



Identifying symptoms using the drawings of 4–7 year olds with cancer

S. Hyslop^a, L. Sung^{a,b}, E. Stein^a, L.L. Dupuis^{a,c,d}, B. Spiegler^e, E. Vettese^a, D. Tomlinson^{a,*}



^a Child Health Evaluative Sciences, Toronto, Canada

^b Division of Haematology and Oncology, Toronto, Canada

^c Department of Pharmacy, The Hospital for Sick Children, Toronto, Canada

^d Leslie Dan Faculty of Pharmacy, University of Toronto, Toronto, Canada

^e Department of Psychology, The Hospital for Sick Children, Toronto, Canada

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ABSTRACT

Purpose: Symptom burden in children with cancer who are less than 8 years old is not well understood. Our research focuses on identifying how to structure a self-report instrument for younger children. Our aim was to describe how children with cancer, aged 4–7 years, express their symptoms through drawings.

Methods: Children were asked to make drawings of a day when they were “feeling bad or not good”. Content of 18 children's drawings was analyzed.

Results: Four themes were established: physical symptoms, emotions, location and miscellaneous. Most of the drawings illustrated specific symptoms important to this age group, while also facilitating our understanding of how children with cancer view their symptoms.

Conclusion: Having children draw pictures may help initiate communication regarding how they feel, and develop rapport between the interviewer and children.

1. Introduction

Active symptom screening is important for children receiving cancer treatments. In order to accurately capture symptoms, it is important to utilize patient-reported symptoms as well as those proxy-reported by guardians or healthcare professionals. Self-reported symptoms are particularly important to ensure identification of symptoms most important to each child (Dupuis et al., 2010; Tomlinson et al., 2014).

A primary step in improving symptom control, maximizing quality of life (QoL) and reducing morbidity for children with cancer is the development of a symptom assessment tool. An assessment tool can provide a clinical profile of symptom severity, and establishes a context for understanding symptoms over time. Previous research within our team determined that existing multi-symptom screening and assessment tools were inadequate for children of all ages since they lacked content validity, were too long or too difficult to understand (O'Sullivan et al., 2014; Tomlinson et al., 2014).

Recent advances of the self-report of multiple symptoms in children with cancer include the development of electronic applications including, SISOM, a computer-based animated tool to elicit symptoms and psychosocial concerns from children with cancer (Arvidsson et al., 2016), validated in children 6–12 years; and Symptom Screening in

Pediatrics (SSPedi), an electronic tool that asks about severity of bother for 15 symptoms, validated for use in children with cancer 8–18 years of age (Dupuis et al., 2017).

We recently conducted a systematic review of symptom assessment tools in children with cancer less than 8 years of age. Existing data do not support the reliability and validity of scales for younger children and claims of robust psychometrics are supported by study populations including mainly older children with only a few younger than 8 years of age (Tomlinson et al., 2016). At the time of the systematic review, symptom assessment tools used in this population were PedsQL™, Child's Health and Illness Profile, Wong Baker Faces/Doll scale, 6 point face Likert scale and self-report symptom checklist. The review found concerns about reliability and validity in this age cohort. More specifically, internal consistency was not shown for at least one dimension for all 6 studies in which it was assessed in a younger cohort. Concerns were raised about test re-test and internal reliability. Validity was not described in any study. These findings raised concerns about the suitability of instruments in which psychometrics were evaluated in a cohort that included young children but was predominated by older children.

Unfortunately, little is known about the best approaches for developing self-report instruments for children younger than 8 years (Patel

* Corresponding author. Child Health Evaluative Sciences Hospital for Sick Children Peter Gilgan Centre for Research and Learning, 686 Bay Street, Toronto, Ontario, M5G 0A4, Canada.

E-mail address: deborah.tomlinson@sickkids.ca (D. Tomlinson).

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et al., 2016). It is understood that cognitive representation develops at around age 3–5, with the ability to think about one's own thoughts developing at age 6–8 (Arbuckle and Abetz-Webb, 2013; Patel et al., 2016). Autobiographical memory is thought to be stable among children 3–6 years old (Arbuckle and Abetz-Webb, 2013; Docherty and Sandelowski, 1999), with children as young as 4 or 5 years of age being capable of providing concrete statements regarding aspects of their health (Arbuckle and Abetz-Webb, 2013). Close-ended questions may be required to initialize engagement with the younger child (Irwin and Johnson, 2005; Kortessuoma et al., 2003). Additionally, children less than 8 years old may have difficulty differentiating between past, present and future (Arbuckle and Abetz-Webb, 2013).

Self-report issues need to be better understood from the perspective of children 4–7 years old. Identification of key symptom-related terms that are used by children of this age would enable appropriate wording to be used in a self-report instrument. In this study we used an exploratory design that included cognitive interviews to probe various aspects associated with child self-report of symptoms. Numerous studies have found that drawing can facilitate communication with children, particularly with topics they may have difficulty explaining (Altay et al., 2017; Bradding and Horstman, 1999; Driessnack, 2005; Horstman et al., 2008). As an introduction to interviews with children, in our study, based on a study by Linder and colleagues (Linder et al., 2017) and to enhance communication (Angstrom-Brannstrom and Norberg, 2014), we asked the children to draw a picture of themselves on a day where they were “feeling bad or not good”. This provided a further dimension to their interview responses, while also aiming to alleviate anxiety and aid with discussion of the child's symptom experience (Patel et al., 2016).

The aim of this study is to describe how children with cancer, aged 4–7 years, express their symptoms through drawings, as part of a larger study using cognitive interview methodology in the development of a symptom screening and assessment tool for these children.

2. Methods

This phase of our research focuses on identifying how to structure a self-report instrument for children younger than 8 years old, starting with SSPedi (O'Sullivan et al., 2016) and looking at aspects of the instrument, including possible response options, and understanding of the language used, that may differ for younger versus older children. Utilising the principles previously discussed regarding representation abilities in this age group, and how these abilities inform interview techniques, we aim to develop a version of SSPedi for children 4–7 years of age, and have named this instrument mini-SSPedi. The analysis presented here is a sub-component of a larger study that describes the results of cognitive interviews with these children.

2.1. Sample and setting

All children were receiving treatment at The Hospital for Sick Children in Toronto, Canada. Sampling for the study was purposive to ensure that a range of underlying diagnoses and age groups were included. Respondents were children 4–7 years of age. All children were receiving or had completed therapy for cancer, which included chemotherapy and/or hematopoietic stem cell transplantation. We asked primary health care providers to identify potential respondents and to introduce the researcher to the family. We excluded those with illness severity or cognitive disability that precluded their involvement, as reported by the primary healthcare team, and respondents who could not understand English.

We approached potential respondents in the inpatient or outpatient setting. For those who consented/assented to participate, demographic information was obtained directly from respondents and from their health records.

2.2. Ethics

Ethics approval was obtained from the Research Ethics Board (REB) at The Hospital for Sick Children. Informed written consent was obtained from parents. Following written parental consent, the study was explained in simple terms to the child, using the REB pre-approved assent form, that emphasised the voluntary nature of the study, the value of their thoughts and that there were no right or wrong answers. Assent was obtained if the child agreed to participate following this explanation.

2.3. Data collection

All personal interviews were performed with the children by the same Research Nurse (DT). Interviews were conducted in the hospital in either the inpatient or outpatient oncology departments. A second team member (SH, EV or ES) was also present during the interviews, to record detailed field notes that would aid in summarizing the interviews. Interview field notes and opinions were discussed with the interviewer immediately after the interview in order to obtain consensus on how the child's understanding was rated. Each cognitive interview was also audio-recorded and recordings were transcribed. A hand puppet was used by the interviewer to assist in the development of rapport with the children (Aldiss et al., 2009; Epstein et al., 2008). At the beginning of each interview the child was given the option to draw a picture of themselves on a day where they were “feeling bad or not good”. These words were considered, by the experience of the research team (including pediatric oncology health care professionals and parents), to be easily understood in this age group. Colouring sets and paper were provided. Children were asked to describe their drawing, using the probe, “tell me about your drawing”. Over-probing was avoided to ensure the child did not believe they had given a wrong answer (Conrad and Blair, 2009), and to ensure the task of explanation was not emotionally draining (Bradding and Horstman, 1999). The methods used for this part of our study are very similar to the “draw and write” technique (Bradding and Horstman, 1999; Horstman et al., 2008). This technique involves the child drawing a picture based on a theme introduced by the researcher, and the child writing down associated ideas. The researcher may also write for the child. For our study, a second researcher was available to record anything that was said or indicated by the child. This enabled the interviewer to maintain rapport and eye contact with the child. The drawing was not required to continue with the interview. The remainder of the interview focused on the larger study that probed children's understanding of the word “bother”, their ability to recall events “yesterday” and “today”, and their ability to use two- or three-option responses.

2.4. Analysis

The analysis of this study data was descriptive. To determine how children use drawings to express their symptoms during cognitive interviews, we described the children's drawings. Three authors (DT, SH, ES) viewed the drawings in relation to symptom identification. The children's drawings were taken at face value to avoid projective analyses (Pridmore and Bendelow, 1995). Documented symptoms and other words used during the probing of the drawing, by the interviewer, were listed and then sorted into themes.

3. Results

Thirty-four children were approached to participate in a cognitive interview; 2 refused and 2 were too shy to participate, as determined by their parents. Of the 30 children who participated, 18 chose to provide a drawing, with 72% depicting a physical symptom and 38.9% showing emotion (Table 1). Three children had completed active treatment, with time since completion ranging from 2 to 11 months (mean = 5

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