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Communication tools used in cancer communication with children: a scoping review protocol

Noyuri Yamaji,1 Daichi Suzuki,2 Maiko Suto,3 Kiriko Sasayama,1 Erika Ota1,4

ABSTRACT

Introduction Despite the potential benefits of effective communication, telling children about cancer, unpredictable and life-threatening conditions is challenging. This study aimed to summarise the communication tools used in cancer communication among children with cancer, caregivers and healthcare professionals.

Methods and analysis We will conduct a scoping review following the preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews checklist. We will search PubMed (including MEDLINE), Embase, CENTRAL, PsycINFO and CINAHL. We will include the qualitative and quantitative studies that reported the communication tools that tell a child diagnosed with cancer about the cancer-related information. We will summarise the communication tools and the impacts of the tools.

Ethics and dissemination Formal ethical approval is not required, as primary data will not be collected in this study. The findings of this study will be disseminated through the presentation at the conference and publication in a peer-reviewed journal.

INTRODUCTION

Rationale

Approximately 300,000 children under the age of 14 are diagnosed with cancer annually worldwide.1 Recently, over 80% of children diagnosed with cancer have survived for at least 5 years.2 However, cancer is one of the life-threatening conditions for which curative treatment may be feasible but can fail.3 Children with cancer face health threats and some of them experience cancer as a stressful and traumatic experience.4 It has been suggested that psychological care during cancer treatments is necessary to reduce the children’s psychological stress.5 Effective communication among patients, caregivers and healthcare professionals (HCPs) promotes that children adequately prepare for their treatments and future,6 while lack of information makes children anxious and distrustful of their parents and HCPs.7 8 Despite the potential benefits of communication, telling children about cancer is difficult for families and HCPs.9 10 HCPs should consider the child’s developmental stage, language, culture, understanding of the diseases, feelings and preferences.11 HCPs require excellent skills to keep a strong alliance with parents and communicate with the child about cancer.12 Some previous studies and guides suggested that children desire to maintain an open and honest approach,8 13 14 and hope.7 15 However, there is a variation of children’s preferences, and HCPs need to adapt to fit the child and family’s needs.16 17 18 More specific guides that consider these factors, such as children’s developmental stages, emotions and interaction among children, families and HCPs, are needed to convey cancer-related information to children. This lack of guidance likely contributes to the HCPs’ anxiety.19 Johnston and Appleby, showed that over 50% of paediatric physicians had anxiety before telling the bad news to children.20 HCPs might provide a limit or carefully adjusted information to children because of their anxiety. One way to deal with this is to use communication tools. Arruda-Colli et al.21 suggested that storybooks can help communicate about dying and death with children.22 Communication tools might help the HCPs convey the bad news of cancer-related information to children. However, communication with children about cancer is necessary for all children diagnosed with cancer, not just children needing end-of-life care.
Moreover, the Cochrane review was conducted in 2008 to assess the effects of interventions for improving communication with children and adolescents about cancer, treatment and implications. They focused on the randomised and non-randomised controlled trials and before and after studies and found 10 studies. This systematic review concluded that interventions for improving communication with children and adolescents about cancer have not been widely or rigorously assessed. Further research is needed to identify those effects. There is still limited evidence to support interventions to improve communication with children and their families about cancer.

Before planning this review, we conducted a systematic review to identify the effects of the audiovisual interventions to communicate with children about cancer. However, we found only two RCTs which assessed the effects of computer games about cancer, and could not show the overall conclusion. It is unclear what kind of communication tools are used to communicate with children about cancer. Although the systematic reviews can identify the effects of the specific intervention, the scoping reviews can map the key concepts that underpin a research area. Therefore, this scoping review aims to systematically map the following questions rather than focusing on the effects of the intervention: (a) What communication tools are used in cancer communication with children? (b) How are these communication tools used? (c) How are these communication tools validated and evaluated? and (d) How do these communication tools affect health outcomes?

**METHODS AND ANALYSIS**

**Study design**

We will be conducting a scoping review from 1 January 2022 through 30 June 2022. This review uses a concept similar to the review conducted by Stein et al., and focuses on communication with children about the diagnosis of their life-threatening conditions. Based on the definition by, Downing et al., cancer was defined as one of the life-threatening illnesses with an uncertain prognosis. Communication tools were defined as items or resources that help HCPs (eg, physicians, nurses, child life specialists) and families (eg, parents, caregivers) talk with children about their illness, including life-threatening conditions.

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<tr>
<th>Author, year</th>
<th>Title</th>
<th>Study design</th>
<th>Purpose of the study</th>
<th>Study setting</th>
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**Table 1** Dummy table of characteristics of included study

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**Table 2** Dummy table of characteristics of communication tools for children with cancer

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<th>Author, year</th>
<th>Contents</th>
<th>Mode/type</th>
<th>Target population</th>
<th>Developer</th>
<th>Access (cost, website, article)</th>
<th>Usage instructions</th>
<th>Evaluation or validation of communication tools</th>
<th>Impact of communication tools on healthcare outcomes and outcome measurements</th>
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conditions, and improve conversation among HCPs, children and caregivers. We will also include any communication tools, such as a checklist, book, brochure, computer game, playing with a doll and drawing. Our protocol was drafted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA-P). The research team members revised the final protocol.

Eligibility criteria
We have decided on the eligibility criteria following the PCC (Population/Concept/Context) framework for the scoping review by Joanna Briggs Institute. Inclusion criteria are specified as (a) population is children between 2 and 18 years of age diagnosed with any type and stage of cancer, (b) concept is communication tools which help HCPs and families who have children with cancer to provide information related to cancer to the children with cancer, including cancer diagnosis, the life-threatening condition, symptoms, treatments, prognosis and psychosocial effects, (c) contexts are healthcare settings to communicate with children about cancer and (d) studies are peer-reviewed original articles. There are no limits on the study design and language. If we cannot separate the data of children with cancer from adults, we will include the studies in which over 80% of the population is under 18. Exclusion criteria are specified as tools cancer-related information or educational elements (e.g., play interventions, symptom management), and interventions featuring distraction techniques to divert the child’s attention from harmful stimuli (e.g., during painful procedures).

Information sources
We will search the following electronic bibliographic databases: PubMed (including MEDLINE), Embase, CENTRAL, PsycINFO and CINAHL. The search strategy will include terms relating to population, concept and contexts, such as cancer, child, tool and communication (online additional file). We will not set any limits on periods and languages for searching.

Selection of sources of evidence
We will screen the eligible studies following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR). We will remove the duplicate studies in EndNote X9 and import them to Rayyan, a web application to screen the eligible studies. We will show the process of study selection using the PRISMA flow diagram. Two or more reviewers will independently screen the titles and abstracts of studies for the potential of meeting the inclusion criteria. Furthermore, two or more reviewers will independently screen the full text of these potentially eligible studies. Disagreements will be discussed and resolved with each other with the assistance of another reviewer.

Data charting
For the included studies, two or more reviewers will independently chart the data into a data-charting Excel form developed for this study and discuss the results (tables 1 and 2). This form was tested using two included studies in the previous study, and updated the data-charting form in an iterative process.

Data item
We will chart the following valuables:
1. Characteristics of included studies
   - year of publication
   - study setting
   - population
   - purpose of the study
   - intervention or concept
   - study design
   - findings regarding the communication tools
2. Characteristics and impacts of communication tools
   - contents
   - mode/type
   - target population
   - developer
   - access (cost, website, article)
   - usage instructions
   - evaluation or validation of communication tools
   - impact of communication tools on healthcare outcomes (e.g., self-efficacy, quality of life, knowledge, anxiety)
   - outcome measurements

Critical appraisal of individual sources of evidence
The purpose of this review is to map the existing evidence; thus, we will not assess the risk of bias for included individual studies.

Data synthesis
We will summarise the characteristics of included studies, the type of settings, populations and study designs for each group, along with the measures used and broad findings. We will also summarise the characteristics and impacts of communication tools on the table and describe the findings narratively.

Patient and public involvement
This work will analyse existing research studies, and we will not involve patients and the public. The design of this scoping review protocol did not involve patients. However, our research is based on the fundamental principle of the child-centred and family-centred care.

Acknowledgements
We wish to thank Kuniko Sato, who is a librarian, for considering the search strategy.

Contributors
NY led the conceptualisation and design of this work. MS, DS, KS and EO each made substantial contributions to the drafting and critical revision of the work, and all authors approved the final manuscript.

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Competing interests
None declared.

Patient consent for publication
Not applicable.

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REFERENCES