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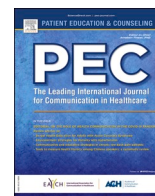
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Child participation in triadic medical consultations: A scoping review and summary of promotive interventions

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ABSTRACT

Objectives: To promote patient centered care, children with health issues should be supported to participate in consultations with health care professionals. We aimed to summarize, in a scoping review, the evidence on child participation in triadic encounters and its promotive interventions.

Methods: Two researchers systematically searched four major databases, and included studies on child participation in medical consultations. A synthesis of quantitative and qualitative data was made.

Results: Of 1678 retrieved records, 39 papers were included: 22 quantitative, 14 qualitative and 3 mixed-methods studies. Child participation, measured by utterances, turns or speech time, ranged between 4% and 14%. Participation increased with age. Equidistant seating arrangements, child-directed gaze and finding the appropriate tone of voice by the physician promoted child participation. Despite all facilitative efforts of doctors and parents, such as social talk, eHealth tools or consultation education, no increase in child participation was observed over the last 50 years.

Conclusions: Children continue to participate only marginally in medical consultations, despite their desire to be involved in various aspects of the clinical encounter and their right to have their voice heard.

Practice implications: Health care professionals should provide more opportunities for children to participate in triadic medical encounters and create an inclusive environment.

1. Introduction

Although children, in terms of the Convention on the Rights of the Child (CRC) defined as individuals younger than 18 years of age, have the right to make themselves heard in medical consultations and prefer to be actively involved, numerous studies have reported that they feel largely ignored by health care professionals (HCPs) and parents during medical encounters [1–5]. Child participation is a construct that refers to children being heard by adults and ultimately taking part in decision making dialogues which can be measured by counting active speech time [6]. This lack of child participation in the triadic relationship between health care professional, parent and child patient adversely affects optimal history taking and collaborative treatment discussions [7]. About two decades ago, the concept of patient-centered care was introduced to tailor health care delivery according to the needs and preferences of patients [8]. This shifted the attention from a biomedical approach in which diagnosis and treatment were offered based on the best available evidence, towards a more client-oriented approach in which it also became important to address the patient's personal

preferences in the medical encounter. For children, these initiatives have been translated into hospital-based efforts such as family-centered ward rounds which take the child's views into account and strive to create an inclusive environment for children fit to participate in their own health care [9].

Child participation in communication exchanges during medical encounters has been the subject of numerous studies since the 1970's. The concept of child participation is operationalized by measuring the child's verbal contribution to a conversation with adults [10–12]. The most recent systematic review investigating this child contribution in medical consultations dates 20 years back, and shows that children's relative contribution in a conversation during an outpatient clinic visit was on average less than 10%, with the doctor contributing for 60% and the parent for 30% [11]. The last qualitative review on children's experiences of participation in consultations in 2008 shows that children's views are rarely sought or considered when treatment plans are drawn [3]. With the increased interest in providing personalized health care in pediatrics, and in view of the child's right to be heard and acknowledged as participant in its own care, an update regarding the current state of

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child participation and methods to measure this is warranted. Furthermore, factors that promote participation in pediatrics are of high clinical relevance: child advocacy is one of the core competencies of pediatric medical specialists in the CanMEDS framework. Insights which can improve this competency in HCPs will directly benefit children's involvement in the medical encounter [13]. Our aim was to identify characteristics of child participation in clinical consultations with HCPs, including pediatricians, general practitioners, residents, nurses and other staff members, delineate the evolution of child participation over time, provide insight into different methods to assess child participation and summarize interventions that can promote child participation and related health outcomes. The results of our study could fuel improvement of patient-centered care for children and their caregivers in clinical practice. We, therefore, undertook this scoping review using a broad search strategy to gauge the nature and extent of the research evidence on child participation in medical consultations involving HCPs, child patients and caregivers.

2. Methods

2.1. Design

We designed a scoping review to clarify the concept of child participation in communication exchange and incorporate a range of observational and experimental study designs, including those published and gray literature to identify gaps in the existing literature, thereby conveying the breadth and depth of this field [14]. We addressed the following research questions using two PICO structured searches:

1. Which quantitative and qualitative methods can be used to assess child participation in clinical consultations? (PICO: Patient: Children up to 18 years of age; Intervention: None; Control: None; Outcome; Child participation).

2. What are the outcomes of interventions aimed at promoting child participation in consultations? (PICO: Patient: Children up to 18 years of age; Intervention: All methods which aim to improve child participation; Control: Care as Usual; Outcome: Child participation).

2.2. Search strategy and selection criteria

The online electronic databases Medline, Embase, CINAHL and PsycInfo were searched using the search terms: children AND (shared decision making OR participation OR involvement) AND consultation from January till March 2021 (full search strategy provided in the appendix). Papers were considered eligible for inclusion if they fulfilled each of the inclusion criteria and none of the exclusion criteria presented in Table 1. The flow chart in Fig. 1 presents reasons for exclusion. No time limit was applied for tracing publications.

In addition to the database search, a gray literature search was performed via Google Scholar, using the search terms [patient participation pediatrics], analyzing the first ten pages of results. Relevant publications were also retrieved via snowballing by searching for related articles in the references of included papers, and by consulting an expert in the field (Professor Sandra van Dulmen, professor of medical communication at the Faculty of Medical Sciences, University of Nijmegen, Nijmegen, the Netherlands) for additional articles.

2.3. Data analysis

After screening of retrieved articles by inclusion and exclusion criteria, the relevance of articles was assessed by two independent researchers (CW and HV) based on title and abstract, after which full texts of publications of interest were read to yield a final selection of papers for the review process. Consensus was reached at each step in the review process by discussing the results and consulting with the third author (PB) when necessary. We followed the PRISMA Extension for Scoping Reviews (PRISMA-ScR) [15].

Table 1
Inclusion and exclusion criteria.

	Inclusion	Exclusion
Type of study	English language Full-text available Qualitative studies Quantitative studies Mixed-Methods studies	Other languages than English Full-text not available
Type of participants	Children < 18 years with enough verbal skills to interact with the doctor	Newborns Parents only
Type of intervention	Video or audio observations of medical consultation to investigate child participation Qualitative interviews	Interventions to measure/improve participation of - Patients with hearing loss - Patients with autism - Patients with impaired language development - Patients with learning disabilities Interventions to assess/improve school engagement Patient engagement in research projects Communication style of the doctor Pediatric patient satisfaction Parent/Doctor's perspective on participation
Type of outcome measure	Participation in medical consultation Triadic dialog Child related measures of participation Child's perspective on participation	

We captured the methodology for quantitative and qualitative assessment of patient participation on a data sheet, along with the major reported results, patient characteristics, setting (general practice, pediatric or subspecialty clinics), authors and year of publication. For quantitative studies, weighted means of participation were calculated for the relative conversational contribution (i.e., the proportion of utterances, turns, speech time or word count in a consultation that the child was speaking) of the children between the different studies. These results were plotted on a timeline to allow for analysis of changes in conversational contribution over time. For qualitative studies that investigated instrumental/task related and affective/socio-emotional utterances as classified by the Roter Interaction Analysis System (RIAS) [16], when possible the contribution of instrumental versus affective communication behavior was calculated as a percentage, based on the number of utterances.

Results from qualitative studies that performed conversation, content or discourse analysis and qualitative studies that investigated children's experiences regarding participation during medical consultations based on interviews were analyzed using thematic analysis by two independent reviewers (CW and HV) following the guidelines from the literature [17]. After coding the text independently, descriptive themes were identified and discussed until consensus was reached, if needed after consulting a third reviewer (PB).

3. Results

Our search yielded 39 studies, 22 of which used a quantitative approach, 14 used qualitative research methods and 3 combined a quantitative with a qualitative research approach. In total, these 39 studies were based on 32 unique patient cohorts (17 with a quantitative research method, 12 with a qualitative research method and 3 with a combined quantitative and qualitative research method). An overview of study characteristics and main results of the quantitative studies is presented in Table 2. Qualitative studies that used conversation, content or discourse analysis are presented in Table 3 and qualitative studies that used thematic analysis are presented in Table 4.

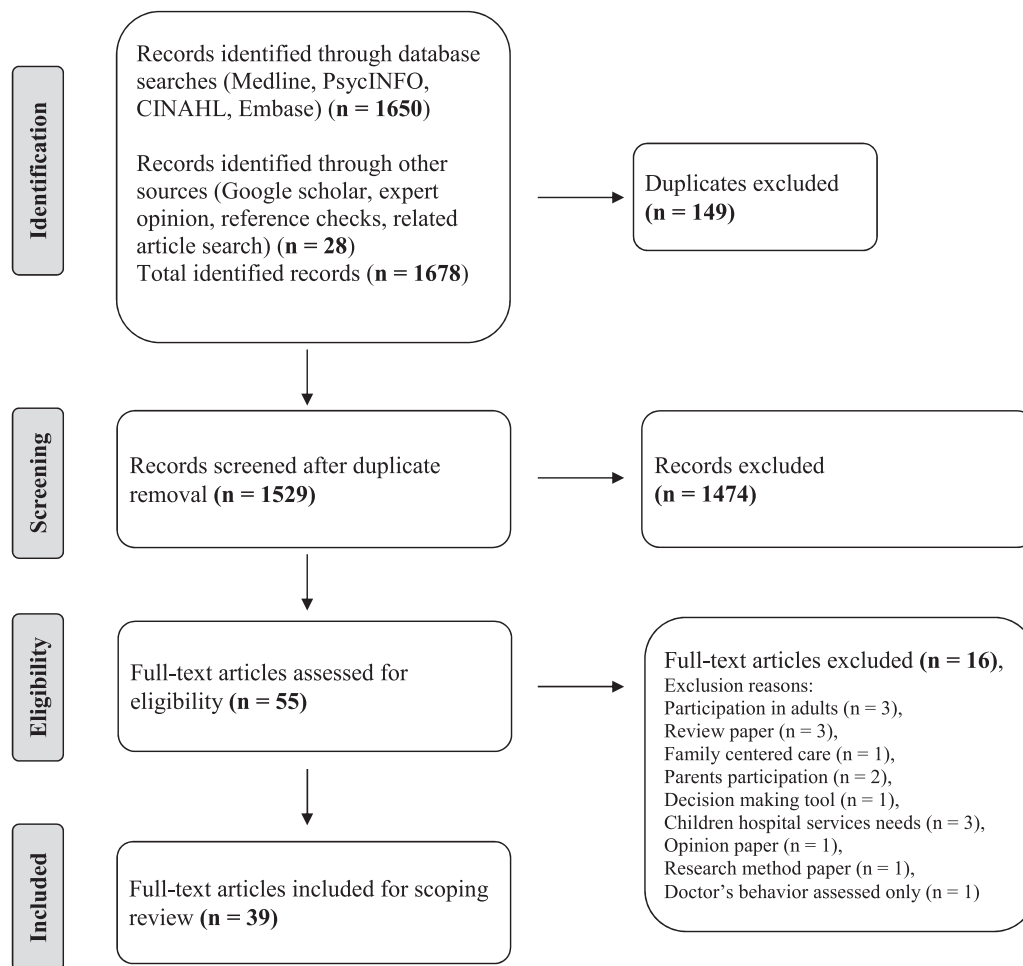


Fig. 1. Flow chart of the selection process.

3.1. Quantitative studies

Of the 20 study cohorts involved in quantitative research studies, 13 were recruited from pediatric hospitals and practices (62%) [10,18–29], 7 from general practice (33%) and one in both primary and hospital care (5%) [30–37]. Overall, the 20 study cohorts included 2697 children and 398 HCPs, 253 of which were pediatricians (64%). The remaining practitioners were general practitioners. Five studies involving pediatricians did not provide the number of participating physicians [22–25, 34].

3.1.1. Quantitative methods to measure of child participation

Various quantitative outcome measures were used in the 25 publications based on 20 study cohorts that investigated child participation. Nineteen unique publications (15 cohorts) calculated the percentage of conversational contribution by children. These conversational contributions were measured by utterance count in 8 study cohorts [10,18,19, 32–34,38–40], turn count in 3 study cohorts [20,30,35], total speech time in 4 study cohorts [20,22–24], plans proposed in 1 study [41], problem presenting in 1 study [25] and word count in 1 study [29]. The remaining 7 publications and 5 study cohorts used other methods to quantify child participation, such as the number of questions asked by children during consultation [36,42], the child's first turns in the consultation [21], the number of child's initiations and responses [26, 32,39], level of participation based on the child's contribution to decisions and plans on a five-point scale [27], and engagement concordance, or investigating the child's desired level of involvement in relation to the observed level of child involvement [37].

3.1.2. Child participation over time

Meeuwesen and Tates investigated interactional changes in the triadic consultation during three time periods: 1975–1978 (36 consultations), 1988–1989 (36 consultations) and 1990–1993 (34 consultations). Child initiatives in the triadic relationship increased over time from 4.6% to 10.0% ($p < 0.01$), with relative contributions rising from 7% to 11%, and children talking directly to the HCP in 3% vs 6% ($p < 0.01$) [35]. The follow-up study in 1993, however, showed declining figures, concerning child initiatives (8.5%) and child to HCP utterances (5%) [30]. To analyze whether child participation changed over time since Meeuwesen and Tates's publications, we calculated the weighted mean participation in percentage per publication that investigated the percentage of child utterances or turns. This analysis revealed that relative conversational contribution of children remained stable over time (Fig. 2A). Participation during consultation was smallest for children (range 4%–14%), intermediate for parents (23%–38%) and highest for HCPs (52%–64%). Furthermore, even when children were actively involved during the consultations by both HCP and parent, almost all consultations ended in a non-participatory manner with HCPs concluding the encounter by discussing management plans with the parents, without physically attending to the children or using child-friendly language [31].

3.1.3. Structural aspects of child participation

Turn taking and direction of talk was investigated by studies that paid attention to the triadic nature of the consultations [25,31,32,34,35] which showed parental control over the child's turn taking in the conversation. Child's initiatives and information sharing occurred more

Table 2
Overview of studies investigating child participation in consultations using quantitative approaches.

	Publication	Study cohort	Health practitioner	Age and sample size	Type of analysis	Percentage of participation by			First turn	Direction and Content	Ref
						Child	Parent	Doctor			
Analysis of Utterances	Cox (2009)	Qnt 1	GP and pediatrician	N = 100 Age = 0–18 years	Utterances	7%	30%	63%		Child: 11 information giving utterances, 1 information gathering utterances, 4 relationship building utterances	[34]
	Vigilante (2015)	Qnt 2	Pediatrician	N = 155 Age = 5–17 years	Utterances	15%				Child-to-doctor utterances not given; 9% instrumental, 3% affective, 3% other	[13]
	Tates (2002)	Qnt 3	GP	N = 106 Age = 4–12 years	Utterances	10%	38%	52%		Child directed communication took place during physical examination and medical history taking	[27]
	Cahill (2007)	Com 1	GP	N = 31 Age = 6–12 years	Utterances	5%			16%		[28]
	van Dulmen (1998)	Qnt 4	Pediatrician	N = 302 Mean age = 5.3 years	Utterances	4%	37%	59%		Child to doctor = 4% (1.9% instrumental 2.1% affective)	[14]
	Pantell (1982)	Qnt 5	GP	N = 115 Age = 4–14 years	Utterances	14%	26%	60%		Child to doctor = 12.5% Doctor to parent = 2%	[29]
	Coburn (2017)	Qnt 6	Pediatrician	N = 99 Age = 11–20 years	Utterances	14%	23%	63%		Child to doctor 11% (4% instrumental, 7% affective)	[18]
Cox (2007)	Qnt 1	GP and pediatrician	N = 100 Age = 0–18 years	Utterances	7%	31%	62%			[36]	
Wisow (1998)	Qnt 7	Pediatric residents, attending physicians, nurse practitioners, and respiratory technicians	N = 104 Age = 4–9 years	Utterances	8%	36%	56%		Doctor to child = 130 utterances (50% procedural information, 30% partnership and rapport building, 10% giving medical information, 12% ask questions) Doctor to parent = 200 utterances Child to doctor = 20 utterances (6%), (5% instrumental, 1% affective)	[30]	
Analysis of Turns	Mean distribution of utterances (N = 896)					9%	33%	59%			
	Wassmer (2004)	Qnt 8	Pediatrician	N = 51 Age = 0–14 years	Turn	10%	38%	52%		Questions asked by child 2%	[19]
	Tates (2000)	Qnt 3	GP	N = 106 Age = 4–12 years	Turn	9%	39%	52%		Child to doctor = 5,2% Doctor to child = 12,9%	[26]
	Meeuwesen (1996; period 1)	Qnt 9	GP	N = 59 Age = 4–12 years	Turn	7%	52%	41%	initiatives	Child to doctor = 3%	[31]
	Meeuwesen (1996; period 2)	Qnt 9	GP	N = 36 Age = 4–12 years	Turn	11%	50%	39%	initiatives	Child to doctor = 6%	[31]
Jenkins (2020)	Com 2	Pediatrician	N = 30 Age = 2–10 years	Turn				33%	Within these 33% Child to doctor = 23% and child to parent = 77%	[20]	
Analysis of Speech Time	Mean distribution of turns (N = 252)					9%	43%	48%			
	Freemon (1971)	Qnt 10	Pediatrician	N = 800 (285 subjects and 515 controls) Age = unknown	Total speech time	2.1%	38.6%	59.3%		Child to doctor = 2,1% Doctor to child = 10,5% (of which 3,7% during history description and 86,7% during physical exam)	[21]
	Tates (2002)	Qnt 3	GP	N = 106 Age = 4–12 years	Total speech time					First selection child 33%	[27]
	Wassmer (2004)	Qnt 8	Pediatrician	N = 51 Age = 0 – 14 years	Total speech time	4.2% (Turn 9%)	25% (Turn 38%)	61% (Turn 52%)			[19]
Downing (2017)	Qnt 11	Pediatrician	N = 58 Age = 11–25 years	Total speech time	17%				Any question asked by 71% of children	[22]	

(continued on next page)

Table 2 (continued)

	Publication	Study cohort	Health practitioner	Age and sample size	Type of analysis	Percentage of participation by			First turn	Direction and Content	Ref
						Child	Parent	Doctor			
	Gilljam (2020)	Qnt 12	Pediatrician	N = 27 (13 cases, 14 controls) Mean Age = 9,5 years (intervention group) 8.1 years (controls)	Total speech time	control: 1.78 min (10%) intervention: 1.14 min (6,4%)				Intervention: Doctor to child = 44.57 min Control: Doctor to child = 56.23 min Situations were scaled to a level of participation Intervention: Level 1: 84/216, Level 2: 25/216, Level 3: 104/216, Level 4: 2/216, Level 5: 1/216, Level 6: 0/216. Control: Level 1: 42/144, Level 2: 39/144, Level 3: 60/144, Level 4: 3/144, Level 5: 0/144, Level 6: 0/144	[23]
Analysis of Plans/ Problems	Cox (2007)	Qnt 1	GP and pediatrician	N = 100 Age = 0–18 years	Plans proposed	2%	9%	89%		Doctor to parent = 79% Doctor to child = 14% Doctor to parent and child = 7% Child to doctor = 5% (2% instrumental, 3% affective)	[36]
	Stivers (2001)	Com 3	Pediatrician	N = 102 Age = unknown	Problem Presenter	32%	66%			Next speaker selection doctor: Child = 53%, Parent = 29,4%, Ambiguous = 17,6%	[24]
Analysis of Asked Questions	Sleath (2011)	Qnt 13	GP	N = 296 Age = 8–16 years	Questions asking					13% of children asked one or more questions about asthma management	[32]
	Sleath (2014)	Qnt 13	GP	N = 296 Age = 8–16 years	Questions asking					Medication questions asked by children during consultation: 11,3% any type of medication problem, 9,3% asthma medication device technique, 4,4% Frequency/timing of use and 1% side effects.	[38]
Other types of analysis	Lewis (1991)	Qnt 14	Pediatrician	N = 131 Age = 6–17 years	measures of physician-patient communication					Intervention: Doctor to child and doctor to child and parent = 50% Control: Doctor to child and doctor to child and parent = 29% No. child initiations and responses: 52,5 (control) 35,3 (intervention)	[25]
	Runeson (2002)	Qnt 15	Pediatrician	N = 24 Age = 0–18 years	categories of consult situations					Situations were scaled to level of participation: Level 1: 10/137, Level 2: 11/137, Level 3: 51/137, Level 4: 17/137, Level 5: 48/137 In 65/137 situations, children's wishes and opinions were totally or partially respected	[15]
	Carpenter (2014)	Qnt 13	GP	N = 296 Age = 8–16 years	Engagement concordance					Doctor to child dyads were: 36,1% concordant, of the discordant dyads, 83,1% are classified as under-engaged and 16,9% were over-engaged.	[33]
	Aronsson (1988)	Qnt 16	Pediatrician	N = 32 Age = 5–17 years	Word count	8%	34%	58%			[17]
	Becker (2018)	Qnt 17	Pediatrician	N = 39 Age = 8–17 years	Communication descriptive					28% of children reported 'a lot of voice' during the consultation, 36% 'quite a bit of voice', and 36% 'a little bit'.	[16]

*Qnt = quantitative research cohort, Com = combined quantitative and qualitative research cohort, which help indicate which publications originated from the same research cohort.

Table 3

Overview of qualitative studies investigating child participation in consultations using a conversation, content, or discourse analysis.

Publication	Health practitioner	Study cohort	Age and sample size	Method	Research Question	Main results	Ref
Cahill (2007)	GP	Com 1	N = 31 Age = 6–12 years	Video recordings of consultations were transcribed verbatim and used for conversation analysis.	Identify features of interaction between doctor, child, and their career in the consultation associated with the child's participation.	Factors that were associated with supported participation were: <ul style="list-style-type: none"> • Triangular seating arrangement • Asking children questions with a limited range of answers • Directly inviting the child to speak • Child directed gaze • Allowing a long switching pause • Early opportunity of the parents to express their concerns decreases parental interference during child-doctor interaction 	[28]
Jenkins (2020)	Pediatrician	Com 2	N = 30* Age = 2–10 years	Video recordings of consultations were transcribed verbatim and used for conversation analysis.	Under what conditions and at which points do children in our pediatric clinic consultations self-select, instigate talk and mobilize response?	<ul style="list-style-type: none"> • Children can self-select to raise relevant issues without prior involvement of parent or practitioner. • Children have restricted rights during consultations which hampers their participation. • Children use subtle, non-verbal resources or escalating verbal interjections to seek attention or to participate. • Children tend to address their parents rather than the doctor. • Children's participation ranges from crucial to irrelevant, but all are important for active participation 	[20]
Stivers (2001)	Pediatrician	Com 3	N = 102 Age not provided	Video and audio recordings of consultations were transcribed and used for conversation analysis.	Examine the organization of conversation between physician, child and parent	<ul style="list-style-type: none"> • Doctors frequently select children as problem presenter. • Parents most likely present the problem, but not after orienting to their children by allowing for a substantial delay to answer, multiple attempts to question the child, or inadequate answers by the child. • Children and parents use gaze, gesture, and silence to negotiate who will present the problem. 	[24]
Nova (2005)	Pediatrician	Qual 1	N = 10 Age = 2–6 years	Video-recordings of consultations were transcribed and analyzed using discourse analysis and content analysis.	What is the quality of the interaction of young children during pediatric visits?	<ul style="list-style-type: none"> • Young children have a personal agenda for the consultation. • Children communicate their subjective experience regarding visit or sickness. • Adults decide how to integrate the child's interaction based on content and relational aspects. 	[50]

* , only 10 out of the 30 consultations were used for this paper. Qual = qualitative research cohort, Com = combined quantitative and qualitative research cohort, which help indicate which publications originated from the same research cohort.

often during physical examination and focussed on psychosocial rather than biomedical themes, whereas parents were responsible for most of the turns during medical history taking. This was also reflected by 8 studies that used RIAS to investigate the nature of child contributions, where children's instrumental contributions ranged from 4% to 7% and their affective contributions from 1% to 5% [10,18–20,28,34,38–40]. Child participation in shared decision making was almost never achieved [12,24,43–45].

3.1.3.1. Factors associated with child participation. Children talked more (25 versus 5 utterances, $p < 0.0001$) when HCPs showed more patient-centered behavior, defined by HCPs displaying above 50th RIAS percentile scores for partnership, interpersonal sensitivity and information giving, but not when providers engaged in a more patient-centered way with parents [34]. Similar findings were observed by Becker et al., who found a positive correlation between child verbal participation with facilitative behaviors of HCPs, including partnership and asking questions. Only chit-chat as a HCPs affective communication strategy correlated positively with the child's ease of understanding [28]. Children were seven times more likely to present the problem

when the HCP had already engaged with the child by general social talk, reciprocal actions such as joke-laughter or shaking hands before soliciting the problem and if the child was invited by the HCP to speak [25]. Seven studies found that the child's age was the principal determinant of child participation: child talk increasing with 1.1% per year (and parental talk decreasing with 1.2% per year) in children aged 3 months to 18 years [38]. Children also formulated the problem more frequently with increasing age [33,39]. Two studies found no association between age and degree of child participation [28,30]. We calculated the weighted mean participation of children and plotted this against the mean age of children of 8 individual publications and found a correlation between age and participation (Fig. 2B).

3.2. Qualitative publications

Our search yielded 17 publications with qualitative results obtained in 15 research cohorts, including 408 children [12,21,25,32,43–55]. Thirteen studies used thematic analysis of verbatim transcripts of audiotaped consultations [12,43–45,47–55] and three studies used conversation analysis of video recorded consultations [21,25,32]. The

Table 4

Overview of qualitative studies investigating child participation in consultations using a thematic analysis.

Publication	Health practitioner	Study cohort	Age and sample size	Method	Research Question	Main results	Ref
Ruhe (2016)	Pediatric oncologists	Qual 2	N = 52, of which 17 children Age = 9–17 years	Interviews were audio-taped and transcribed verbatim followed by thematic analysis.	Explore how patient participation was put into practice in a pediatric oncology setting.	Three main themes were identified: <ul style="list-style-type: none"> • Modes of participation that captured the different ways in which children were involved in their healthcare; <ul style="list-style-type: none"> o Participation in discussions, simultaneous or time-delayed o Ask questions o Participation in decision-making; facultative decisions or essential decisions o Observation • Regulating participation, that is, regulatory mechanisms that allowed children, parents, and oncologists to adapt patient involvement in communication and decision-making <ul style="list-style-type: none"> o Filtering information o Pacing when and which information to get/give o Interfering with decisional outcome • Other factors that influence patient participation. <ul style="list-style-type: none"> o To assure patient collaboration o Involving patients when there is an opportunity o Parenting culture o Circumstances o Physicians' guidance o Children's preferences 	[51]
Ruhe (2020)	Pediatric oncologists	Qual 2	N = 52 (17 children) Age = 9–17 years	Interviews were audio-taped and transcribed verbatim followed by thematic analysis.	Gathering of children's opinions and experiences associated with health care encounters	Themes: <ul style="list-style-type: none"> • Participants' role in medical communication and decision-making <ul style="list-style-type: none"> o Presence during medical communication o Engagement in medical communications and decision-making • The toll of participation • Participants' thoughts and opinions about participation <ul style="list-style-type: none"> o Involvement is natural for the affected person o Wish to receive information from the right authority o Diverging and fluctuating preferences of participation 	[52]
Carlsson (2020)	Various health care professionals (counselor outpatient and inpatient care, pediatric oncology and neurology outpatient care units)	Qual 3	N = 16 Age = 6–13 years	Unstructured interviews were transcribed verbatim followed by categorical analysis	Explore the impact of using an eHealth service to gain the children's perspectives during their healthcare appointments	Themes: <ul style="list-style-type: none"> • Enticing the child to speak instead of the parents. • Avoiding speaking and remaining silent while still being heard. • The eHealth service Sisom gave them time for consideration and reflection before they gave answers. 	[43]
Beresford (2003)	N/A	Qual 4	N = 63 Age = 10–16 years	Semi-structured interviews and discussion groups	Explore experiences of communicating with health professionals	Themes identified that influenced communication experiences: <ul style="list-style-type: none"> • Features of the encounter (familiarity, duration, privacy) • Parental presence (inhibitive, supportive) • Issues of status (status of doctor, self-perceived status) 	[44]

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Table 4 (continued)

Publication	Health practitioner	Study cohort	Age and sample size	Method	Research Question	Main results	Ref
Clift (2007)	Emergency physicians	Qual 5	N = 6 Age = 11–15 years	Audiotaped semi-structured interviews. Data was transcribed. Statements were identified, extracted from transcripts and organized into categories and research themes.	Adolescents' experiences of emergency admission to children's wards	<ul style="list-style-type: none"> • Doctor-centered factors (behavior towards adolescents, approach to consult/condition management, communication skills) • Adolescent-centered factors (age, gender, communication skills) • Type of information needed (personal or sensitive information, perceived negative consequences of the answer, threat of revealing poor adherence or 'forbidden' behaviors, psychosocial information needs) Themes: Participation in care <ul style="list-style-type: none"> • Participants felt some degree of participation and had understanding of the procedures • Participants were involved when decisions were made • Participants indicated the importance of being taken seriously and listened to as an equal individual Adolescents' relationships with health care professionals <ul style="list-style-type: none"> • Parental support and involvement is valued during hospital stay • Interactions with nurses improved their time in hospital 	[45]
Coyne (2006)	Nurses	Qual 6	N = 11 Age = not provided	Interviews following 4 topics (reason for hospitalization; parents' participation; nurses' participation and children's participation). Data was transcribed, coded and analyzed in a categorical manner.	To explore children's parents' and nurses' views on participation in care in the healthcare setting	Children experienced difficulty with participation in care <ul style="list-style-type: none"> • Most children want to be consulted and involved in general decisions • Participation ensures involvement and prepares for procedures and reduces anxiety. • Exclusion from information or the decision-making process <ul style="list-style-type: none"> o Use technical terms and terminology leading to confusion o Ignoring children completely or discussing decisions with parents or other doctors while children were present, leads to feeling upset, angry and depressed. o Lack of participation was caused by workload and pressure and made children feel forgotten depersonalized. • Children use several strategies to obtain information (ask questions, observe, talking to other children, seeking information from books and television programs, and past experiences) 	[39]
Coyne (2011)	N/A	Qual 7	N = 55 Age = 7–18 years	A combination of focus groups and single interviews were transcribed and analyzed according thematic analysis.	To explore hospitalized children and young people's experiences of participation in communication and decision-making	Themes: <ul style="list-style-type: none"> • Children's experiences of communication and decision-making (receiving information/communicating with parents only/preferences being ignored/ 	[41]

(continued on next page)

Table 4 (continued)

Publication	Health practitioner	Study cohort	Age and sample size	Method	Research Question	Main results	Ref
Coyne (2014)	Health care professionals (not otherwise specified)	Qual 8	N = 20 Age = 7–16 years	Audiotaped interviews that were structured on six topics. Interviews transcribed verbatim and organized into categories.	Explore children's experiences with participation in shared decision making, the level of participation and confounding and facilitating factors that influence children's participation	<p>being excluded from decision-making process and decisions)</p> <ul style="list-style-type: none"> • Preferences for participation in communication and decision-making <p>(having a right to be involved/ preferring health professionals to communicate with parents/ wanting to take 'small' decisions/ leaving decisions to doctors and/ or parents/sharing decisions with parents and health professionals/ wanting to take 'serious' decisions)</p> <ul style="list-style-type: none"> • Factors that enhanced or hindered the participation (parents' role/familiarity with the hospital, procedures and health professionals/difficulty knowing health professionals/fear of causing trouble) <p>Core theme: It has to be done. Major decisions are made by the health professional in the best interest of the child. Therefore 'no real' decision could be made by the child or parents.</p> <p>Categories:</p> <ul style="list-style-type: none"> • Best interest of the child <ul style="list-style-type: none"> o Younger children did not want responsibility for major decision-making o Adolescents agreed that major decisions were taken by adults but preferred to be included in the information sharing and the decision-making process. • Lacking involvement in treatment decisions • Allowed choices but not the decision to refuse treatments <ul style="list-style-type: none"> o Adolescents experience frustration over the loss of control and so negotiation was essential. • Assessing children's ability for participation in shared decision making <ul style="list-style-type: none"> o Children indicate that when they were very unwell, they did not want or were unable to be involved in any decisions. • Lacking any real decisions was dissatisfying for adolescents and made them feel powerless, whereas younger children appeared satisfied with their level of decision-making. 	[40]
Coyne (2016)	Health care professionals (20 doctors and 20 nurses/allied professional)	Qual 8	N = 20 Age = 7–16 years	Audiotaped interviews that were structured on six topics. Interviews transcribed verbatim and organized into categories.	Examination of participants' views on children's participation in information-sharing and communication interactions.	<p>Themes:</p> <ul style="list-style-type: none"> • Maintaining an open and honest approach <ul style="list-style-type: none"> o Getting the parents and child 'on board' with open information-sharing o Sharing and receiving information was reported, but only children aged 11 years and older reported asking questions and being listened to. • Maintaining hope and spirit <ul style="list-style-type: none"> o Children expressed a preference to be present for 	[46]

(continued on next page)

Table 4 (continued)

Publication	Health practitioner	Study cohort	Age and sample size	Method	Research Question	Main results	Ref
Garth (2009)	Pediatrician	Qual 9	N = 10 Age = 8–12 years	Semi-structured interviews were video-taped and transcribed. Substantive and theoretical coding was used to analyze the data. Principles of the constant comparison method were followed until theoretical saturation was achieved.	To explore how the doctor-parent-child partnership is experienced and if the child patients is considered a contributor	discussion, but also rely on their parents as being their advocates and communication brokers because of complex information. o Children described situations where parents act as information buffers, because of reluctance to ask questions, fearful of hearing bad news and/or feeling unwell from side effects. • Managing restricted information sharing o Absence of open and honest information about the diagnosis can result in mistrust and anger.	[47]
Kluthe (2018)	N/A	Qual 10	N = 18 Age = 6–17 years	Semi-structured interviews were audio-recorded and transcribed and analyzed on qualitative content.	To elicit children and parent perspectives following a diagnosis	Themes: • Roles in care and decision-making o Children expressed a wide range of involvement in creating care plan. o Most children were part of the conversation regarding treatment options, but the decisions were made by their parents and the doctors.	[42]
Koller (2017)	N/A	Qual 11	N = 26 Age = 5–18 years (divided per age group; adolescents, school-age, young children)	Semi-structured interviews were recorded and transcribed, Data analysis followed the six-stage thematic analysis described by Braun and Clarke (2006)	Examine how children with chronic medical conditions view health care education and decision-making	Themes: • Knowledge of illness was evaluated as high, average and low, which was largely related to patient age. • Communication with health care providers o Feeling listened to while receiving adequate and honest information o Feeling comfortable with the health care provider improves communication o Frustrating to repeat information to a new doctor, or to give too much information at once, or feeling dismissed during discussion. o Medical terminology can be hard to understand o Communication is important for patients as it lessened fears and anxieties and is essential for good care • Participation and decision-making o Patients felt listened to and provided examples of participation and decision-	[48]

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Table 4 (continued)

Publication	Health practitioner	Study cohort	Age and sample size	Method	Research Question	Main results	Ref
Young (2003)	N/A	Qual 12	N = 13 Age = 8–17 years	Interviews were audiotaped and transcribed. Data analysis was based on the constant comparative method.	To examine young people’s and parents’ accounts of communication about cancer in childhood	<p>making. Most participants described a collaborative decision-making process</p> <ul style="list-style-type: none"> o The level of participation was associated with age, but even young children participated in self-care tasks. • Recommendations <ul style="list-style-type: none"> o Children expressed the need to receive health education at an early age and is essential to prepare for self-care <p>Themes:</p> <ul style="list-style-type: none"> • Setting the tone: form of disclosure. Diagnosis was disclosed by doctor to parents first. • Parental involvement in setting information barriers could be problematic for young people, although young people do not regard their parents’ involvement as inappropriate. • Patients saw their own position during consultations as only marginal. • Patients describe the role of the parents as: <ul style="list-style-type: none"> o Facilitators of communication between health professionals and themselves o Envoys for information on their behalf o Communication buffers o Human databases for information about the illness o Communication brokers for clarification and reiteration of the given information 	[49]

*Qual = qualitative research cohort, which help indicate which publications originated from the same research cohort.

following themes were developed by thematic analysis of the combined results of these studies:

3.2.1. Importance of child participation

Children stressed the importance of their participation and preference for involvement as the affected person. They expressed the desire to receive information directly from their HCP [47,48] and be listened to [45,51,54]. Unlike younger children, adolescents preferred involvement in treatment decisions [44], but even young children expressed a personal agenda and participated in communicating their subjective experience regarding the visit or the sickness [46]. Being involved during consultations and participating in decision-making assured their collaboration with the hospital staff and following the standardized treatment protocols [47,48]. Moreover, participation reduced anxiety [43] and created collaboration between child and the treatment process [47,52]. So, even though participating in consultations was sometimes described as stressful [47], the importance of child participation was emphasized in all studies.

3.2.2. Supportive circumstances for participation

The qualitative studies investigating child participation indicated various circumstances that supported children in their ability to participate during consultations, including environmental setting, electronic decision aids and tools, and parental influences. Office-related supportive circumstances included seating in triangular

arrangement (HCP positioned at the same distance from child and parent), asking the child questions that narrow the selection of responses, inviting the child to speak, directing gaze at the child and accounting for a longer switching pause (i.e. child needs longer time to respond to questions compared to adults) [32].

The use of the Sisom tool supported child participation by preparing children for their visit with the HCP. Sisom is an eHealth tool, developed in collaboration with children, to help children with chronic illnesses, but originally developed for children with cancer, to communicate in health care by playfully engaging them in a virtual world: children can navigate a self-created avatar to five islands in a virtual archipelago [49]. The islands represent topics for 82 questions they can answer, notably (1) to handle things, (2) my body, (3) thoughts and feelings, (4) things you may be afraid of, and (5) in the hospital. HCPs can read a printed report of the questionnaire and use it as a guide to talk with the children about their perceived health situation, the healthcare system, and social issues. Children indicated that the Sisom tool was enjoyable to use and enabled them to make their voice heard instead of letting their parents speak. Also, the children were able to communicate without speaking by answering on the tablet, which helped them to answer tough questions related to bullying at school or fear of dying. Sisom also created time and space for the children during their hospital appointments, allowing them time for consideration and reflection [49].

Parents could have a supportive role in child involvement by acting as child advocates on behalf of their children, thereby aiding in the

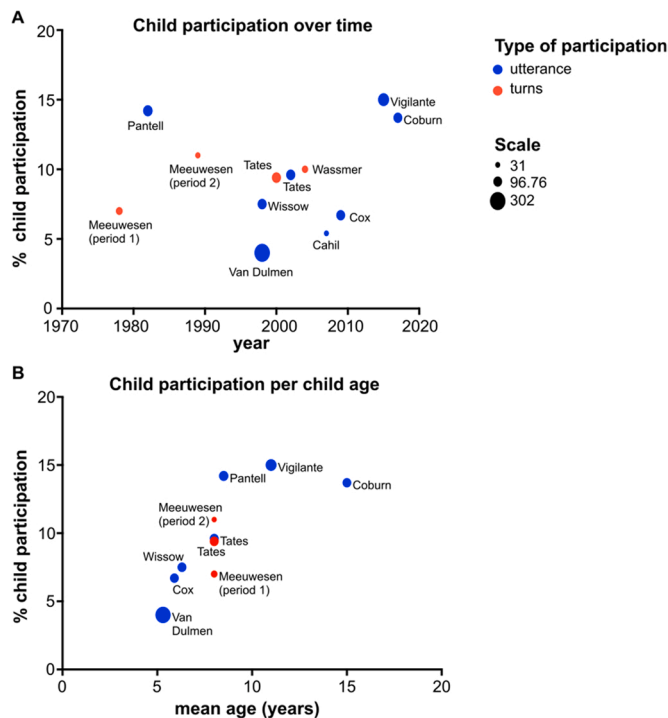


Fig. 2. Child participation. A) Child participation by publication year was depicted by the weighted mean participation by children on the y-axis and year of publication of the study on the x-axis. B) Child participation by child age was depicted by the weighted mean participation by children on the y-axis and mean age on the x-axis. The dot size reflects the study size. Child participation was depicted in % utterances in blue or % turns in red.

collection and discussion of information with the HCP [52,53,55]. Other supportive circumstances included children looking up information [43], the familiarity of parents with the hospital and the HCP [12,50], and interaction with nurses [51].

3.2.3. Difficulty of participation

Children related that the difficulty and perceived limited usefulness of the provided information hampered their participation in consultations. They also highlighted the stress involved in receiving information or making decisions [47,48]. Child participation was negatively affected by multiple factors, including physical absence during the consultation or the decision-making process, parenting culture, HCP guidance and child preferences. Children could not always be present, as discussion of the diagnosis sometimes occurred while the child was recovering from surgery, or when it was first discussed with the parents without the child being present [47]. Child participation was regulated by both parents and HCPs, by filtering information, pacing the type and time of information and occasionally by interfering with the decisional outcome (e.g. in case of sperm preservations, where a 14 year old boy stated 'No, I don't want to have kids', which was overruled by his parents) [46,47]. Parental influence could buffer information, which can be perceived as dishonest and lead to mistrust and anger [52].

3.2.4. Interactional strategies

Children participated during the consultations by gazing at the conversation partners, by physically presenting skin lesions that were discussed during history-taking and by engaging in history taking when the subject was within their knowledge domain [21]. They asked attention by embodied actions (e.g. tapping on a parent's arm), summons (calling their parent with final rising intonation), prosodic changes (change in rhythm, intonation) and gaze, further supported by hand gestures and initial speech to claim the floor ('Uhm, uh') [25]. Children asked for clarification of difficult words, contributed with relevant

remarks at an odd place (which the HCP had to acknowledge but deferred to a more appropriate moment) or placed an irrelevant remark which was used by the doctor to engage with the child (e.g. in medical examination) [21]. In addition, a silence pause usually indicated the beginning of a child's response initiation [25].

3.3. Interventions aiming to promote child participation

We found three studies assessing outcomes of interventions aimed at promoting child participation in consultations. In a randomized controlled trial, Lewis et al. assessed the effects of three short videos and written instructions directed at child, parent and HCP, designed to build skills and motivation for increased child competence and motivation during pediatric office consultations [26]. The trial involved 141 children (5–15 years of age). Standardized interviews and instruments assessed children's rapport with the HCP, their anxiety and preference for an active health role, as well as children's recall of information, parents' satisfaction with the medical visit, and satisfaction of the HCP. Children in the intervention group showed more satisfaction (3.30 vs 3.10 on a 4-point scale, 4 = high satisfaction, $p < 0.05$), displayed more active health role preference (2.66 vs 2.5 on a 3-point scale, 3 = active health role preference, $p < 0.01$), recalled more medication recommendations (77% vs 47%, $p < 0.01$) and tended to show more substantive initiations and responses (53% vs 36% $p < 0.06$). Health care professionals in the intervention group more often included children in discussions of medical recommendations (50% vs 29%, $p < 0.05$) and parent satisfaction was similar in both groups.

Downing et al. developed a downloadable package for preparation of upcoming consultations at home and in clinic: a prompt sheet for children to identify topics they would like to discuss, a website with animations to support the HCPs explanation, and a summary sheet with take-home messages [23]. They assessed the feasibility of this communication tool. A purposive sample of 24 patients was recruited for video-observation of their consultation, 15 of whom chose to use this communication tool. A slightly higher proportion of children who used the tool asked questions compared to those who did not (73% vs 63%). The study showed that most children and teenagers were willing to try the tool that could help them to get involved in the consultation. Effectiveness of the intervention could not be established because of the observational nature of the study.

Gilljam et al. performed a controlled non randomized trial comparing six 6–12 year old children with cancer who were offered the use of the Sisom tool in the pediatric oncologist's waiting room to eight children in the same setting who were not offered the use of the tool [24]. Consecutive children were recruited; data on the control group were collected before inclusion of the intervention group. Groups differed in mean age (9.5 and 8.5 years in the intervention and control groups, respectively) and sex (boy:girl ratio 66% for the intervention and 25% for the control group). Duration of child-to-HCP statements was similar in both groups (0.81 min in the intervention group versus 0.80 min in the control group). Qualitative level of participation was assessed by ranking data from the videos according to predefined categories of participation. High levels of participation in which children could share power and responsibility over decision making were observed in neither group. Health care professionals took the lead in all conversations and more often addressed parents than children in both groups. Difficult language and lack of patience to allow the child to answer were observed to inhibit child participation.

4. Discussion and conclusion

4.1. Discussion

In total, our scoping review covers 39 studies from 32 study cohorts. Our review provides an overview of the various strategies to assess child participation, with a unique overview of the quantitative and qualitative

outcomes of child participation. Besides, our scoping review recommends a best practice method to evaluate child participation and for future research.

4.1.1. Child participation in the last five decades

A range of quantitative measurements including speech time, utterance and turn count have been used to compare the child's contribution with the contribution of the HCP and parent to the conversation. The child's relative contribution to the dialogue is consistently reported to be rather small and did not change across the 50 years of research output that we examined in our review. This is surprising, because of the steadily increasing emphasis on patient-centered medicine, also in pediatrics [9]. Application of patient-centered medicine in pediatrics is possibly hampered by the use of medical jargon [12,43,54], limitations in medical consultation time, agenda setting by the parents or other child specific factors [43,47,50,55]. Alternatively, a paternalistic stance in medicine in general could limit patient participation further [56]. Nevertheless, as engaging children in social talk strongly improves their aptness to present the medical problem, HCPs should first invest on getting to know the child at a personal level before taking a detailed medical history [25].

4.1.2. Factors that contribute to child participation

Variations in child participation were in part affected by factors that cannot be influenced by HCPs, such as the children's age, but also by the type of visit, factors already observed and described in the review of Tates et al., 20 years ago [10,30,33,35]. However, our review also indicates various factors that positively impact child participation that can be influenced by HCPs, such as equidistant seating arrangements, child-directed gaze and finding the appropriate tone of voice by the HCP [32]. In addition, HCPs need to be aware of the silence pauses that children need to formulate an answer, which is essential to allow for child participation. Also, non-verbal signs of the child's attempts of interaction include the child's gaze at the conversation partners, embodied actions and asking for clarification. Although often not happening within the flow of the adult conversation, these actions should be seen as complementary to moments of verbal interjection and should be seen as potential springboards for the child to join the conversation [21].

4.1.3. Children's right to participate

The studies that investigated child participation with qualitative methods illustrated increased awareness of child experiences regarding their participation. Children repeatedly voiced the importance of being included during medical encounters in these studies [45,51,54]. During the child's maturation, there is a growing need to be involved in the decision-making process as well [44]. Therefore, the HCP should tailor the level of engagement according to the child's individual needs. The child's turn taking is often controlled by parents because they want their reason for encounter to be heard or they want to buffer the information to protect their child when the doctor is breaking bad news. This, however, leads to ignoring the child's right to participate while children are willing to take decisions at their appropriate level of responsibility [12]. Nevertheless, not all parental involvement impairs children in their participation. Some studies also showed child-supportive parental actions and physical circumstances through careful qualitative content analysis. For example, parents answered a child-directed question only after multiple failed attempts by the HCP to retrieve an answer from the child [25]. Therefore, all adults in the room should support the child's maturation towards independence and taking ownership over his own health process and engage the child at the desired and appropriate level.

4.1.4. Interventions to improve child participation

Interventions that aim to improve child participation are scarce. Our search strategy found only three intervention studies [23,24,26], with varying methods to improve child participation and varying outcomes.

Although designed as an observational study, the favorable engagement of children who were socially engaged by the HCP prior to medical problem solicitation strongly suggests that improvement of soft skills and small talk may contribute to child participation considerably [25]. This illustrates the need for new interventions to improve child participation that consider children's thoughts and opinions. It is very well possible that children want to explore other forms of interaction to express themselves, such as by drawing or in role play. We have, however, not found studies that explored this in relation to child participation. As children use electronic applications increasingly to express themselves in various social contexts, HCPs might have to adapt to these types of interactions as well to find a better connection with children, which was illustrated by the example of the Sisom implementation study [24]. Future interventions, ideally also targeting all three participants in the encounter, should be developed in agreement with children's preferences and context. Apart from these interventions, tailoring of the communication skills to meet the needs for an environment fit for child participation is crucial.

4.1.5. Transferability of the results

Although this scoping review focuses on consultations in pediatric settings, triadic conversations are also common when patients receive support from relatives during healthcare visits, including geriatrics or care for people with special needs. Therefore, we believe that the findings of this scoping review are of interest to all HCPs interested in promoting or researching patient participation during (triadic) medical consultations.

4.1.6. Strengths and limitations of the study

We performed a broad and sensitive literature search including the consultations of authors and experts to capture the width of available literature on this subject. However, as our review has a scoping review design it is possible that relevant studies were missed. Furthermore, we did not consider studies that evaluated child participation based on the HCPs' or the parent's opinion without the child's own perspective. Therefore, observations that could benefit child participation from the adult's perspective could have been missed.

5. Conclusion

Detailed analysis of studies that investigated child participation during medical consultations reveal no improvement of child participation during the past 50 years and indicated that innovations to promote child participation in clinical encounters are scarce. Studies used various quantitative methods to investigate the child verbal contribution, including counting utterances, speech turn and time. Qualitative analysis of content and structure can provide insight to what extent the child's words are incorporated in a meaningful triadic interaction with the HCP and the parent. As communication might be the most essential competency for HCPs to build a therapeutic relationship with the patient, this may be an opportunity to target the need for better child participation with a more appropriate conversation strategy in consultations [57].

5.1. Practice implications

The timing of the child's initiatives, in relation to the content being discussed, should provide the overall structure of the conversation. We, therefore, propose the following steps in analyzing child contribution in conversational analysis:

Quantitative count of utterances and words or speech time.
Qualitative analysis of participation: non-verbal signs and recording child's initiatives (asking questions, presenting the problem, proposing a plan).

Content analysis of child-initiated subjects, agenda setting and outcome description

Evaluating the child's opinion regarding their preferred and experienced level of participation.

Given the lack of recent quantitative research on child participation, this could be a starting point for new studies. In addition, it would be rather informative to investigate the conversation process from a linguistic point of view. This may reveal examples of successful engagement strategies and might show less successful patterns of HCP child communication in which a true dialogue is not achieved.

CRedit authorship contribution statement

Christiaan van Woerden: Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing, Project administration, Supervision. **Heleen Vroman:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing, Visualization. **Paul L.P. Brand:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, review, Project administration, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

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Appendix 1. Used search strings

MEDLINE

PICO A.

infan* [tiab] OR child* [tiab] OR adolescen* [tiab] OR pediatric* [tiab] OR pediatric* [tiab] OR pube* [tiab] OR juvenil* [tiab] OR school-child* [tiab] OR schoolchild* [tiab] OR toddler* [tiab] OR youngster* [tiab] OR preschool* [tiab] OR kindergart* [tiab] OR kid [tiab] OR kids[tiab] OR prepube* [tiab] OR preadolescenc* [tiab] OR junior-high* [tiab] OR highschool* [tiab] OR senior-high[tiab] OR young-people* [tiab] OR minors[tiab].

AND.

Involvement[tiab] OR engagement[tiab] OR empowerment[tiab] OR participation[tiab] OR input[tiab] OR contribution[tiab] OR patient-involvement[tiab] OR patient-engagement[tiab] OR patient-empowerment[tiab] OR patient-participation[tiab] OR consumer-involvement[tiab] OR childrens-participation[tiab] OR active-involvement[tiab] OR Concordanc* [tiab] OR "Patient Participation"[Mesh] OR consumer-participation[tiab] OR Patient-interview* [tiab] OR Patient-input[tiab] OR Participating-patient* [tiab] OR patient-contribution* [tiab] OR patients-contribution* [tiab].

OR.

"Decision Making"[Mesh] OR Shared-decision* [tiab] OR "Physician-Patient Relations"[Mesh] OR "Professional-Patient Relations"[Mesh] OR Physician-Patient-Relation* [tiab] OR Physician-patient-communication[tiab] OR "Patient-Centered Care"[Mesh] OR Patient-focused-care [tiab] OR Patient-centered-intervention* [tiab] OR Patient-focused-intervention[tiab] OR Patient-centered[tiab] OR Patient-centred[tiab] OR patient-centredness[tiab] OR Individualized-care[tiab] OR person-centered-care[tiab] OR person-centred-care[tiab] OR client-centered-care[tiab] OR client-centred-care[tiab] OR Patient-Information[tiab] OR patient-counseling[tiab] OR patient-counselling[tiab] OR patient-

consult* [tiab] OR patient-communication[tiab] OR brown-bag[tiab].

AND.

Measurement OR assessment OR "Surveys and Questionnaires"[Mesh] OR Questionnaire* OR Survey* OR Survey-Method OR Survey-Methodology OR assessment* .

AND.

Improv* OR Acknowledge* .

AND.

Shared-decision OR shared-decision-making OR decision-making-process OR decision-making OR "Decision Making"[Mesh] OR "Decision Support Techniques"[Mesh] OR decision-making[tiab] OR decision-aid* [tiab] OR choice-behavior* [tiab] OR choice-behaviour* [tiab] OR decisionmaking* [tiab] OR medical-decision* [tiab] OR treatment-decision* [tiab] OR clinical-decision* [tiab].

PICO B.

(Pediatric consult* OR Pediatric consult* OR medical-consult* OR medical-counsel* OR pediatric-visit OR pediatric-interview*) AND (Involvement[tiab] OR engagement[tiab] OR empowerment[tiab] OR participation[tiab] OR input[tiab] OR contribution[tiab] OR patient-involvement[tiab] OR patient-engagement[tiab] OR patient-empowerment[tiab] OR patient-participation[tiab] OR consumer-involvement[tiab] OR childrens-participation[tiab] OR active-involvement[tiab] OR Concordanc* [tiab] OR "Patient Participation"[Mesh] OR consumer-participation[tiab] OR Patient-interview* [tiab] OR Patient-input[tiab] OR Participating-patient* [tiab] OR patient-contribution* [tiab] OR patients-contribution* [tiab]).

PsycINFO

PICO A.

TI child OR AB child OR TI children OR AB children OR TI adolescent OR AB adolescent OR TI adolescents OR AB adolescents OR TI youth OR AB youth OR TI teenager OR AB teenager OR TI teenagers OR AB teenagers OR TI infant OR AB infant OR TI infants OR AB infants OR TI pediatric OR AB pediatric OR TI pediatric OR AB pediatric OR DE "Puberty" OR TI pube* OR AB pube* OR TI juvenile* OR AB juvenile* OR TI school W0 child* OR AB school W0 child* OR TI toddler OR AB toddler OR TI youngster OR AB youngster OR DE "Emerging Adulthood" OR DE "Preschool Students" OR TI preschool OR AB preschool OR DE "Kindergarten Students" OR TI kindergart* OR AB kindergart* OR TI kid* OR AB kid* OR TI prepube* OR AB prepube* OR TI preadolescenc* OR AB preadolescenc* OR DE "Junior High School Students" OR TI junior W0 high OR AB junior w0 high OR TI highschool OR AB highschool OR TI senior W0 high OR AB senior W0 high OR TI young W0 people OR AB young W0 people OR TI minors OR AB minors.

AND.

DE "Involvement" OR TI involvement OR AB involvement OR TI engagement OR AB engagement OR DE "Empowerment" OR TI empowerment OR AB empowerment OR DE "Participation" OR DE "Client Participation" TI patient W0 participation OR AB patient W0 participation OR TI child* W0 participation OR AB child* W0 participation OR TI input OR AB input OR TI contribution OR AB contribution OR TI patient W0 involvement OR AB patient W0 involvement OR TI patient W0 engagement OR AB patient W0 engagement OR TI consumer W0 involvement OR AB consumer W0 involvement OR TI active W0 involvement OR AB active W0 involvement OR TI concordanc* OR AB concordanc* OR TI consumer W0 participation OR AB consumer W0 participation OR TI patient W0 interview OR AB patient W0 interview OR TI patient W0 input OR AB patient W0 input OR TI participating W0 patient OR AB participating W0 patient OR TI patient* W0 contribution OR AB patient* W0 contribution OR DE "Decision Making" OR DE "Choice Behavior" OR TI decision W0 making OR TI shared W0 decision* OR TI shared W0 decision W0 making OR TI physician W0 patient W0 relation* OR TI professional W0 patient W0 relation* OR TI physician W0 patient W0 communication* OR TI patient W0 centered W0

care OR TI patient W0 focused W0 care OR TI patient W0 centered W0 intervention* OR TI patient W0 focused W0 intervention* OR TI patient W0 centered OR TI patient W0 centred OR TI patient W0 centredness OR TI individualized W0 care OR TI person W0 centered W0 care OR TI person W0 centred W0 care OR TI client W0 centered W0 care OR TI client W0 centred W0 care OR TI patient W0 information OR TI patient W0 counselling OR TI patient W0 consult* OR TI brown W0 bag.

AND.

DE "Professional Consultation" OR TI consultation* OR DE "Communication" OR TI communication.

AND.

DE "Measurement" OR TI measurement OR AB measurement OR TI assessment* OR AB assessment* OR DE "Surveys" OR TI survey* OR AB survey* OR DE "Questionnaires" OR TI questionnaire* OR AB questionnaire* .

AND.

(DE "Measurement" OR TI measurement OR AB measurement OR TI assessment* OR AB assessment* OR DE "Surveys" OR TI survey* OR AB survey* OR DE "Questionnaires" OR TI questionnaire* OR AB questionnaire*) AND (S1 AND S2 AND S3 AND S4).

PICO B.

TI child OR AB child OR TI children OR AB children OR TI adolescent OR AB adolescent OR TI adolescents OR AB adolescents OR TI youth OR AB youth OR TI teenager OR AB teenager OR TI teenagers OR AB teenagers OR TI infant OR AB infant OR TI infants OR AB infants OR TI pediatric OR AB pediatric OR TI pediatric OR AB pediatric OR DE "Puberty" OR TI pube* OR AB pube* OR TI juvenile* OR AB juvenile* OR TI school W0 child* OR AB school W0 child* OR TI toddler OR AB toddler OR TI youngster OR AB youngster OR DE "Emerging Adulthood" OR DE "Preschool Students" OR TI preschool OR AB preschool OR DE "Kindergarten Students" OR TI kindergart* OR AB kindergart* OR TI kid* OR AB kid* OR TI prepube* OR AB prepube* OR TI preadolescen* OR AB preadolescen* OR DE "Junior High School Students" OR TI junior W0 high OR AB junior w0 high OR TI highschool OR AB highschool OR TI senior W0 high OR AB senior W0 high OR TI young W0 people OR AB young W0 people OR TI minors OR AB minors.

AND.

DE "Involvement" OR TI involvement OR AB involvement OR TI engagement OR AB engagement OR DE "Empowerment" OR TI empowerment OR AB empowerment OR DE "Participation" OR DE "Client Participation" TI patient W0 participation OR AB patient W0 participation OR TI child* W0 participation OR AB child* W0 participation OR TI input OR AB input OR TI contribution OR AB contribution OR TI patient W0 involvement OR AB patient W0 involvement OR TI patient W0 engagement OR AB patient W0 engagement OR TI patient W0 empowerment OR AB patient W0 empowerment OR TI consumer W0 involvement OR AB consumer W0 involvement OR TI active W0 involvement OR AB active W0 involvement OR TI concordanc* OR AB concordanc* OR TI consumer W0 participation OR AB consumer W0 participation OR TI patient W0 interview OR AB patient W0 interview OR TI patient W0 input OR AB patient W0 input OR TI participating W0 patient OR AB participating W0 patient OR TI patient* W0 contribution OR AB patient* W0 contribution OR DE "Decision Making" OR DE "Choice Behavior" OR TI decision W0 making OR TI shared W0 decision* OR TI shared W0 decision W0 making OR TI physician W0 patient W0 relation* OR TI professional W0 patient W0 relation* OR TI physician W0 patient W0 communication* OR TI patient W0 centered W0 care OR TI patient W0 focused W0 care OR TI patient W0 centered W0 intervention* OR TI patient W0 focused W0 intervention* OR TI patient W0 centered OR TI patient W0 centred OR TI patient W0 centredness OR TI individualized W0 care OR TI person W0 centered W0 care OR TI person W0 centred W0 care OR TI client W0 centered W0 care OR TI client W0 centred W0 care OR TI patient W0 information OR TI patient W0 counselling OR TI patient W0 consult* OR TI brown W0 bag.

AND.

DE "Professional Consultation" OR TI consultation* OR DE

"Communication" OR TI communication.

AND.

DE "Measurement" OR TI measurement OR AB measurement OR TI assessment* OR AB assessment* OR DE "Surveys" OR TI survey* OR AB survey* OR DE "Questionnaires" OR TI questionnaire* OR AB questionnaire* .

AND.

(DE "Measurement" OR TI measurement OR AB measurement OR TI assessment* OR AB assessment* OR DE "Surveys" OR TI survey* OR AB survey* OR DE "Questionnaires" OR TI questionnaire* OR AB questionnaire*) AND (S1 AND S2 AND S3 AND S4).

AND.

clinician patient relationship AND shared decision making AND (children or adolescents or youth or child or teenager).

CINAHL

(MH "Infant+") OR (MH "Child+") OR (MH "Adolescence+") OR (MH "Puberty+") OR "school child" OR (MH "Child, Preschool") OR (ti kid*) OR (ab kid*) OR (MH "Students, Middle School") OR (MH "Students, High School") OR (MM "Young Adult") OR (ti juvenil*) OR (ab juvenile*) OR (ti toddler*) OR (ab toddler*) OR (ti youngster*) OR (ab youngster*).

AND.

(MH "Consumer Participation") OR (ti involvement) OR (ab involvement) OR (ti engagement) OR (MH "Empowerment") OR (ti empowerment) OR (ti participation) OR (ti input) OR (ti contribution) OR (ti patient involvement) OR (ab patient involvement) OR (ti patient engagement) OR (ab patient engagement) OR (ti patient empowerment) OR (ab patient empowerment) OR (ti patient participation) OR (ab patient participation) OR (ti consumer involvement) OR (ab consumer involvement) OR (ti childrens participation) OR (ab childrens participation) OR (ti active involvement) OR (ab active involvement) OR (ti concordance) OR (ab concordance) OR (MH "Interviews+") OR (ti patient interview) OR (ab patient interview) OR (ti patient input) OR (ab patient input) OR (ti participating patient) OR (ab participating patient) OR (ti patient contribution) OR (ab patient contribution) OR (ti patients contribution) OR (ab patients contribution).

AND.

(MH "Decision Making+") OR (MH "Decision Making, Patient+") OR (MH "Decision Making, Shared") OR (MH "Physician-Patient Relations") OR (MH "Professional-Patient Relations+") OR (ti physician patient communication) OR (ab physician patient communication) OR (MH "Patient Centered Care") OR (ti patient focused care) OR (ab patient focused care) OR (ti patient centered intervention) OR (ab patient centered intervention) OR (ti patient focused intervention) OR (ab patient focused intervention) OR (ti patient centered) OR (ab patient centered) OR (ti patient centred) OR (ti patient centredness) OR (ab patient centredness) OR (ti individualized care) OR (ab individualized care) OR (ti person centered care) OR (ab person centered care) OR (ti person centred care) OR (ab person centred care) OR (ti client centered care) OR (ab client centered care) OR (ti client centred care) OR (ab client centred care) OR (ti patient information) OR (ab patient information) OR (ti patient counselling) OR (ab patient counselling) OR (ti patient consult*) OR (ab patient consult*) OR (ti patient communication) OR (ab patient communication) OR (ti brown bag).

OR (MH "Referral and Consultation+") OR (ti consultation*) OR (ab consultation*) OR (MH "Communication+") OR (ti communication) OR (AB communication).

AND.

(ti measurement) OR (ab measurement) OR (ti assessment) OR (ab assessment) OR (MH "Surveys+") OR (ti survey*) OR (ab survey*) OR (MH "Questionnaires+") OR (ti questionnaire*) OR (ab questionnaire*) OR (ti survey method*) OR (ab survey method*).

AND.

children AND shared decision making AND consultation.

EMBASE

'child'/exp OR 'infant'/exp OR 'adolescent'/exp OR 'puberty'/exp OR 'juvenile'/exp OR 'school child'/exp OR 'toddler'/exp OR 'pre-school child'/exp OR 'kindergarten'/exp OR 'prepuberty'/exp OR 'preadolescence'/exp OR 'young adult'/exp OR 'minor (person)'/exp OR youngster:ab,ti OR kid* :ab,ti OR junior near high:ab,ti OR high near school:ab,ti OR young near people:ab,ti.

AND.

'involvement'/exp OR 'engagement'/exp OR 'empowerment'/exp OR 'patient participation'/exp OR 'patient engagement'/exp OR 'patient empowerment'/exp OR 'concordance'/exp OR input:ab,ti OR contribution:ab,ti OR consumer near participation:ab,ti OR child near participation:ab,ti OR active near involvement:ab,ti OR patient near interview:ab,ti.

OR.

'decision making'/exp OR 'shared decision making'/exp OR 'doctor patient relationship'/exp OR 'professional-patient relationship'/exp OR 'doctor patient communication'/exp OR 'patient care'/exp OR 'personalized medicine'/exp OR 'person centred care'/exp OR 'client centered therapy'/exp OR 'patient information'/exp OR 'patient counseling'/exp OR shared near decision:ab,ti OR patient near consult* :ab,ti OR patient near communication:ab,ti OR brown near bag:ab,ti.

OR.

'consultation'/exp OR consultation* :ab,ti OR 'interpersonal communication'/exp OR communication:ab,ti.

AND.

'measurement'/exp OR 'assessment'/exp OR 'assessment of humans'/exp OR 'questionnaire'/exp OR 'survey'/exp OR survey near method* :ab,ti.

Google scholar

Patient Participation Pediatrics.

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