



Exploring key elements of approaches that support children's preferences during painful and stressful medical procedures: A scoping review

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ARTICLE INFO

Article history:

Received 7 December 2020

Revised 24 June 2021

Accepted 24 June 2021

Keywords:

Children

Medical procedures

Coping

Choice

Shared decision-making

Family-centered care

ABSTRACT

Problem: Children undergoing medical procedures can experience pain and distress. While numerous interventions exist to mitigate pain and distress, the ability to individualize the intervention to suit the needs and preferences of individual children is emerging as an important aspect of providing family-centered care and shared decision making. To date, the approaches for supporting children to express their preferences have not been systematically identified and described. A scoping review was conducted to identify such approaches and to describe the elements that are included in them.

Eligibility criteria: Studies that (a) described approaches with the aim to support children to express their coping preferences during medical procedures; (b) included the option for children to choose coping interventions; (c) included a child (1–18 years).

Sample: Searches were conducted in December 2019 and November 2020 in the following databases: Cinahl, Embase, PubMed and Psycinfo.

Results: Thirteen studies were identified that included six distinct approaches. Four important key elements were identified: 1) Aid to express preferences or choice, 2) Information Provision, 3) Assessment of feelings/emotions, 4) Feedback/Reflection and Reward.

Conclusions: Identified approaches incorporate components of shared decision-making to support children in expressing their preferences during medical procedures and treatments.

Implications: Children undergoing medical procedures can be supported in expressing their coping needs and preferences by using components of shared decision-making.

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Introduction

When children receive medical treatment in a hospital or other settings outside the hospital, they regularly undergo painful medical procedures and treatments. Evidence from Canadian hospitals shows that 75 % of the children admitted have on average one painful procedure a day (Stevens et al., 2011). Moreover, untreated pain and stress caused by medical procedures can have severe short term and long term consequences for children (Caes et al., 2014; Fox et al., 2016; Price et al., 2016). Short term consequences are increases in pain and fear during subsequent procedures and the need for higher doses of

analgesics (McMurtry et al., 2015). Long term consequences include post-traumatic stress symptoms, the development of needle fears, and health care avoidance behaviours (McMurtry et al., 2015; Price et al., 2016). Together, these consequences may adversely influence a child's development (Price et al., 2016). Therefore, it is important to address pain and distress in children and to provide interventions to prevent or reduce the negative effects of these procedures.

There are several different ways to support and comfort children during a medical procedure which could be divided into different categories. For needle related pain, the 5 P's of pain management was developed which included procedural, physical, pharmacological, psychological and process interventions (Taddio et al., 2015). In general, supporting interventions could be roughly divided into two types, pharmacological and non-pharmacological interventions (Leroy et al., 2016).

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Pharmacological interventions include sedation or local anesthesia cream, and these interventions are often effective to reduce pain but sometimes have side effects. Non-pharmacological interventions include distraction, imagery and cognitive behavioral interventions, and give children feelings of control and stimulate the development of personalized coping strategies (Chambers et al., 2009; Cohen et al., 2002; Leroy et al., 2016).

Research data indicate that non-pharmacological interventions are an essential part of procedural pain management (Chambers et al., 2009; Murphy, 2009; Nunns et al., 2018). A Cochrane review concludes there is strong evidence for the efficacy of the use of distraction, hypnosis, and combining multiple strategies to reduce needle-related pain and distress in children and adolescents (Birnie et al., 2018). However, no single non-pharmacological intervention is effective for all patients, and effectiveness may at least partially depend on the preferences and circumstances of the child and their parents (Koller & Goldman, 2012; Leroy et al., 2016; Murphy, 2009). Therefore, it is important for all healthcare professionals involved in medical procedures and who give support to the child before or during the procedure, to collaborate closely with children and parents, and to take into account their preferences, values and needs when choosing the best interventions to reduce pain and distress, because every child is unique (Koller & Goldman, 2012). Giving the child the possibility to choose, could be fostering personal power and encourage a strong internal locus of control which reduces fear (Harvey & Harris, 1975; Koller & Goldman, 2012). To determine children's preferences and needs, it is necessary to involve children (and their parents) when making choices and decisions in pain management interventions. This approach is consistent with two important care concepts: family centered care and shared decision-making.

Family Centered Care (FCC) is a care concept which emphasizes an active collaboration between patient, family and professional. It is based on the principles of partnership, uniqueness and focus on patient and family, and is associated with improved health outcomes, communication and increased satisfaction of the offered care (Fumagalli et al., 2015; Sharma et al., 2015). The key principles of FCC should be fundamental in care for children, also in medical procedures. An important factor in FCC care is shared decision-making. It is an approach in which clinicians and patients work together to make patient-centered healthcare decisions and has been demonstrated to increase decision-making ability and feelings of control, promote preparedness, reduce healthcare use, and decrease fears and concerns (Alderson et al., 2006; Coyne et al., 2016; S. M. Miller, 1979; Kunneman et al., 2016; V. A. Miller, 2009; Nannis et al., 1982). To involve children in choice will allow the child possibilities to take initiatives of his or her own and gain control (Coyne, 2008). Nevertheless, it is a challenge for healthcare professionals to engage children in active participation and to assess whether young people have the skills to be able to make decisions about their care and treatment (Ruhe et al., 2015; Soderback et al., 2011).

Professionals including nurses and child life specialists play an important role in managing pain and fear in children when undergoing medical procedures and treatments. To enable professionals to provide personal care during medical procedures, they need a systematic, evidence-based approach that supports children in expressing their own preferences. However, little research has been done on the process to create an inventory of personal needs and preferences during medical procedures and how to involve children to express their needs and preferences (Leroy et al., 2016).

As a first step to get insight in the process of involving children in their medical care with respect to medical procedures specifically, we undertook this scoping review. The objective was to provide an overview of different approaches that are available and the key elements that are included supporting children in expressing their own preferences for coping strategies during procedures and treatment, in order to decrease pain and distress.

Methods

A scoping review methodology was selected as it is appropriate for our research question. Specifically, it allows us to provide an overview of the available evidence, and to identify and analyze knowledge gaps (Munn et al., 2018). The nature of the literature does not lend itself to a systematic review due to the heterogeneous representation of the methodologies, limited number of approaches and varied outcomes reported.

For this review, the methodological framework of Arksey & O'Malley and Levac was applied (Arksey & O'Malley, 2005; Levac et al., 2010). The following steps were employed to complete this review: (1) identifying the research question(s); (2) identifying relevant studies; (3) selecting the studies; (4) charting the data; (5) collating, summarizing and reporting the results. Typically, in scoping reviews, the appraisal and inclusion of evidence is not limited by the methodological quality of that evidence, therefore a quality assessment of the studies was not carried out. The findings were reported according to the guidelines set by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018).

Search

A search strategy was developed in collaboration with a librarian, and included five concepts: (a) child, adolescent, student, infant; (b) medical procedure and related terms (e.g. venipuncture, vaccination, emergency procedure, dental); (c) (procedural) pain and distress (e.g. pain, fear, anxiety, distress, stress); (d) intervention, instrument, tool, kit, questionnaire, survey; (e) coping, preference, choice, involvement, cooperation.

Search terms were included for each concept using the Boolean operator "OR", and concepts were combined using the operator "AND"; search terms for each database were mapped using database bibliography tools and a mixture of key word and subject headings (the final search strategy is listed in appendix A).

Searches were conducted in December 2019 and then repeated in November 2020, in the following databases: Cinahl, Embase PubMed and Psycinfo. Extracted records from each of the above mentioned databases were exported to RefWorks ProQuest, through which the duplicated records were identified and excluded. In addition, Google Scholar was also searched using key words from the search strategy.

To get insight into the use of developed approaches, also including available unpublished approaches in use in practice, the first author surveyed chairs of the Pediatric Nursing Association of Europe and psychologists in Europe, United States of America and Australia. There were few responses and none identified an approach that embedded children's choices; therefore, it was decided not to include these practical applications in the review.

Article selection

Two reviewers (E.W.S. and A.H.) screened titles and abstracts of articles identified by the search according to the inclusion criteria:

- (a) Interventions, instruments or tools aiming to support children to express their own preferences (coping strategies, non-pharmacological interventions, procedure options) before a medical procedure or treatment in and out hospitals.
- (b) Possibility for children to choose, with help of their parents as necessary, and described a clear procedure of the approach.
- (c) Child or adolescent population (from 1 to 18 years).
- (d) All types of articles or guidelines will be included.
- (e) No restrictions in publication date of literature.
- (f) Papers written in English or Dutch.

For those titles/abstracts that were identified as potentially meeting the inclusion criteria, the full articles were obtained and were subject to

further review. Discrepancies in article selection were resolved through discussion between the two reviewers.

Data extraction

To extract data from each reviewed article in order to classify them in relevant themes and to describe the approaches completely a table was drawn up based on the Template for Intervention Description and Replication (TIDieR) checklist and guide (Hoffmann et al., 2016), see appendix 1.

When the process of supporting children to express their preferences was unclear or wasn't described in the article, the first author of the article was contacted by email. If no response was received a reminder was sent once. When no more information about the intervention/approach was received, the intervention was described using the information in the published papers.

Two reviewers (E.W.S. and A.H.) performed data extraction for each of the included articles. Any issues of discrepancy in extracting the procedures were resolved through mutual discussion. Both reviewers have experience in conducting systematic and scoping reviews, where AH is an academic lecturer in all kinds of reviews including scoping reviews.

Scoping analysis

A narrative synthesis (Popay et al., 2006) was conducted, summarizing the similarities and differences in building blocks of the approaches found. It included a descriptive analysis of features of the studies (e.g. population, design) and content analysis to

identify the key elements of the different approaches (Braun & Clarke, 2006). Three reviewers (E.W.S., A.H. and M.A.C.P.M.) discussed and analyzed the extracted data to identify the key elements. Disagreements were resolved by discussion until consensus was reached.

Results

Study selection and characteristics

The search produced 1595 studies from the four included electronic databases (Fig. 1). The search in November 2020 yielded no new publications. Once duplicates were removed, 1276 articles were reviewed for eligibility based on title and abstract. Subsequently, 44 articles were reviewed for eligibility based on full text review, which produced 13 eligible articles. The 13 articles included six unique approaches. Four approaches were evaluated in one article each (Ballard et al., 2017; Marsac et al., 2012; Nabors et al., 2019; Rodd et al., 2019;). One approach was evaluated in three articles (L. Jones, 2015; L. M. Jones & Huggins, 2013; Yee et al., 2017). One approach was reviewed in six articles (Freedman, Taddio, Alderman et al., 2019; Freedman, Taddio, McMurtry et al., 2019; Taddio, Freedman et al., 2019; Taddio, Ilersich et al., 2019; Taddio, Alderman, et al., 2019; Taddio, McMurtry, et al., 2019). There was 100% agreement on study inclusion between two independent reviewers.

Table 1 provides a descriptive summary of included studies.

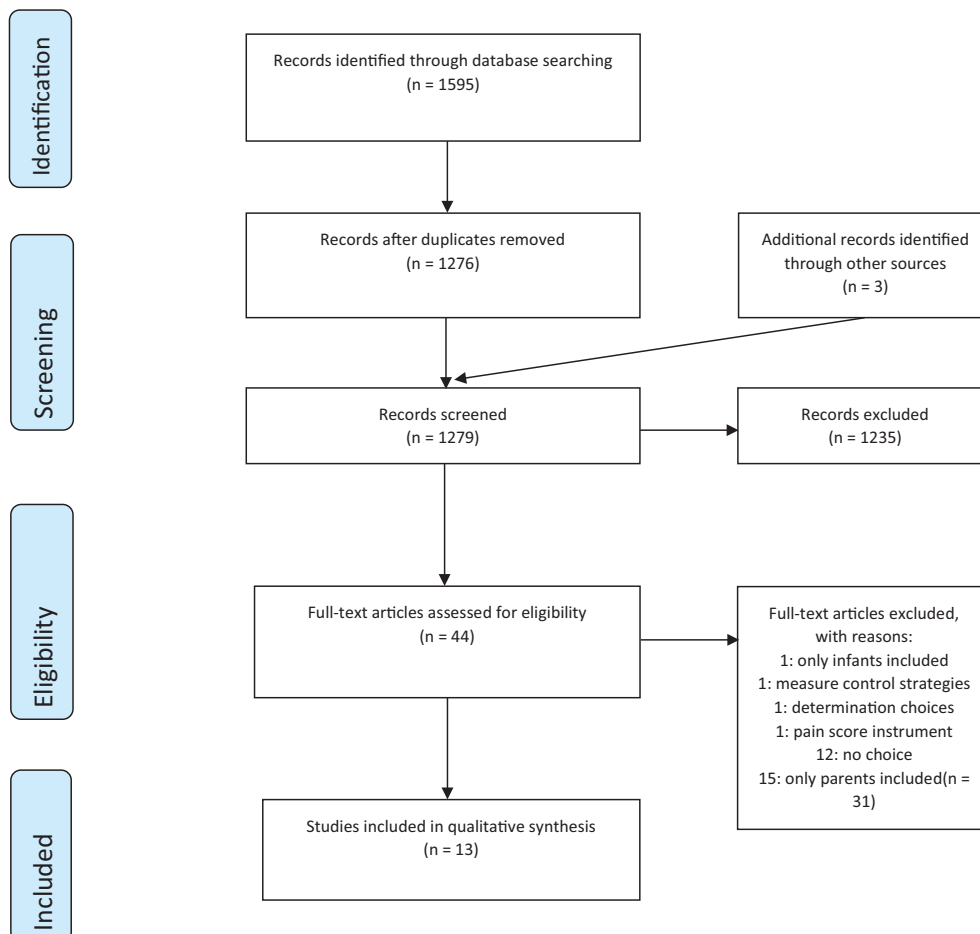


Fig. 1. PRISMA flowchart.

Table 1
Baseline characteristics of studies.

First author (year) country,	Study design	Aim of the study	Setting	Sample	Outcomes comments
Ballard et al. (2017) Canada	A one-group pre-experimental design (pilot study)	To assess the feasibility, usefulness, and acceptability of distraction kits, tailored to age, for procedural pain management.	Emergency department (ED) of a pediatric university health center	Young children, visiting the emergency department and requiring a needle-related procedure. Group 2: 3–5 yrs., 25 participants Parents and nurses assessed the distraction kits.	Distraction kits are assessed as useful and acceptable by parents and nurses. Comment: Toys which solicit more than one sense, are deemed to be more effective.
Jones and Huggins (2013) NZ	Pilot study	To pilot the Survey of Anxiety and Information to the Dentist (SAID): usability for children.	School	Children (10–13 yrs.) 34 participants in five focus groups	All children were able to complete the prototype and give feedback. Comment: Dental anxiety and coping preferences were important for children.
Jones (2015) NZ	RCT	To evaluate dental anxiety (Pre- and post- anxiety scores) and validate the SAID	School dental clinic	Children (10–13 yrs.), visiting a school dental clinic 168 participants	Significant lower anxiety level post questionnaire in intervention group. The anxiety and preferred coping subscales were robust Comment: Children wanted to be selected in the intervention group, wanted to actively engage in discussion.
Yee et al. (2017) UK	RCT	To evaluate benefits, anxiety and cooperation of the eSAID during dental visit.	Specialist pediatric dental units	Children (8–13 yrs.), visiting the specialist pediatric dentistry units 56 participants: 28 intervention, 28 control	Significant lower anxiety level post questionnaire in intervention group. Comment: Children wanted to talk to their dentist about their fears.
Marsac et al. (2012) USA	Feasibility study (quant. / qual.)	To examine the acceptability and feasibility of the Cellie Kit.	Pediatric center	Children (6–12 yrs.) diagnosed with cancer and undergoing treatment and their parents. Study 1 (qual.): 15 children, 15 parents Study 2 (quant.): 17 children, 17 parents	The kit is assessed as engaging, helpful and easy to use by children and parents.
Nabors et al. (2019) USA	Qualitative review of preferred coping styles	To examine personalization and selection of coping strategies by children for disease related worries.	Children's medical center	26 Children (4–17 yrs. mean age 9 SD 3) with different chronic illnesses and their parents, treated in a children's medical center	Children have the ability to develop personalized coping strategies for managing their anxiety. Parents, family members and pets are key support figures.
Rodd et al. (2019) UK	Pre/post design	To compare self-reported worries and pain scores before and after treatment, differences in scores between primary and secondary care settings and gender. -Insight into children's specific dental fears, coping strategies, self-reflexion, rewards.	-General dental clinic -Hospital dental clinic	Children (9–16 yrs.) deemed to be anxious for dental treatment: -53 children from hospital clinic -52 children from general dental clinic	Significant reduction of self-report pain Insight in worries: pain, uncertainty, errors
(Taddio et al., 2019) Canada	Descriptive design	To provide an overview of the steps involved in developing a knowledge translation intervention to improve vaccination experience at school	Middle school	A multidisciplinary project group of 20 members, included one parent and two students, were involved	A multifaceted knowledge translation tool is developed and implemented to address vaccination pain, fear and fainting
Freedman, Taddio, Alderman, et al. (2019) Canada	Qualitative design	To examine stakeholder perceptions of barriers and facilitators to better practices of school vaccinations	Middle school	School staff, nurses, parents, students. Focus groups: two parent groups ($n = 7$); one grade 7 to 8 student group ($n = 9$); two nurse groups ($n = 12$); and one school staff group ($n = 6$).	School is accepted as an appropriate setting for student vaccinations. Students, nurses, school staff, and parents reported being un-informed and ill-equipped to minimize student fear and pain during school vaccinations
Taddio, Freedman, et al. (2019) Canada	Quantitative and qualitative design	To assess acceptability of key tools included in a multifaceted knowledge translation intervention and their impact on knowledge and attitudes about vaccination pain and fear	Middle school	School staff, nurses, parents, students. Focus groups: four school staff groups: ($n = 16$), one nurse group: ($n = 10$); one parent group ($n = 3$); two student groups: ($n = 22$)	Preliminary acceptability and effectiveness of KT tools about pain, fear and fainting on conceptual knowledge and attitudes about pain and fear.
Taddio, Ilersich, et al. (2019) Canada	Pre-post mixed methods design	To determine the acceptability and impact of a multifaceted knowledge translation intervention on student knowledge, attitudes and perceptions of vaccination experience	Middle school	11 Students (12 yrs.) in two focus groups	Preliminary evidence of acceptability and positive impact on vaccination experience. Comment: Students used the information to plan coping strategies. However, their choices were not always supported by immunizing nurses or teachers.
Freedman, Taddio, McMurtry, et al. (2019) Canada	Mixed methods design	To evaluate a multifaceted knowledge translation intervention on student attitudes, knowledge, coping strategies used, and symptoms during school-based vaccinations	Middle school	Grade 7 students (12 yrs.) Ten schools, five experimental schools, five control schools. Focus groups: 23 students ($n = 13$ experimental, $n = 10$ control)	Preliminary evidence of the effectiveness of the intervention in improving vaccination experiences for students at school
Taddio, McMurtry, et al. (2019) Canada	Mixed methods design	To assess a multifaceted knowledge translation intervention on program evaluation outcomes (stakeholder perceptions of the vaccination process and school-based vaccination rates)	Middle school	Ten schools, five experimental schools, five control schools. Nurses ($n = 19$), school staff ($n = 27$), and parents ($n = 9$) participated in 15 focus groups.	Preliminary evidence of acceptability, appropriateness, feasibility, and satisfaction of the intervention. No difference in the school vaccination rate in experimental versus control schools.

Study and approaches characteristics

The approaches generally utilized a questionnaire to determine preferences. One approach used a visual aid: a distraction box. The identified approaches were developed for different settings and for different age categories. The distraction box was developed for use in an emergency unit for children between one and five years of age (Ballard et al., 2017). Only information about children aged 3–5 years is included in this review due to need for children to be able to provide report their preferences. Two approaches, the Survey of Anxiety and Information for Dentists (SAID) and the Message to Dentist, were developed for children between eight and 16 years to prevent or decrease fear for the dentist (L. M. Jones & Huggins, 2013; Rodd et al., 2019). One approach, the Cellie Coping Kit, was designed to be used by children with cancer, aged 6–12 years, and their parents (Marsac et al., 2012). There was one approach, the Coping with Worries Manual, for children aged 4–17 years with a chronic disease to help them with fear and worries for their treatment. Finally, the CARD System (C-Comfort, A-Ask, R-Relax, D-Distract) was designed for students 10–12 years of age undergoing vaccinations at school (Freedman, Taddio, Alderman, et al., 2019; Freedman, Taddio, McMurtry, et al., 2019; Taddio et al., 2019; Taddio, Alderman, et al., 2019; Taddio, Freedman, et al., 2019; Taddio, McMurtry, et al., 2019).

The included studies used different designs and study outcomes to evaluate the approaches (see Table 1), although five of the six approaches were investigated for feasibility and acceptability. Except for the Coping with Worries Manual and the Message to Dentist, all approaches were considered to be useful and acceptable for children in their investigated setting. Most studies did not evaluate effectiveness and outcomes were too diverse to compare, therefore, effectiveness was not evaluated in the review.

Key elements of the different approaches

Content analysis identified four distinct elements across the six approaches, described below and in Table 2.

Aid to express preferences or choice

All six approaches have the option to express preferences and choices, because this key element was a condition to be selected in this review. Preferences could be expressed about coping strategies before and during the procedure and options to get control during treatment. In five of the approaches, expressing of the preferences took place before the procedure, e.g. in the waiting room or at home

(L. M. Jones & Huggins, 2013; Marsac et al., 2012; Nabors et al., 2019; Rodd et al., 2019; Taddio et al., 2019).

Four different choice aids could be distinguished: a toy box, a questionnaire, a booklet and cards. In one study, parents were asked to help the child to make a choice from the distraction box (Ballard et al., 2017). In approaches developed for older children, the children themselves chose. In the Cellie Coping Kit, the Coping with Worries Manual and the Message to Dentist children made a choice by going through the choice options with help of their parents (Marsac et al., 2012; Nabors et al., 2019; Rodd et al., 2019). In the CARDS approach, distraction kits were available for children that did not have their own items but wanted to be distracted (Freedman et al., 2019).

Children could choose from different evidence based distraction techniques or cognitive behavioral options in all approaches. Only one approach, the CARD system, measured whether the child's choice was taken into account during the procedure (Freedman, Taddio, McMurtry, et al., 2019; Taddio et al., 2019).

See Table 2 and appendix 1 for further details of expressing preferences or choice in each approach.

Information provision

Five approaches included information provision (Ballard et al., 2017; Marsac et al., 2012; Nabors et al., 2019; Rodd et al., 2019; Taddio et al., 2019). The emergency room distraction box, the Coping with Worries Manual and the Message to the Dentist informed about the negative consequences of unmanaged pain, distress, and coping strategies (Ballard et al., 2017; Nabors et al., 2019; Rodd et al., 2019;). The Cellie Coping Kit and the CARD system provided information about the procedures (Marsac et al., 2012; Taddio et al., 2019; Taddio, Ilersich, et al., 2019; Taddio, McMurtry, et al., 2019).

The distraction box approach for young children (aged 3–5 years) developed information booklets for parents (Ballard et al., 2017;). The other approaches, for children aged 4–17 years, gave information to parents and children (Marsac et al., 2012; Nabors et al., 2019; Rodd et al., 2019; Taddio et al., 2019). Information targeted to parents was intended to help children express their preferences or to cope with the procedure and to deal with distress.

Assessment of feelings/emotions

In four approaches children aged 9–18 years were asked about their feelings (e.g., anxiety, fear, worry) before the procedure that awaits them (L. M. Jones & Huggins, 2013; Nabors et al., 2019; Rodd et al., 2019; Taddio et al., 2019). Three approaches, the SAID, the Message to Dentist and the CARD system gave children the possibility to rate their

Table 2
Characteristics of approaches.

First author (year) country	Why: approach and aim	What: procedure and Materials	What: approach key elements	Tailoring: choice options	Who: -Interventionist (helps with choice) -Executive professional (takes in account choice)
Ballard et al. (2017) Canada	Abox with toys to distract, tailored to specific age groups. To distract children during needle related procedures, giving sense of control over pain and improving hospital experience.	-Parents got kit before procedure with an information booklet -Nurse prompted parents to help their child to use toys from a kit to distract their child before procedure -The child was offered the kit at the end of the procedure and allowed to continue playing with the toys in the kit.	-Information for parents -Toys, tailored to age groups	Choice options: Toy, choice by parent (or child) Choice when: Before/during emergency visit	Interventionist: Nurse Executive professional: Nurse
Jones and Huggins (2013) NZ	Survey of Anxiety and Information for Dentists (SAID): reporting children's' coping preference.	Before treatment in waiting room: completion of a questionnaire. A print-out of the questionnaire was	- 24 questions about: + Feelings + Requests of	Choice options: Treatment request options suitable for	Interventionist: -Dental assistant in waiting

Table 2 (continued)

First author (year) country	Why: approach and aim	What: procedure and Materials	What: approach key elements	Tailoring: choice options	Who: -Interventionist (helps with choice) -Executive professional (takes in account choice)
Jones (2015) NZ Yee et al. (2017) UK	To inform clinicians how children wanted to be managed, patient centered/empathic approach.	given to the dentist by the child. (Not clear what happens during dental treatment)	treatment +Coping preferences Most answers using a 7 point faces scales, some questions with space for free text responses	Blunting coping style or Monitoring coping style Choice when: Before treatment in waiting room	room Executive professional: -Dentist
Marsac et al. (2012) USA	The Cellie Cancer Kit: a stuffed toy, 30 Cancer coping cards and a caregiver book. To augment childrens' coping strategies and to decrease distress related to cancer treatment.	The Cellie Kit provides a stuffed toy, 30 Cancer coping cards and a caregiver book with instructions for parents and children to work together. Each coping card includes cancer-related stressor and three to six specific techniques to cope with that stressor. The caregiver book parallels the coping cards, providing cancer-related stressors and specific tips plus guidance for parents on how to help children. Child and parent decide together which tips to try.	-Information for parents (psycho education stressors and coping) -Decision coaching by parents -Decision aid (cards)	Choice options: For each stressor were three to six specific coping techniques provided. Choice when: At home, before medical treatment or procedures.	Interventionist: Parent Executive professional: Professional in hospital?
Nabors et al. (2019) USA	The Coping with My Worries Manual, focused on cognitive behavioral strategies To provide children with coping strategies, increasing feelings of control and reducing stress.	A manual includes: Information for parents about anxiety management strategies and information for children about worries and five coping strategies. A coping menu for children to record worry triggers and coping strategies, and to identify rewards if used the coping strategies.	-Information for parents and child (worries and coping) -Decision aid (menu) to make personalized coping plan	Choice options: 5 coping strategies: distraction, imagination, relaxation and positive self-talk/thinking Choice when: Before or during medical treatment	Interventionist: ? Parent Executive professional: Professional in hospital?
Rodd et al. (2019)UK	The "Message to the dentist" (MTD) communication aid, part of a cognitive behavioral therapy approach To inform the dentist of worries and coping strategy. To stimulate coping strategies, self-reflexion, to have control.	Procedure: Prior to subsequent dental visit: MTD questionnaire will be completed or together with clinician before treatment. Questionnaire to get insight in worries, unhappy things, accepted care, stop signal (child and clinician), what works well, reward. Before treatment: the MTD will be discussed and acknowledged with the dentist. After treatment: reflexion on treatment and coping, current anxiety and pain with dental team and parents.	-Self report worry score before and after. -Decision aid: Questionnaire to make personalized coping plan	Choice options: -Stop sign, -Coping strategies (from a list of six suggested options: distraction, cognitive behavioral), options during treatment Choice when: Before subsequent visit, about whole treatment	Interventionist: Dental team Executive professional: Dentist, and after treatment: dental team
-Taddio, Alderman, et al. (2019) Canada -Freedman, Taddio, Alderman, et al. (2019) Canada -Taddio, Freedman, et al. (2019) Canada -Taddio, llersich, et al. (2019) Canada -Freedman, Taddio, McMurtry, et al. (2019) Canada -Taddio, McMurtry, et al. (2019) Canada	The CARD System (C-Comfort, A-Ask,R-Relax, D-Distract) is a framework for planning and delivering vaccinations. A part of the intervention is a student CARD pamphlet with spaces to record students' preferred coping interventions. To improve student's vaccination experience.	Procedure: Before vaccination day: Explanation of the tool by nurses, stimulation of selecting preferred coping strategies in the different letter categories of the word CARD (comfort, ask, relax, distract) using in class presentation including videos. Information about: procedure, coping strategies in the different letter categories. Stimulation to write down: preferences for coping strategies in the different letter categories. Vaccination day: Nurses ask students about level of fear, answer their questions and support them in their choices for comfort, relaxing and distraction. Students report their symptoms and offer suggestions for the future.	Key elements: -Staff plan and administer vaccinations with consideration of children's needs and preferences - Self rating fear -Information for students, parents and school staff -Decision aid: space to write: preferences and questions - Student participation	Choice options: Comfort, Ask, Relax, Distract (suggestions are given for each CARD letter category) Choice when: Before and during vaccination	Interventionist: Nurse Executive professional: Nurse

feelings of fear and anxiety on a scale (L. M. Jones & Huggins, 2013; Rodd et al., 2019; Taddio et al., 2019). One approach, the Coping with Worries Manual, gave children the possibility to verbally express and write down their worry triggers (Nabors et al., 2019).

Feedback/reflection and reward

Two studies, Message to Dentist and the CARD system, described the possibility of feedback or reflection and provided space in their approach to reflect on the procedure (Rodd et al., 2019; Taddio et al., 2019). They asked the children about things that worked well and to reflect on their current anxiety and pain scores. Additionally, in Message to Dentist children could describe the rewards they had planned for themselves.

The Coping with Worries Manual asked children to describe their favorite reward when they had used their chosen coping strategies (Nabors et al., 2019). All studies indicated that encouraging reflection on the procedure and choosing a reward could build positive memories for children.

Discussion

This scoping review identified approaches that support children to choose their coping preferences for medical procedures and treatment in order to decrease pain and distress, and explored the key elements included in these approaches. Altogether, six approaches were identified for the following clinical contexts: dental treatment, vaccinations, Emergency units, cancer and chronic diseases. Four distinct elements were identified across the six approaches, including: 1) choices for coping during procedures and treatments, 2) information provision, 3) assessment of symptoms, and 4) feedback/reflection and rewards.

Comparing the outcomes of this review with research of Family Centered Care (FCC) and shared decision-making (SDM) it is noteworthy that principles of both FCC and SDM are evident in the included approaches of this review. The key element 'Information provision' exhibits an important FCC principle. It included information targeted to teach parents and children, which was always intended to help children express their preferences or to cope with the procedure and to deal with distress. Where the key principles of FCC are fundamental in care for children, also in medical procedures, SDM is actively practicing this in making choices. The key elements that emerged from the included approaches in this review fit with components of SDM. Bomhof-Roordink et al. described the prominence of key components in SDM models per healthcare setting. In pediatric SDM models, the components 'provide and tailor information', 'describe treatment options', 'patient preferences', 'determine next step', 'foster partnership' and 'make the decision' occur frequently (Bomhof-Roordink et al., 2019).

The key elements can also be recognized in the dimensions information, probabilities, values, and decision guidance as described in the International Patient Decision Aid Standards checklist, which provides information on content, development, and effectiveness of decision aids (Joseph Williams et al., 2014).

Literature about SDM in children emphasizes the need to take into account the developmental stage of the child. Professionals need to provide choice options based on the child's age, experiences and emotional state, and should be aware that children's preferences may change due to different circumstances (Coyne et al., 2014; Ruhe et al., 2015). In the approaches included in this review, the choice options that children received was mainly tailored to the child's age, which varied from three to 17 years. Approaches for younger children (three –5 years) gave the option to choose a concrete subject (toy) at the moment just before the procedure. Children from four years onwards received information about choice options before the medical procedure and they could also choose from more abstract, cognitive-behavioral interventions. The younger the children, the more involved the parent was in the choice process. The studies did not include children with developmental

delay and therefore does not provide insight into options for personalized pain and distress management for this patient population.

The key element 'asking for feelings' is an element specific for the approaches of this review, aiming to decrease associated symptoms, including fear and anxiety. As described earlier, medical procedures not only cause pain but also fear and other symptoms (e.g., anxiety, distress, fainting), therefore interventions are required to address all of these, not just pain (Heden et al., 2016). Nevertheless, questions can be raised as to whether asking for fear and worry can cause or exacerbate fear. Research suggests that negative suggestions before or during medical procedures might result in greater anxiety but that asking about symptoms in a neutral way may avoid this (Lang et al., 2005). In one approach, the CARDS system, Taddio et al. observed a lower fear score in the experimental group and students indicated afterwards that being asked about fear showed them that nurses cared about them (Taddio et al., 2019). It is helpful for children when professionals are attentive to their feelings and experiences (Soderback et al., 2011).

A limitation of the results is that they are based on a small number of approaches in the included studies of this review. It is possible that more tools exist but that they have not been evaluated or published in scientific papers, and were therefore not identified. Given that 5 of the 6 included approaches were published in the last five years suggests, however, that research in this area is relatively new.

Another limitation of this review is the gap in knowledge about the use of the approaches in practice (see appendix 1). This became clear by using the TiDieR checklist as a data extraction form, which is developed to improve the quality of intervention descriptions. Several intervention features mentioned in the TiDieR checklist were not described in the included studies, such as training of professionals, modifications during the course of the study and assessment of adherence. Only the studies evaluating the CARD System gave insight into intervention characteristics (Taddio, Alderman et al., 2019; Taddio et al., 2019). It seems that after the development, the long-term implementation at institutional level has not been investigated for most of the approaches. This makes it difficult to get insight in use and impact of the approach as intended. For example, it is not clear whether the child's choice was finally taken into account, the role of the parents in the choice process and how the coping strategies were applied during the medical procedure in daily practice. More research is required about the implementation of interventions after the developing phase in order to get more insight in the possible barriers. Using an evidence based framework such as the Consolidated Framework For Implementation Research (CFIR) or the MRC framework for developing complex interventions is highly recommended to provide evidence based, useful interventions that meets the needs of the stakeholders (Craig et al., 2008; Damschroder et al., 2009).

The strengths of this review are the rigor of the methods, including the comprehensive search strategy, the use of the TiDieR checklist as a data extraction form and inclusion of multiple raters to extract and analyze the data. To the best of our knowledge, this is the first review reporting on approaches to support children's preferences before medical procedures, and identified their key elements that can form the basis for further developments, adaptations and evaluations that will support effective participation of children's in their health care.

Conclusion

This review provides an overview of six approaches which support children in expressing their preferences for coping strategies during procedures and treatment. Four elements were identified which fit in the concept of SDM. The given choice options in the approaches were age-related. Components of SDM can be used to support children in expressing their preferences for procedures and treatment and to personalize procedural pain and distress management. Further research is needed to gain insight in the process of implementation and the actual

use of the approaches in practice, including the experiences of children and parents.

The findings reveal the importance of providing patient-oriented information prior to the procedure about the problem (fear and pain for medical procedures) and the choice options, before children (often, with help of their parents) are able to make their choice. Afterwards, it is helpful for children when there is attention for their feelings, experiences and reward.

Funding

This research did not receive any specific grant from funding agencies on the public, commercial, or not-for-profit sectors.

CRediT authorship contribution statement

E.W. Segers: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Writing - original draft, Visualization. M. Ketelaar: Conceptualization, Methodology, Writing - review & editing, Supervision. A. Taddio: Writing - review & editing. M.A.C.P. de Man: Formal analysis, Writing - review & editing. L. Schoonhoven: Conceptualization, Validation, Writing - review & editing. E.M. van de Putte: Conceptualization, Validation, Writing - review & editing. A. van den Hoogen: Conceptualization, Methodology, Investigation, Formal analysis, Writing - review & editing, supervision.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pedn.2021.06.018>.

References

- Alderson, P., Sutcliffe, K., & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, *91*(4), 300–303.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32.
- Ballard, A., Le May, S., Khadra, C., Lachance Fiola, J., Charette, S., Charest, M., ... Tsimicalis, A. (2017). Distraction kits for pain management of children undergoing painful procedures in the emergency department: A pilot study. *Pain Management Nursing*, *18*(6), 418–426. <https://doi.org/10.1016/j.pmn.2017.08.001>.
- Birmie, K. A., Noel, M., Chambers, C. T., Uman, L. S., & Parker, J. A. (2018). Psychological interventions for needle-related procedural pain and distress in children and adolescents. *Cochrane Database of Systematic Reviews*, *10*, <https://doi.org/10.1002/14651858.CD005179.pub4>.
- Bomhof-Roordink, H., Gärtner, F. R., Stiggelbout, A. M., & Pieterse, A. H. (2019). Key components of shared decision making models: A systematic review. *BMJ Open*, *9*(12), e031763–031763. <https://doi.org/10.1136/bmjopen-2019-031763>.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.
- Caes, L., Vervoort, T., Devos, P., Verlooy, J., Benoit, Y., & Goubert, L. (2014). Parental distress and catastrophic thoughts about child pain: Implications for parental protective behavior in the context of child leukemia-related medical procedures. *The Clinical Journal of Pain*, *30*(9), 787–799. <https://doi.org/10.1097/AJP.000000000000028>.
- Chambers, C. T., Taddio, A., Uman, L. S., & McMurtry, C. M. (2009). Psychological interventions for reducing pain and distress during routine childhood immunizations: A systematic review. *Clinical Therapeutics*, *31*(Suppl. 2), S77–S103. <https://doi.org/10.1016/j.clinthera.2009.07.023>.
- Cohen, L. L., Bernard, R. S., Greco, L. A., & McClellan, C. B. (2002). A child-focused intervention for coping with procedural pain: Are parent and nurse coaches necessary? *Journal of Pediatric Psychology*, *27*(8), 749–757. <https://doi.org/10.1093/jpepsy/27.8.749>.
- Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, *45*(11), 1682–1689. <https://doi.org/10.1016/j.ijnurstu.2008.05.002>.
- Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing*, *18*(3), 273–280. <https://doi.org/10.1016/j.ejon.2014.01.006>.
- Coyne, I., O'Mathuna, D. P., Gibson, F., Shields, L., Leclercq, E., & Sheaf, G. (2016). Interventions for promoting participation in shared decision-making for children with cancer. *The Cochrane Database of Systematic Reviews*, *11*, CD008970. <https://doi.org/10.1002/14651858.CD008970.pub3>.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., & Medical Research, C. G. (2008). Developing and evaluating complex interventions: The new

- medical research council guidance. *BMJ*, *337* a1655; a1655–a1655. <https://doi.org/10.1136/bmj.a1655>.
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, *4* 50–50. <https://doi.org/10.1186/1748-5908-4-50>.
- Fox, J. K., Halpern, L. F., Dangman, B. C., Giramonti, K. M., & Kogan, B. A. (2016). Children's anxious reactions to an invasive medical procedure: The role of medical and non-medical fears. *Journal of Health Psychology*, *21*(8), 1587–1596. <https://doi.org/10.1177/1359105314559620>.
- Freedman, T., Taddio, A., Alderman, L., McDowall, T., de Vlaming-Kot, C., McMurtry, C. M., ... Pain Pain Go Away Team (2019). The CARD system for improving the vaccination experience at school: Results of a small-scale implementation project on student symptoms. *Paediatrics & Child Health*, *24*(Suppl. 1), S42–S53. <https://doi.org/10.1093/pch/pxz020>.
- Freedman, T., Taddio, A., McMurtry, C. M., Wong, H., MacDonald, N., McDowall, T., ... Pain Pain Go Away Team (2019). Involving stakeholders in informing the development of a knowledge translation (KT) intervention to improve the vaccination experience at school. *Paediatrics & Child Health*, *24*(Suppl. 1), S19–S28. <https://doi.org/10.1093/pch/pxz017>.
- Fumagalli, L. P., Radaelli, G., Lettieri, E., Bertele, P., & Masella, C. (2015). Patient empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health Policy*, *119*(3), 384–394. <https://doi.org/10.1016/j.healthpol.2014.10.017>.
- Harvey, J. H., & Harris, B. (1975). Determinants of perceived choice and the relationship between perceived choice and expectancy about feelings of internal control. *Journal of Personality and Social Psychology*, *31*(1), 101–106. <https://doi.org/10.1037/h0076169>.
- Heden, L., von Essen, L., & Ljungman, G. (2016). The relationship between fear and pain levels during needle procedures in children from the parents' perspective. *European Journal of Pain*, *20*(2), 223–230. <https://doi.org/10.1002/ejp.711>.
- Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., ... Michie, S. (2016). Better reporting of interventions: Template for intervention description and replication (TIDieR) checklist and guide. *Gesundheitswesen (Bundesverband Der Ärzte Des Öffentlichen Gesundheitsdienstes (Germany))*, *78*(3), 175–188.
- Jones, L. (2015). Validation and randomized control trial of the e-SAID, a computerized paediatric dental patient request form, to intervene in dental anxiety. *Child: Care, Health and Development*, *41*(4), 620–625.
- Jones, L. M., & Huggins, T. J. (2013). The rationale and pilot study of a new paediatric dental patient request form to improve communication and outcomes of dental appointments. *Child: Care, Health and Development*, *39*(6), 869–872.
- Joseph Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. <https://doi.org/10.1016/j.pec.2013.10.031>.
- Koller, D., & Goldman, R. D. (2012). Distraction techniques for children undergoing procedures: A critical review of pediatric research. *Journal of Pediatric Nursing*, *27*(6), 652–681. <https://doi.org/10.1016/j.pedn.2011.08.001>.
- Kunnen, M., Montori, V. M., Castaneda-Guarderas, A., & Hess, E. P. (2016). What is shared decision making? (and what it is not). *Academic Emergency Medicine: Official Journal of the Society for Academic Emergency Medicine*, *23*(12), 1320–1324. <https://doi.org/10.1111/acem.13065>.
- Lang, E. V., Hatsiopolou, O., Koch, T., Berbaum, K., Lutgendorf, S., Kettenmann, E., ... Kaptchuk, T. J. (2005). Can words hurt? Patient-provider interactions during invasive procedures. *Pain*, *114*(1–2), 303–309. doi:S0304-3959(04)00615-3 [pii].
- Leroy, P. L., Costa, L. R., Emmanouil, D., van Beukering, A., & Franck, L. S. (2016). Beyond the drugs: Nonpharmacologic strategies to optimize procedural care in children. *Current Opinion in Anaesthesiology*, *29* Suppl 1, 1. <https://doi.org/10.1097/ACO.0000000000000312>.
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*(1), 69.
- Marsac, M. L., Hildenbrand, A. K., Clawson, K., Jackson, L., Kohser, K., Barakat, L., ... Alderfer, M. A. (2012). Acceptability and feasibility of family use of the cellie cancer coping kit. *Supportive Care in Cancer*, *20*(12), 3315–3324.
- McMurtry, C. M., Pillai Riddell, R., Taddio, A., Racine, N., Asmundson, G. J. G., Noel, M., ... HELPinKids&Adults Team (2015). Far from "just a poke": Common painful needle procedures and the development of needle fear. *The Clinical Journal of Pain*, *31*.
- Miller, S. M. (1979). Controllability and human stress: Method, evidence and theory. *Behaviour Research and Therapy*, *17*(4), 287–304.
- Miller, V. A. (2009). Parent-child collaborative decision making for the management of chronic illness: A qualitative analysis. *Families, Systems & Health*, *27*(3), 249.
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, *18*(1) 143–x. <https://doi.org/10.1186/s12874-018-0611-x>.
- Murphy, G. (2009). Distraction techniques for venepuncture: A review. *Paediatric Nursing*, *21*(3), 18–20.
- Nabors, L., Odar Stough, C., Combs, A., & Elkins, J. (2019). Implementing the coping positively with my worries manual: A pilot study. *Journal of Child and Family Studies*, *28*(10), 2708–2717. <https://doi.org/10.1007/s10826-019-01451-3>.
- Nannis, E. D., Susman, E. J., Strope, B. E., Woodruff, P. J., Hersh, S. P., Levine, A. S., & Pizzo, P. A. (1982). Correlates of control in pediatric cancer patients and their families. *Journal of Pediatric Psychology*, *7*(1), 75–84.
- Nunns, M., Mayhew, D., Ford, T., Rogers, M., Curle, C., Logan, S., & Moore, D. (2018). Effectiveness of nonpharmacological interventions to reduce procedural anxiety in children and adolescents undergoing treatment for cancer: A systematic review and

- meta-analysis. *Psycho-Oncology*, 27(8), 1889–1899. <https://doi.org/10.1002/pon.4749>.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews. A Product From the ESRC Methods Programme Version. 1.* (pp. b92).
- Price, J., Kassam-Adams, N., Alderfer, M. A., Christofferson, J., & Kazak, A. E. (2016). Systematic review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *Journal of Pediatric Psychology*, 41(1), 86–97. <https://doi.org/10.1093/jpepsy/jsv074>.
- Rodd, H., Timms, L., Noble, F., Bux, S., Porritt, J., & Marshman, Z. (2019). "Message to dentist": Facilitating communication with dentally anxious children. *Dentistry Journal*, 7(3), <https://doi.org/10.3390/dj7030069> (doi:E69 [pii]).
- Ruhe, K. M., Wangmo, T., Badarau, D. O., Elger, B. S., & Niggli, F. (2015). Decision-making capacity of children and adolescents—suggestions for advancing the concept's implementation in pediatric healthcare. *European Journal of Pediatrics*, 174(6), 775–782. <https://doi.org/10.1007/s00431-014-2462-8>.
- Sharma, T., Bamford, M., & Dodman, D. (2015). Person-centred care: An overview of reviews. *Contemporary Nurse*, 51(2–3), 107–120. <https://doi.org/10.1080/10376178.2016.1150192>.
- Soderback, M., Coyne, I., & Harder, M. (2011). The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *Journal of Child Health Care : For Professionals Working with Children in the Hospital and Community*, 15(2), 99–106. <https://doi.org/10.1177/1367493510397624>.
- Stevens, B. J., Abbott, L. K., Yamada, J., Harrison, D., Stinson, J., Taddio, A., ... CIHR Team in Children's Pain (2011). Epidemiology and management of painful procedures in children in Canadian hospitals. *Cmaj*, 183(7), E403–E410. <https://doi.org/10.1503/cmaj.101341>.
- Taddio, A., Alderman, L., Freedman, T., McDowall, T., McMurtry, C. M., MacDonald, N., ... Pain Pain Go Away Team (2019). The CARD system for improving the vaccination experience at school: Results of a small-scale implementation project on program delivery. *Paediatrics & Child Health*, 24(Suppl. 1), S54–S67. <https://doi.org/10.1093/pch/pxz021>.
- Taddio, A., Freedman, T., Wong, H., McMurtry, C. M., MacDonald, N., Ilersich, A. N. T., ... Pain Pain Go Away Team (2019). Stakeholder feedback on the CARD system to improve the vaccination experience at school. *Paediatrics & Child Health*, 24(Suppl. 1), S29–S34. <https://doi.org/10.1093/pch/pxz018>.
- Taddio, A., Ilersich, A. N. T., Ilersich, A. L. T., Schmidt, C., Chalmers, G., Wilson, E., ... Pain Pain Go Away Team (2019). Piloting the card™ system for education of students about vaccination: Does it improve the vaccination experience at school? *Paediatrics and Child Health (Canada)*, 24, S35–S41. <https://doi.org/10.1093/pch/pxz019>.
- Taddio, A., McMurtry, C. M., Bucci, L. M., MacDonald, N., Ilersich, A. N. T., Ilersich, A. L. T., ... Pain Pain Go Away Team (2019). Overview of a knowledge translation (KT) project to improve the vaccination experience at school: The CARD system. *Paediatrics & Child Health*, 24(Suppl. 1), S3–S18. <https://doi.org/10.1093/pch/pxz025>.
- Taddio, A., McMurtry, C. M., Shah, V., Riddell, R. P., Chambers, C. T., Noel, M., ... HELPinKids&Adults (2015). Reducing pain during vaccine injections: Clinical practice guideline. *CMAJ: Canadian Medical Association Journal*, 187(13), 975.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473.
- Yee, R., Jones, L. M., & Hosey, M. T. (2017). What the child "SAID" to the dentist: A UK randomized controlled trial. *Child: Care, Health and Development*, 43(6), 926–932.