. Some participants may not have felt well enough to be externally motivated to use the app each day. Existing rewards within the app may not have provided sufficient motivation for others.

Acceptability, another interrelated aspect of feasibility [[40]], was evident among both children and parents. Both children and parents addressed the app's developmental relevance and its role in supporting the child's autonomy. Children, specifically, named the elements of having choices, an outlet for creativity, and the opportunity for personalization within the app. Parents valued that the app supported the ability of the child to provide his or her own symptom report and that he or she was

the one who generated the report. Several parents specifically related that their children do not like to provide verbal reports and that the app provided a less intimidating format for symptom reporting. By incorporating multisensory approaches that allow children time to reflect and organize their responses, the app may enhance children's recall, leading to improved symptom reporting [[44]]. Of further clinical relevance, parents indicated that the app supported their own awareness of the child's symptoms, even on days when the child appeared to be feeling well. Several parents related a greater perceived benefit of tracking symptoms earlier in the child's treatment continuum, an important consideration for future implementation.

Although both children and parents provided suggestions to improve navigation, parents endorsed the app's overall ease of use and that the child could use the app independently. Consistent with the iterative, user-centered process guiding the app's development [[32], [46]], interview questions were structured to avoid social desirability of responses and to retain the child in the position of collaborator and co-designer. Allowing children and parents to propose improvements for the app supported a more generative discussion beyond stating likes and dislikes and engaged them in the app's continued development.

Limitations
Limitations included a single site and limited racial/ethnic diversity. Although the study sample was small, it represented diagnoses typical among children 6 to 12 years of age. The heterogeneity with regard to treatment stage supported exploration of how the app might be utilized at different times during the child's treatment to support a personalized approach to symptom management. Because date/time stamps were generated only as data were saved, the actual duration time that children interacted with the app each day was unable to be assessed.

Future directions
Both children and parents provided guidance to further optimize the child user's experience to support the app's future adoption by child and parent users [[23]]. Priorities for future development include enhancement of existing features, inclusion of additional activities, and expansion of the incentive/reward system. Additional priority should be given to enhancing aspects of navigation within the app which will further support the app's usability.

Priorities for research include investigation of the app's potential for success as a developmentally relevant resource for symptom reporting. Consistent with a personalized health approach, research is needed to identify children and parents who are most likely to benefit from a symptom-reporting app and when they are likely to receive the greatest benefit. Gaining additional understanding of the reasons for variability in use including intra-individual characteristics of children and/or parents, perceived need for symptom monitoring based on treatment phase, and potential burden associated with daily reporting will further guide implementation of the app. Studies exploring parents' and clinicians' responses to reported symptoms and initiation of management strategies whether in the home or healthcare setting are needed. Additionally, studies addressing the app's efficacy as a resource to guide shared decision-making to alleviate symptoms are needed.

As the user experience is optimized and further clinical utility of the app is demonstrated, future directions for the app's development include collaboration with clinical informatics experts and

continued efforts toward integration with electronic health record (EHR) systems. Engaging clinicians as research collaborators with attention to clinician workflow will be essential to determining how best to integrate the child's self-reported data in a manner that can guide clinical decisions. Preliminary efforts to support future integration of the child's data are in place to support future work. The.json file format, currently used for saving children's self-reported data in the app, is a standard data interchange format primarily used to transmit data between a web application and a server [[47]]. Additional efforts to support EHR integration include supporting semantic interoperability by mapping terminology within the app to standard-based terminologies such as SNOMED and LOINC [[48]].

This study describes the initial evaluation of a newly developed game-based symptom-reporting app among school-age children receiving treatment for cancer. Results provide guidance for future refinements to the app and its potential role to support a personalized approach to symptom management.

Funding information

Data availability

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

Compliance with ethical standards

Institutional review board approval was granted for the study. Parents provided written permission for the child's participation and informed consent for their own participation. Children 7 to 12 years of age provided written assent. Children who were 6 years of age provided verbal assent.

Conflict of interest

The authors declare that they have no conflict of interest.

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References

1. Hinds PS, Gattuso JS, Fletcher A, Baker E, Coleman B, Jackson T, Jacobs-Levine A, June D, Rai SN, Lensing S, Pui CH (2004) Quality of life as conveyed by pediatric patients with cancer. Qual Life Res 13:761–762
2. Momani TG, Mandrell BN, Gattuso JS, West NK, Taylor SL, Hinds PS (2015) Children's perspective on health-related quality of life during active treatment for acute lymphoblastic leukemia: an advanced content analysis approach. Cancer Nurs 38:49–58

3. Withycombe JS, Haugen M, Zupanec S, Macpherson CF, Landier W (2019) Consensus recommendations from the Children's Oncology Group Nursing Discipline's State of the Science Symposium: symptom assessment during childhood cancer treatment. J Pediatr Oncol Nurs 36:294–299

4. Dupuis LL, Lu X, Mitchell HR, Sung L, Devidas M, Mattano LA Jr, Carroll WL, Winick N, Hunger SP, Maloney KW, Kadan-Lottick NS (2016) Anxiety, pain, and nausea during the treatment of standard-risk childhood acute lymphoblastic leukemia: a prospec- tive, longitudinal study from the Children's Oncology Group. Cancer 122:1116–1125

5. Hockenberry MJ, Hooke MC, Rodgers C, Taylor O, Koerner KM, Mitby P, Moore I, Scheurer ME, Pan W (2017) Symptom trajecto- ries in children receiving treatment for leukemia: a latent class growth analysis with multitrajectory modeling. J Pain Symptom Manag 54:1–8

6. Hockenberry MJ, Taylor OA, Pasvogel A, Rodgers C, McCarthy K, Gundy P, Montgomery DW, Ribbeck P, Scheurer ME, Moore IM(K) (2014) The influence of oxidative stress on symptom occur- rence, severity, and distress during childhood leukemia treatment. Oncol Nurs Forum 41:E238–E247

7. Linder LA, Al-Qaaydeh S, Donaldson G (2018) Symptom charac- teristics among hospitalized children and adolescents with cancer. Cancer Nurs 41:32–32

8. Miller E, Jacob E, Hockenberry MJ (2011) Nausea, pain, fatigue, and multiple symptoms in hospitalized children with cancer. Oncol Nurs Forum 38:E382–E393

9. Baggott C, Dodd M, Kennedy C, Marina N, Matthay KK, Cooper BA, Miaskowski C (2010) Changes in children's reports of symp- tom occurrence and severity during a course of myelosuppressive chemotherapy. J Pediatr Oncol Nurs 27:307–315

10. Torres V, Nunes MDR, Silva-Rodrigues FM, Bravo L, Adlard K, Secola R, Fernandes AM, Nascimento LC, Jacob E (2019) Frequency, severity, and distress associated with physical and psy- chosocial symptoms at home in children and adolescents with can- cer. J Pediatr Health Care 33:404–414

11. Linder LA, Bratton H, Nguyen A, Parker K, Wawrzynski S (2018) Symptoms and self-management strategies identified by children with cancer using draw-and-tell interviews. Oncol Nurs Forum 45:290–300

12. Rodgers CC (2011) Health promotion of the school-age child and family. In: Wilson MJHD (ed) Wong's nursing care of infants and children, 9th edn. Elsevier Inc., St. Louis, pp 645–683

13. Greene S, Hill M (2005) Researching children's experience: methods and methodological issues. In: Greene S, Hogan D (eds) Researching children's experience. Sage Publications, Inc., Thousand Oaks, pp 1–21

14. Wesley KM, Fizur PJ (2015) A review of mobile applications to help adolescent and young adult cancer patients. Adolesc Health Med Ther 6:141–148

15. Linder L, Ameringer S, Erickson J, Macpherson CF, Stegenga K, Linder W (2013) Using an iPad in research with children and ado- lescents. J Spec Pediatr Nurs 18:158–164

16. Rogers Y, Price S (2009) How mobile technologies are changing the way children learn. In: Druin A (ed) Mobile technology for children: designing for interaction and learning. Morgan Kaufmann Publishers, Burlington, pp 3–22

17. Kato PM, Cole SW, Bradlyn AS, Pollock BH (2008) A video game improves behavioral outcomes in adolescents and young adults with cancer: a randomized trial. Pediatr 122:e305–e317

18. Johnson D, Deterding S, Kuhn KA, Staneva A, Stoyanov S, Hides L (2016) Gamification for health and wellbeing: a systematic review of the literature. Internet Interv 6:89–106

19. Theng YL, Lee JW, Patinadan PV, Foo SS (2015) The use of videogames, gamification, and virtual environments in the self- management of diabetes: a systematic review of the evidence. Games Health J 4:352–361

20. Jibb LA, Stevens BJ, Nathan PC, Seto E, Cafazzo JA, Johnston DL, Hum V, Stinson JN (2017) Implementation and preliminary effectiveness of a real-time pain management smartphone app for adolescents with cancer: a multi-center pilot clinical study. Pediatr Blood Cancer 64:e26554

21.	Macpherson CF, Linder LA, Ameringer S, Erickson J, Stegenga K, Woods NF (2014) Feasibility and acceptability of an iPad application to explore symptom clusters in adolescents and young adults with cancer. Pediatr Blood Cancer 61:1996–2003

22. Jupp JCY, Sultani H, Cooper CA, Peterson KA, Truong TH (2018) Evaluation of mobile phone applications to support medication adherence and symptom management in oncology patients. Pediatr Blood Cancer 65:e27278

23.	Venkatish V, Bala H (2008) Technology acceptance model 3 and a research agenda on interventions. Decis Sci 39:273–315

24.	Magnussun D (2000) The individual as the organizing principle. In: Bergman LR, Cairns RB, Nillson LG, Nystedt L (eds) Developmental science and the holistic approach. Lawrence Erlbaum Associates, Publishers, Mahwah, pp 33–47

25.	Miles MS, Holditch-Davis D (2003) Enhancing nursing research with children and families using a developmental perspective. In: Miles MS, Holditch-Davis D (eds) Annual review of nursing re- search. Springer, New York, pp 1–22

26.	Cleeland CS, Fisch MJ, Dunn AJ (2011) Introduction to cancer symptom science. In: Cleeland CS, Fisch MJ, Dunn AJ (eds) Cancer symptom science: measurement, mechanisms, and manage- ment. Cambridge University Press, New York, pp 1–3

27.	Cleeland CS, Mendoza TR (2011) Symptom measurement by pa- tient report. In: Cleeland CS, Fisch MJ, Dunn AJ (eds) Cancer symptom science: measurement, mechanisms, and management. Cambridge University Press, New York, pp 268–284

28.	Humphreys J, Lee KA, Carrieri-Kohlman V et al (2008) Theory of symptom management. In: Smith MJ, Liehr PR (eds) Middle range theory for nursing, 2nd edn. Springer Publishing, New York, pp 145–158

29.	Linder LA, Altizer R (2018) Engaging children and healthcare pro- viders in the co-design of a mobile technology-based symptom a s s e s s m e n ta p p . A P H O N . h t t p: // 1ad5fbcf8a40b07276ffe8d7f0d21a986d23058582d1d01f2732.r54. cf1.rackcdn.com/210-1-Engaging-Children-and-Healthcare- Providers-i.pdf. Accessed 15 July 2019

30.	Linder LA, Wawrzynski SE (2018) Staff perceptions of symptoms, approaches to assessment, and challenges to assessment among children with cancer. J Pediatr Oncol Nurs 35:332–341

31.	Therapeutic Games and Apps Lab. https://library.med.utah.edu/ synapse/gapp/. Accessed March 23, 2019

32. Altizer R, Zagal J (2014) Designing inside the box or pitching practices in industry and education. DiGRA Proceedings. https://pdfs. semanticscholar.org/2043/1576e97d55a62c0a8cb61594e2c8c0edf7a4. pdf. Accessed 15 Jul 2019

33.	Bruggers CS, Baranowski S, Beseris M et al (2018) A prototype exercise-empowerment mobile video game for children with can- cer, and its usability assessment: developing digital empowerment interventions for pediatric diseases. Front Pediatr 9:69

34.	Elo S, Kyngäs H (2008) The qualitative content analysis process. J Ad Nurs 62:107–115

35.	Krippendorff K (2004) Content analysis: an introduction to its methodology, 2nd edn. Sage, Thousand Oaks

36.	Starkweather A, Jacelon CS, Bakken S, Barton DL, DeVito Dabbs A, Dorsey SG, Guthrie BJ, Heitkemper MM, Hickey KT, Kelechi TJ, Kim MT, Marquard J, Moore SM, Redeker NS, Schiffman RF, Ward TM, Adams LS, Kehl KA, Miller JL (2019) The use of technology to support precision health in nursing science. J Nurs Scholarsh 51:614–623

37.	Woodgate RL (2008) Feeling states: a new approach to understand- ing how children and adolescents with cancer experience symptoms. Cancer Nurs 31:229–238

38.	Tomlinson D, Dupuis LL, Gibson P, Johnston DL, Portwine C, Baggott C, Zupanec S, Watson J, Spiegler B, Kuczynski S, Macartney G, Sung L (2014) Initial development of the symptom screening in pediatrics tool (SSPedi). Support Care Cancer 22:71– 75

39. Tomlinson D, Hyslop S, Stein E et al (2019) Development of mini- SSPedi for children 4-7 years of age receiving cancer treatments. BMC Cancer 19:32. https://doi.org/10.1186/s12885-018-5210-z

40. Bowen DJ, Kreuter M, Spring B, Cofta-Woerpel L, Linnan L, Weiner D, Bakken S, Kaplan CP, Squiers L, Fabrizio C, Fernandez M (2009) How we design feasibility studies. Am J Prev Med 36:452−457

41. Orsmond GI, Cohn ES (2015) The distinctive features of a feasibility study: objectives and guiding questions. OTJR 35:169−177

42. Fortier MA, Chung WW, Martinez A, Gago-Masague S, Sender L (2016) Pain buddy: a novel use of m-health in the management of children's cancer pain. Comput Biol Med 76:202−214

43. Stinson JN, Jibb LA, Nguyen C, Nathan PC, Maloney AM, Dupuis LL, Gerstle JT, Alman B, Hopyan S, Strahlendorf C, Portwine C, Johnston DL, Orr M (2013) Development and testing of a multidi- mensional iPhone pain assessment application for adolescents with cancer. J Med Internet Res 15:e51

44. Driessnack M, Furukawa R (2012) Arts-based data collection tech- niques used in child research. J Spec Pediatr Nurs 17:3−9

45. Gross J, Hayne H, Drury T (2009) Drawing facilitates children's reports of factual and narrative information: implications for educa- tional contexts. Appl Cogn Psychol 23:953−971

46. Druin A (1999) Cooperative inquiry: developing new technologies for children with children. In Proceedings of the SIGCHI confer- ence on Human factors in computing systems: the CHI is the limit (pp. 592−599). Association for Computing Machinery. Accessed at: http://hcil2.cs.umd.edu/trs/99-14/99-14.html. Accessed 30 Apr 2020

47. Crockford D Introducing JSON. http://json.org. Accessed March 23, 2019

48. SNOMED-CT: the global language of healthcare. https://www. snomed.org/snomed-ct. Accessed March 24, 2019

49. LOINC: the universal standard for identifying health measure- ments, observations, and documents. https://loinc.org. Accessed March 24, 2019