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TITLE PAGE

How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis

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ABSTRACT

Objective

Explore children's and adolescents' (CADs') lived experiences of healthcare professionals (HCPs).

Design

Scoping review methodology provided a six-step framework to, first, identify and organise existing evidence. Interpretive phenomenology provided methodological principles for, second, an interpretive synthesis of the life-worlds of CADs receiving healthcare, as represented by verbatim accounts of their experiences.

Data Sources

Five key databases (Ovid MEDLINE, Embase, Scopus, CINAHL Plus, and Web of Science), from inception through to January 2019, reference lists, and opportunistically identified publications.

Eligibility criteria

Research articles containing direct first-person quotations by CADs (aged 0-18 years inclusive) describing how they experienced HCPs.

Data extraction and synthesis

Tabulation of study characteristics, contextual information, and verbatim extraction of all 'relevant' (as defined above) direct quotations. Analysis of basic scope of the evidence-base. The research team worked reflexively and collaboratively to interpret the qualitative data and construct a synthesis of children's experiences. To consolidate and elaborate the interpretation, we held two focus groups with CAD inpatients in a children's hospital.

Results

669 quotations from 99 studies described CADs' experiences of HCPs. Favourable experiences were of forming trusting relationships and being involved in healthcare discussions and decisions; less favourable experiences were of not relating to or being unable to trust HCPs and/or being excluded from conversations about them. HCPs fostered trusting relationships by being personable, wise, sincere, and relatable. HCPs made CADs feel involved by including them in conversations, explaining medical information, and listening to CADs' wider needs and preferences.

Conclusion

These findings strengthen the case for making CADs partners in healthcare despite their youth. We propose that a criterion for high-quality child-centred healthcare should be that HCPs communicate in ways that engender trust and involvement.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Our findings have advanced current evidence by providing a comprehensive overview of CADs' experiences of HCPs, while providing a blueprint for the child-centred care conceptual model.
- In addition to completing a scoping review in line with a published protocol, this article reports an interpretive phenomenological synthesis of the evidence-base
- Restricting included articles to the English language limited the scope of our review
- Limitations in the metadata provided by primary researchers prevented subgroup analyses
- The subjectivity of interpretive synthesis is both a limitation and a strength: a limitation, because it does not meet quantitative, experimental standards of proof; and a strength because we used our subject position as clinicians to help fellow clinicians earn the trust of CADs.

BACKGROUND

Children's experiences, like patients' experiences in general, are of fundamental importance in healthcare.[1–3] Research consistently shows that favourable experiences are associated with a wide range of positive health outcomes, including adherence to recommended treatments, uptake of preventive care, and utilisation of healthcare resources.[3] Exploring, understanding, and adapting to patients' experiences, particularly those concerning interpersonal communication, is the hallmark of patient-centred care (PCC), which is what patients 'strongly want'.[4,5] Accordingly, PCC has become the dominant ideology in healthcare design and delivery.[6]

In the case of children, however, it has proven more difficult to establish a model of PCC. Children and adolescents (CADs) are distinct from adults; they are developing physically, intellectually, and emotionally, and they occupy different positions in society and by law.[7] CADs, therefore, typically experience healthcare as part of a family unit, accompanied by parents or guardians who often act on their behalf. These factors affect the roles that CADs occupy within healthcare settings – how they interact and communicate with others – and predispose them to asymmetric relationships with adults. To address this, two specific theoretical models of care – family-centred care (FCC) and child-centred care (CCC) – have been developed for use in paediatric practice, based on the principles of PCC but incorporating modified conceptualisations of centredness.[8]

In FCC, the family is the central unit of care, with the aspiration of an equal partnership between healthcare professionals (HCPs) and families. FCC, which first originated in the 1950s, was an important conceptual advance because, up to this point, no framework existed to involve parents in their children's care.[7] Recent research shows, however, that even within the FCC framework, parents and professionals tend to predominate and CADs struggle to be true participants.[9] In contrast, the newer concept of CCC situates CADs at the centre of healthcare practice, giving primacy to their voices and experiences. Rather than being guided by outsider perspectives of children's best interests, CCC compels HCPs to consciously perceive and understand children's conditions, experiences, and priorities, as viewed through their eyes:[8,10,11]

> "[CCC] requires providers to critically consider the child's perspective in every situation while ensuring collaboration with the family who the [child] is part of."[8]

While aspects of FCC and CCC may be pertinent in different clinical contexts,[12] experts now advocate a move towards CCC,[13] arguing that it better upholds values laid down by the UN Convention on the Rights of the Child and governing bodies (such as the General Medical Council),[14,15] and could improve how CADs experience healthcare.[8,13]

Adopting the CCC approach, however, requires a major shift in thinking and practice. Research suggests that HCPs' realities are incompatible with CADs', with HCPs focused on prioritizing tasks, 'getting the job done', and mitigating, rather than engaging with, CADs' demands.[16] Furthermore, HCPs' communication strategies adopted for consulting CADs are largely underpinned and conceptualized by biomedical or psychosocial models, from the clinical gaze,[17] with little or no input from CADs.[18,19] And while CADs' healthcare experiences overall are generally positive, large-scale studies have identified shortcomings in how HCPs interact and communicate,[20–22] impacting on CADs' ability to manage their conditions and participate in decision-making.[23] HCPs, too, continue to find communicating with CADs challenging, supporting a change in thinking and practice.[19]

To achieve the vision of CCC, then, HCPs need greater insight into the experiences of sick children.[11] This reflects a wider drive towards co-production (providers and service users working in equal partnership to effect change) in children's healthcare;[24,25] and also complements the present impetus to acknowledge and examine CADs' *own* experiences, opinions, and priorities, within research,[26,27] quality improvement,[28–30] and standard setting.[31] To date, however, most research and surveys examining experiences in paediatric settings have relied on parents' accounts, while CADs have participated less, if at all.[32] Nevertheless, the few studies that have explored CADs' own experiential accounts have found them to be informative and distinct from parents'.[23,33] At present, these accounts are widely dispersed, yet if compiled, synthesised, and interpreted, these could provide a rich account of CADs' lived experiences of how they encounter HCPs.

This study aimed to explore how CADs experience HCPs within interpersonal interactions, in order to provide practitioners, organisations, and policymakers with evidence that could promote child-centred communication. First, we conducted a scoping literature review to systematically gather evidence on CADs' experiences of HCPs. Second, we interpreted CADs' extracted quotations from the perspective of phenomenology. This well-established methodological tradition, grounded in philosophy, enables researchers to produce valid interpretations by examining and interpreting participants' verbatim accounts of their lived experience.[34] Finally, we organised the interpretation into a synthetic account of how CADs experience their interactions with HCPs.

METHODS

Methodological orientation

Scoping review methodology has a pragmatic orientation in the sense that it sets out to map existing published evidence on a topic but it is adaptable in the sense that the usefulness of its procedures is not tied to any one specific epistemology (theory of the nature of knowledge).[35–37] As in our previously published research,[38] this review augments scoping review procedures with interpretive phenomenology. The latter has an ontology (theory of the nature of being) derived from the philosophy of Husserl, according to which the lived experience of research participants is a legitimate topic of qualitative inquiry.[34] Interpretive phenomenology helps researchers respond reflexively to spoken or written words and arrive at valid, subjective interpretations. Phenomenologists typically take a reflexive stance that consciously sets aside strong a priori preconceptions whilst allowing their own experiences (such as, in our case, having experience of caring for sick children) to help them construct an informative interpretation. The quality of a constructivist interpretation is to be judged by its trustworthiness, authenticity, and ability to catalyse action – which, in this case, would be to improve future children's healthcare experiences.[39]

Study procedures

The research followed a published protocol (accessible at https://rdcu.be/b2FFk),[40] which proposed to supplement traditional scoping review procedures with an interpretive synthesis, the distinction between which is explained in the previous paragraph. The scoping component followed the 6-step framework outlined by Arksey & O'Malley,[35] Levac et al.,[36] and Colquhoun et al.,[37] adhering to PRISMA-ScR reporting guidance (included in online supplementary file 1).[41]

Step 1: Defining the research question

This was: *'What is known about children's and adolescents' experiences of healthcare professionals, from their present perspective?'*, the final phrase emphasizing our commitment to CADs' contemporaneous accounts of their experiences expressed in their own words, rather than parents' descriptions or adults describing childhood memories.

Step 2: Identifying relevant articles

We designed a STARLITE search strategy (summarised in table 1) to identify all published articles containing CADs' experiences of HCPs expressed as first-person direct quotations.[42] A subject librarian constructed a database search (included in online supplementary file 2), using the population, context, and concept framework,[43] combining the terms ‘children’ or ‘adolescents’, ‘healthcare’, and ‘experience’ (and synonyms), limiting it to English language articles, ‘qualitative research’, and ‘0 to 18 years’, and then running it on Ovid MEDLINE, Embase, Scopus, CINAHL Plus, and Web of Science from inception to 11th January 2019. We included other articles found by searching relevant reference lists or found opportunistically.

Table 1 STARLITE summary of search strategy[42]

Sampling strategy	Comprehensive: attempting to identify all published materials
Types of studies	Any published study contributing to the research question: qualitative (with or without other methodologies (i.e., mixed method)); primary or secondary sources
Approaches	Electronic database searching; manual searching of reference lists; articles found opportunistically
Range of years	From database inception until 11th January 2019
Limits	Articles published in English language; ‘qualitative research’; children aged 0-18 years (inclusive)
Inclusion and exclusion criteria	See table 2 and Step 3: Study selection
Terms used	See online supplementary file 2
Electronic databases	Ovid MEDLINE; Embase; Scopus; CINAHL Plus; Web of Science

Step 3: Study selection

Refinement of selection criteria

As is customary in scoping review, the process iterated between searching, selecting, extracting data, and refining the research question. To enhance the rigour of this process, and in keeping with our interpretive stance, we responded reflexively to the accumulating evidence, discussing our interpretations, and articulating a clear rationale for each refinement. All records were imported to Mendeley Reference Manager, duplicates removed, titles and abstracts screened against five screening questions (Box 1), and full texts of those that screened positive reviewed against eligibility criteria.

Box 1 Screening questions

1. Are the participants CADs ($\leq$ 18 years)?
2. Is the study examining an aspect of health, illness, or healthcare?
3. Are CADs participating as recipients of healthcare?
4. Are participants aged > 18 years excluded from the study?
5. Do children or adolescents describe experiences?

These criteria, at first provisional (table 2A), were progressively refined in response to the heterogeneity of evidence. Table 2B shows final criteria. GD led the process of first-screening, annotating, sorting, and collating articles. MK & TD supported her by second-screening 10% of records, discussing results, assessing articles whose eligibility was in doubt, and responding to the often-imprecise details given by researchers. Any ambiguities (i.e., lack of age ranges) during screening led to full-text review and a final decision about eligibility against criteria. To optimise validity of the selection process, GD rescreened all records and annotations after each refinement and, finally, after definitive criteria had been set.

Rationale for criteria

We included children up to and including 18 years because late adolescents are increasingly cared for in paediatric settings.[44,45] Our age range conforms, also, with the United Nations' influential definition of adolescence.[46] We included articles that contained verbatim quotations irrespective of methodology. Judgement of methodological quality was not a criterion for three reasons: it is not standard practice in scoping reviews; it is notoriously difficult to judge qualitative research categorically;[46] and the interpretive synthesis used verbatim quotations, whose validity does not depend on what the primary researchers did with CADs' words. Because authors often failed to report the exact age of patient participants they quoted, we excluded any study that included patient participants aged > 18 years (see, for example, Tjaden et al. [47]).

Table 2 Eligibility criteria for article selection

A. Provisional	B. Definitive
Inclusion criteria:	
1. CADs speaking about HCPs, through first-person direct quotations. 2. HCP defined as a member of a healthcare team. 3. CADs defined as ≤ 18 years old, regardless of health status or illness type.	1. CADs speaking about one or more HCPs, on one or more instances, from any experience, through first-person direct quotation(s), where there had been direct contact between the two parties, and where CADs were the persons receiving healthcare. 2. An HCP defined as a member of a healthcare team with professional qualifications and training, such as a qualified doctor, nurse, therapist, psychologist, or social workers, regardless of grade. 3. CADs defined as ≤ 18 years, regardless of health status or illness type.
Exclusion criteria:	
1. Adults aged >18 years included in the study. 2. Non-English language publications.	1. Adult patients aged >18 years included in the study with or without CADs as defined above. 2. Non-English language publications. 3. CADs speaking about HCP(s) not from memory of personal experience as a patient; for example, third-party description (e.g., parent). 4. Age range of CAD participants unclear. 5. No full-text manuscript available; only an abstract available, or unobtainable by searching online, directly emailing authors, or by university librarians requesting inter-library loans.

Step 4: Charting the data

GD and MK piloted a spreadsheet to chart study characteristics, contextual information, and all CADs' verbatim quotations on 10 articles; this resulted in the final dataset shown in box 2, which GD then used to extract data on the remaining articles.

Box 2 Data extracted

Study characteristics:
- First author
- Year published
- Country of origin
- No. CAD participants
- Age range of CAD participants
- Male to female (or non-binary) ratio
- Other participants (e.g., parents)
- Methods
- Methodology (or analytical approach)

Contextual information:
- Study focus (the experience being explored)
- Health setting
- Health condition
- Length of healthcare encounter being explored

CADs' quotations:
- All first-person direct quotations, where CADs are talking about HCPs
- Age and gender referenced to each quotation

When key information was missing or unclear, we sought clarification from primary authors. All authors independently reviewed the extracted information for its fitness to address the aims and purpose of the study, subsequently conferring to optimise the validity of the dataset.

Step 5: Collating, summarising, and reporting the results

We first analysed the basic characteristics of included studies. We then identified themes in the verbatim quotations following Braun and Clarke's method of thematic analysis as defined by their checklist (included in online supplementary file 3).[48,49] GD immersed herself in the data, reviewing all quotations on Microsoft Excel, using NVivo 12 qualitative analysis software to support generation of codes and construction of themes.[50] Other team members supported her interpretation, by reviewing quotations first individually, and then collectively. We systematically interrogated the data for themes that had meaning in relation to the research question, revising candidate themes periodically (with the aid of a visual thematic map) to ensure these were coherent, distinctive, complementary, and relevant. The ensuing thematic structure had central concepts, which we used to organise subordinate themes and their associated codes. Throughout this process, we constantly compared our evolving interpretation against the original data, including a final 'quality control' check of the synthesis against all quotations.[49]

In keeping with our interpretive stance, we used our different subject positions as paediatricians, a family doctor, and an adult internist to interpret CADs' words reflexively and arrive at 'beyond-surface insights', so that the themes were amenable to an additional stage of phenomenological synthesis.[48,49] As we did this, the gamut of emotional content in CADs' words became an increasingly compelling influence on our interpretation. CADs' emotional expressions tended to have quite distinct 'valence' (defined as the attractiveness [positive valence] or averseness [negative valence] of the emotions described) which linked in recurring ways to HCPs' reported behaviours.[51,52] So, for example, a HCP who related well to a child might engender trust, while an HCP who related poorly might engender mistrust.

Whilst crude dichotomies between positive/negative emotions and behaviours do not reflect the subtlety of interpretive research, links between these contrasting behaviours were so clearly present that they offered a parsimonious way of presenting our results. The Results section uses the terms 'favourable' and 'unfavourable' to specify what are, in reality, nuanced polarities. To epitomize these important themes in ways that could encourage HCPs to emulate favourable behaviours, we present predominantly favourable behaviours, but provide negative counter-examples to emphasize the breadth of CADs' experiences. As in previous research,[53] we used CADs' own words, as far as possible, to construct a narrative of findings that was as true as possible to the phenomena experienced and narrated by children. We use the wording 'HCPs did X' as a shorthand for the more correct wording, 'CADs experienced HCPs as doing X'.

Step 6: Stakeholder consultations

As recommended by Levac et al.,[36] GD, AT, and RC (with research ethics and governance approvals) recruited CADs aged 8-16 from inpatient wards in the Royal Belfast Hospital for Sick Children (RBHSC) to two focus groups whose aim was to consolidate and elaborate on findings. Participants and parents chose whether parents should attend. We presented candidate themes along with exemplar quotations and facilitated discussions, asking participants to comment on provisional findings and provide suggestions for practice. We audio-recorded sessions and transcribed recordings verbatim. We reviewed transcripts alongside the provisional findings to authenticate, build upon, and summarise a final narrative of results. Participants' identities are pseudonymised in the results section.

Patient and public involvement

The essence of this research was to involve children, albeit as expressed verbatim by other researchers. The stakeholder consultation further fulfilled the patient and public involvement component of the research by ensuring findings disseminated were intelligible and relevant.

RESULTS

We identified 1,359 articles, excluding 1,015 by screening and 245 by reviewing full texts, and categorised reasons for exclusion on a PRISMA flow diagram (shown in figure 1).

Overview of included studies

Table 3 presents an overview of included studies (n=99), published between 1992 and 2018. In total, 4,448 CADs, aged 11 months to 18 years, participated. Most studies included 8 to 50 participants (n=73), aged 7 or older (n=70), and used interviews only (n=64). Studies commonly included CADs with chronic and potentially debilitating or life-threatening conditions (such as asthma and cancers), explored long-term experiences (over months to years), and focused on hospital care. Further descriptive findings and figures are presented in online supplementary file 4.

Table 3 Study characteristics

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Aalsma *et al.*, 2014[54]	US	19	11-17	12:7	INT	Qualitative	CAMHS	Non-specific	Mental health illness	Long-term	5
Alex MR, 1992[55]	Canada	24	7-11	13:11	INT, Q	Content analysis	Pain	Hospital	Surgical (post-op)	Short-term	4
Anderson *et al.*, 2017[56]	England	6	15-18	3:3	INT	Interpretative phenomenological analysis	Lung transplantation	Hospital	Post-lung transplantation	Long-term	6
Ångström-Brännström *et al.*, 2008[57]	Sweden	7	4-10	3:4	INT (PT)	Thematic analysis	Being comforted	Hospital	Chronic	Short-term	6
Ångström-Brännstrom *et al.*, 2014[58]	Sweden	9	3-9	5:4	INT	Content analysis	Comfort during cancer treatment	Hospital	Cancer	Long-term	3
Beresford *et al.*, 2003[59]	England	63	11-16	27:36	INT, FG (PT)	Framework method	Communicating	Hospital	Chronic	Long-term	14
Boyd *et al.*, 1998[60]	Canada	6	10-13	2:4	INT (PT), WT	Grounded theory	Hospital and coping strategies	Hospital	Surgical (chronic)	Long-term	3
Brown *et al.*, 2014[61]	US	19	11-17	12:7	INT	Grounded theory	Therapeutic alliances	Hospital	Mental health illness	~	16
Carney *et al.*, 2003[62]	Scotland	213	4-17	115:98	INT, FTQ	Thematic analysis	Healthcare	Hospital	Non-specific	Non-specific	9
Cheng *et al.*, 2003[63]	Taiwan	90	5-14	45:45	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Cheng *et al.*, 2016[64]	Taiwan	11	12-18	7:4	INT	Content analysis	Cancer recovery	Hospital	Cancer	Long-term	1
Christofides *et al.*, 2016[65]	Canada	19	8-18	7:12	INT	Thematic analysis	Research participation	Hospital	Cystic fibrosis	Long-term	3
Clift *et al.*, 2007[66]	Wales	6	11-15	3:3	INT	Qualitative	Emergency admission	Hospital	Non-specific	Short-term	7
Colver *et al.*, 2018[67]	England	374	14-18	219:155	INT, Q, OBS	Constant comparison	Transition	Hospital	Medical	Long-term	2
Corsano *et al.*, 2015[68]	Italy	27	6-15	12:15	INT	Qualitative	Emotional events	Hospital	Cancer/ blood disorders	Long-term	4
Coyne, 2006[69]	Ireland	55	7-18	30:25	INT, FG	Constant comparison analysis	Participating/ decision-making	Hospital	Non-specific	Non-specific	52
Coyne, 2006a[70]	Ireland	11	7-14	~	INT	Grounded theory	Hospitalisation	Hospital	Non-specific	~	1
Coyne, 2006b[71]	Ireland	11	9-14	~	INT (PT), FTQ, OBS	Grounded theory	Participating	Hospital	Non-specific	~	4
Coyne *et al.*, 2007[72]	Ireland	17	7-16	~	INT	Qualitative	Hospitalisation	Hospital	Non-specific	Non-specific	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Coyne, 2011[73]	Ireland	55	7-18	31:24	INT, FG	Qualitative	Communicating/ decision-making	Hospital	Non-specific	Non-specific	20
Coyne, 2012[74]	Ireland	38	7-18	~	INT (PT)	Content analysis	Hospital and HCPs	Hospital	~	~	24
Coyne, 2014[75]	Ireland	20	7-16	11:9	INT (PT)	Constant comparison analysis	Participating/ decision-making	Hospital	Cancer	Long-term	2
Coyne *et al.*, 2015[76]	Ireland	15	12-18	6:9	INT, FG	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	6
Coyne *et al.*, 2016[77]	Ireland	20	7-16	11:9	INT	Grounded theory	Communicating	Hospital	Cancer	Long-term	6
Curtis *et al.*, 2017[78]	England	17	5-16	~	INT (PT), OBS	Ethnographic	Single/ shared rooms	Hospital	~	~	3
Das *et al.*, 2017[79]	India	14	8-15	~	FG	Qualitative	Living with HIV	Non-specific	HIV	Long-term	1
Day *et al.*, 2006[80]	England	11	9-14	5:6	FG	Thematic Analysis	CAMHS	Non-specific	Mental health illness	Long-term	13
Dell'Api *et al.*, 2007[81]	Canada	5	10-17	2:3	INT	Qualitative	Interacting with HCPs	Hospital	Non-specific	Long-term	19
Dixon-Woods *et al.*, 2002[82]	England	20	8-16	9:11	INT	Constant comparison analysis	Asthma services	Community	Asthma	Long-term	12
Edgecombe *et al.*, 2010[83]	England	22	11-18	16:6	INT	Thematic analysis	Asthma services	Hospital	Asthma	Long-term	5
Ekra *et al.*, 2012[84]	Norway	9	7-12	5:4	INT, OBS (PT)	Hermeneutic phenomenology	Hospitalisation	Hospital	TIDM	Long-term	2
Engvall *et al.*, 2016[85]	Sweden	13	5-15	6:7	INT (PT)	Content Analysis	Radiotherapy	Hospital	Cancer	Long-term	2
Forsner *et al.*, 2005[86]	Sweden	7	7-10	4:3	INT	Thematic analysis	Illness	Hospital	~	Short-term	4
Forsner *et al.*, 2009[87]	Sweden	9	7-11	2:7	INT, OBS	Hermeneutic phenomenology	Fear	Hospital	Non-specific	Short-term	4
Garth *et al.*, 2009[88]	Australia	10	8-12	3:7	INT	Grounded theory	Participating	Non-specific	Cerebral palsy	Long-term	3
Gill *et al.*, 2016[89]	England	12	14-17	2:10	INT	Thematic analysis	CAMHS inpatient ward	Non-specific	Mental health illness	Long-term	2
Griffiths *et al.*, 2011[90]	Australia	9	8-16	~	INT	Interpretative phenomenological analysis	Living with cancer	Non-specific	Cancer	Long-term	3
Haase *et al.*, 1994[91]	US	7	5-18	3:4	INT (PT)	Colaizzi's method of phenomenological analysis	Completing cancer treatment	Non-specific	Cancer	Long-term	6
Hall *et al.*, 2013[92]	England	17	8-17	~	INT	Thematic analysis	Life with repaired cleft lip/ palate	Non-specific	Cleft lip/ palate	Long-term	1

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Han *et al.*, 2011[93]	China	29	7-14	16:13	INT	Content analysis	Cancer	Hospital	Cancer	Long-term	2
Hanson *et al.*, 2017[94]	US	30	4-14	16:14	INT	Narrative analysis	Pain	Hospital	Fractured arm	Short-term	5
Harper *et al.*, 2013[95]	England	10	16-18	3:7	INT	Interpretative phenomenological analysis	CAMHS	Non-specific	Mental health illness	Long-term	8
Hart *et al.*, 2018[96]	England	14	14-16	~	INT	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	2
Hawthorne *et al.*, 2011[97]	England	21	7-16	12:9	FG	Thematic analysis	Diabetes services	Hospital	T1DM	Long-term	8
Hinton *et al.*, 2015[98]	England	21	8-17	6:15	INT (PT)	Constant comparison analysis	A multiple sclerosis diagnosis	Non-specific	Multiple sclerosis	Long-term	3
Hodgins *et al.*, 1997[99]	Canada	85	5-13	38:41	INT, Q	Mixed-method	Venepuncture	Hospital	Non-specific	Short-term	3
Hutton, 2005[100]	Australia	7	13-18	3:4	INT (PT)	Qualitative	Adolescent wards	Hospital	Cystic fibrosis/ asthma	Long-term	3
Jachyra *et al.*, 2018a[101]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	6
Jachyra *et al.*, 2018b[102]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	4
Jensen *et al.*, 2012[103]	Denmark	8	8-10	5:3	INT (PT)	Thematic analysis	Acute hospitalisation	Hospital	Medical	Short-term	6
Jongudomkarn *et al.*, 2006[104]	Thailand	49	4-18	31:18	INT, FG, OBS, PT	Content analysis	Pain	Non-specific	Non-specific	Long-term	1
Kluthe *et al.*, 2018[105]	Canada	18	6-17	11:7	INT	Content analysis	IBD diagnosis	Hospital	IBD	Long-term	1
Koller *et al.*, 2010[106]	Canada	21	5-18	12:9	INT (PT)	Grounded theory	Hospitalisation during SARS	Hospital	Non-specific	Long-term	2
Koller, 2017[107]	Canada	26	5-18	11:15	INT (PT)	Thematic analysis	Medical education/ participating	Hospital	Chronic	Long-term	10
Kortesluoma *et al.*, 2006[108]†	Finland	44	4-11	~	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Kortesluoma *et al.*, 2008[109]†	Finland	44	4-11	27:17	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	7
Lewis *et al.*, 2007[110]	Australia	9	8-16	5:4	INT	Cognitive mapping	Receiving care	Hospital	~	~	5
Livesley *et al.*, 2013[16]	England	15	5-15	3:2	INT (PT), OBS	Critical ethnography, constant comparison analysis	Hospitalisation	Hospital	Surgical	Long-term	4
Lowes *et al.*, 2015[23]	Wales	518	7-15	~	FTQ	Qualitative descriptive analysis	Life with T1DM and services	Hospital	T1DM	Long-term	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Macartney *et al.*, 2014[111]	Canada	12	9-18	6:6	INT	Content analysis	Life after a brain tumour	Non-specific	Brain tumour	Long-term	1
Manookian *et al.*, 2014[112]	Iran	6	6-17	3:3	INT	Interpretative phenomenological analysis	Stem cell transplantation	Hospital	Cancer & blood disorders	Long-term	4
Marcinowicz *et al.*, 2016[113]	Poland	22	10-16	8:14	INT	Content analysis	Nurse relationships and wards	Hospital	~	~	7
Marshman *et al.*, 2010[114]	England	10	12-14	5:5	INT, Q	Framework analysis	Malocclusion treatment	Non-specific	Malocclusion	Long-term	1
McNelis *et al.*, 2007[115]	India	11	7-15	6:5	FG	Thematic analysis	Living with epilepsy	Non-specific	Epilepsy	Long-term	2
McPherson *et al.*, 2017[116]	Canada	17	6-18	8:9	INT	Phenomenology, thematic analysis	Talking about weight	Hospital	Spina Bifida	Long-term	3
McPherson *et al.*, 2018[117]	Canada	18	10-17	9:9	INT, FG	Thematic analysis	Talking about weight	Hospital	Non-specific	Long-term	3
Moules, 2009[118]	England	138	9-14	82:56	INT (PT)	Framework analysis	Hospital care	Hospital	~	~	3
Nguyen *et al.*, 2010[119]	Sweden	40	7-12	~	INT, Q, vital signs	Content analysis	Music therapy for lumbar puncture	Hospital	Cancer	Short-term	1
Nilsson *et al.*, 2011[120]	Sweden	39	5-10	32:7	INT	Content analysis	Pain	Hospital	Skin trauma	Short-term	4
Noreña Peña AL *et al.*, 2011[121]†	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	24
Noreña Peña AL *et al.*, 2014[122]†	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	22
Olausson *et al.*, 2006[123]	Sweden	18	4-18	8:10	INT	Hermeneutic phenomenology	Life after transplantation	Non-specific	Post- transplant	Long-term	6
Pelander *et al.*, 2004[124]	Finland	40	4-11	28:12	INT	Content analysis	Nursing care	Hospital	Chronic (T1DM & other)	Long-term	3
Pelander *et al.*, 2010[125]	Finland	388	7-11	198:188 *	FTQ	Content analysis	Hospitalisation	Hospital	Non-specific	Non-specific	2
Pölkki *et al.*, 1999[126]	Finland	20	7-11	~	INT, WT	Content analysis	Pain	Hospital	Non-specific	~	1
Pope *et al.*, 2018[127]	Australia	15	4-8	11:4	INT (PT)	Thematic analysis	Pain and nurses' roles	Hospital	Trauma	Short-term	1
Randall, 2012[128]	England	21	0.9-17	8:12 *	INT, FG (PT), PTD	Colaizzi’s method of phenomenological analysis	Community children's nursing	Community	Non-specific	Long-term	4
Rankin *et al.*, 2018[129]	Scotland	24	9-12	13:11	INT (PT)	Thematic analysis	Managing T1DM	Non-specific	T1DM	Long-term	1
Roper *et al.*, 2018[27]	England	16	7-15	9:7	INT	Qualitative	Research participation/ consent	Hospital	Asthma or anaphylaxis	Short-term	7

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Ruhe *et al.*, 2016[130]	Switzerland	17	9-17	11:6	INT	Thematic analysis	Participating	Hospital	Cancer	Long-term	1
Ryals, 2011[131]	US	8	13-17	6:2	INT	Phenomenology	Therapeutic relationships	Non-specific	Mental health illness	Long-term	59
Saarikoski *et al.*, 2018[132]	Finland	19	6-12	7:12	FG	Content analysis	Therapeutic intervention	Community (school)	Enuresis	Long-term	1
Salmela *et al.*, 2010[133]	Finland	90	4-6	~	INT	Colaizzi's method of phenomenological analysis	Hospital related fears	Hospital	~	~	4
Schalkers *et al.*, 2014[134]	The Netherlands	63	6-18	31:32	INT (PT), WT	Action research	Hospital care	Hospital	Non-specific	~	8
Schmidt *et al.*, 2007[135]	US	65	5-18	34:31	INT, FTQ	Thematic analysis	Nurses in hospital	Hospital	Non-specific	Non-specific	45
Spalding *et al.*, 2016[136]	England	7	8-14	2:5	WS (PT)	Action research, thematic analysis	Good doctors	Hospice	Palliative	Long-term	3
Stevens *et al.*, 2006[137]	Canada	14	7-16	9:5	INT	Content analysis	Home chemotherapy	Community (home)	Cancer	Long-term	1
Taylor *et al.*, 2010[138]	England	14	12-18	~	INT	Framework analysis	Life after transplantation	Non-specific	Liver transplant	Long-term	6
Vejzovic *et al.*, 2014[139]	Sweden	17	10-17	5:12	INT	Content analysis	Preparing for colonoscopy	Hospital	Suspected IBD	Short-term	4
Vindrola-Padros, 2012[140]	Argentina	10	8-16	5:5	INT (PT)	Narrative analysis	Living with cancer	Non-specific	Cancer	Long-term	4
Wangmo *et al.*, 2016[141]	Switzerland	17	9-17	11:6	INT	Qualitative	Cancer services and treatment	Hospital	Cancer	Long-term	5
Watson *et al.*, 2009[142]	US	9	14-18	7:1:1#	INT	Grounded theory	Accessing CAMHS & mental illness	Non-specific	Mental health illness	Long-term	1
Wen *et al.*, 2013[143]§	Singapore	203	4-18	~	INT, OBS	Thematic analysis	Pain	Non-specific	Surgical (post-op)	Non-specific	15
Wise, 2002[144]	US	9	7-15	~	INT (PT)	Hermeneutic phenomenology	Transplantation	Non-specific	Liver transplant	Long-term	7
Wong *et al.*, 2012[145]	China	79	10-13	54:25	FG	Qualitative	Weight-loss program	Community (school)	Obesity	Long-term	1
Woodgate, 2008[146]	Canada	13	9-17	7:6	INT	Constant comparison analysis	Cancer symptoms	Non-specific	Cancer	Long-term	1
Wray *et al.*, 2018[147]	England	543	8-16	~	INT, FG, Q	Framework Analysis	Healthcare	Hospital	~	~	5
Xie *et al.*, 2016[148]	China	21	7-12	12:9	INT	Content Analysis	Lumbar puncture	Hospital	ALL	Short-term	15
Young *et al.*, 2003[149]	England	13	8-17	8:5	INT	Constant comparison analysis	Communicating	Hospital	Cancer	Long-term	7

Note:

Non-specific, not focusing on a certain type or area; ALL, acute lymphoblastic leukaemia; ASD, autism spectrum disorder; CAMHS, child and adolescent mental health service; HIV, human immunodeficiency virus; IDB, inflammatory bowel disease; SARS, severe acute respiratory syndrome; T1DM, type 1 diabetes mellitus.

FG, focus groups; FTQ, free-text questionnaires; INT, interviews; OBS, observations; PT, participatory techniques employed; PTD, photo talk diaries; Q, quantitative questionnaires; WS, workshops; WT, writings; ~, unable to ascertain; *, numerical inconsistency detected in source article; †, same study with different quotations presented; §, qualitative systematic review; #, non-binary gender.

Children's and adolescents' experiences

Six-hundred and sixty-nine quotations referred to CADs' experiences of HCPs, most of whom were doctors or nurses. CADs also spoke about their experiences with counsellors, psychologists, social workers, and dentists. CADs' ages (available for 397 quotations), ranged from 5-18 years (average 13); male and female participants were equally represented (see supplementary file 5). All quotations extracted are available at doi:10.5061/dryad.z08kprrc2; quotations presented below are cited in online supplementary file 6.

CADs' favourable experiences were of HCPs forming trusting relationships and involving them in healthcare discussions and decisions and their unfavourable experiences were generally towards the opposite pole.

Forming trusting relationships

Their nature

Being in a trusting relationship was feeling a 'bond', having an 'emotional attachment', or having a 'best friend'. CADs and HCPs knew each other, could 'relate to' each other, and really understood each other. There was openness, transparency, and there was trust. CADs trusted in HCPs to provide 'good care', knowing they would do everything necessary, and do it right.

Their origins

At first, HCPs were 'strangers'; CADs did not know the HCPs, who they were, and how they were. HCPs, likewise, did not know CADs, their histories, or their personalities. Repeated contact and dialogue built and reinforced relationships: 'As time passed, […] we created that bond.'

HCPs engendered trusting relationships by demonstrating positive attributes, including being able to empathise. CADs trusted in HCPs who were 'very smart', 'experienced', '[knew] what to do', '[took] care', and did 'everything the best they [could]'. They trusted HCPs who were 'truthful', '100% with you', and 'just [told] you straight up.' Such HCPs did 'not tell children any lies'; 'nothing [was] hidden'. CADs built trusting relationships with HCPs who were 'really nice', 'nurturing, caring, and helpful people who [were] there for you', and had a 'good sense of [humour]'.

HCPs related to CADs by understanding them: 'she knew what I was talking about, she knew what I was feeling, she knew how I was feeling.' HCPs 'took time to get to know' CADs and had 'real conversations, not just [HCP]-patient discussions', in which they shared experiences and got to know each other personally. CADs could better relate to HCPs who were 'down to earth' and had 'a lot in common'.

Their effects

Trust was vital: 'you gotta have trust.' Trusting relationships improved CADs' healthcare experiences by promoting positive emotions. CADs felt 'satisfied' and 'happy'. They enjoyed their time with HCPs and had 'good memories'. CADs were more able to 'open up' or 'tell anything' to HCPs whom they trusted. Trusting relationships gave CADs hope that HCPs could 'cure [the] illness' or help lessen the pain. CADs who trusted HCPs submitted themselves more willingly to recommended treatments: 'whatever happens I let them [HCPs] do what they have to do to help me get better.' And they consciously chose to remain with or seek out HCPs they trusted. CADs admired trustworthy HCPs: 'individually [they're] all heroes.' And they aspired to be like them: 'Because you can save people […] I'm going to be a children's doctor.'

Being involved in healthcare discussions and decisions

The nature of involvement

CADs who were fully involved in healthcare discussions felt they knew everything; ‘everything [was] always clear’ to them. They had a seat at the table to discuss issues that affected them and felt acknowledged as key stakeholders. CADs worked ‘together’ with HCPs and parents; they felt as though they were respected, taken ‘seriously’, and treated ‘as an equal’.

Its origins

HCPs involved CADs by including them in conversations, sharing information, providing opportunities to ask questions, taking time to answer, and listening to their wider needs and preferences. HCPs who promoted involvement used simple words, communicated in a timely way, gave accurate information at the right pace, and explained things so that CADs understood. These HCPs brought CADs ‘into all the conversations’ by talking to CADs ‘as much as they [talked to the] parents’. Parents facilitated CADs’ involvement in the presence of HCPs or afterwards by ‘[breaking] the words down in an easier explanation’. HCPs promoted participation by ‘listening’ to and respecting CADs’ requests: ‘I tell them I don’t want this and they … understand’. For more complex decisions, CADs took a joint approach: ‘me because I know my own body, my parents because they know what’s best for me […] and the paediatrician because they are qualified.’

Its effects

CADs viewed involvement as ‘most important, as in the end it is about [them]’. CADs enjoyed being involved; it was ‘brilliant’, and they looked forward to their next visit. CADs were more satisfied with healthcare; they found it ‘interesting and informational’. Getting to ‘learn something new’ made them feel ‘comfortable and confident’. CADs could ‘make better decisions’ because they were ‘fully informed’. This promoted self-advocacy and self-efficacy: ‘I’m asking the doctor more questions myself than having my Dad do it.’

Not forming trusting relationships or being involved

CADs described unfavourable experiences, which broadly *mirrored* favourable ones. For instance, trust was undermined by HCPs getting things wrong, being ‘nasty’, and not ‘[seeming] that concerned’. HCPs being unfamiliar to CADs because they were ‘too busy’ or because HCPs or CADs moved to other services prevented trusting relationships forming. HCPs excluded CADs by using ‘big words’, speaking too fast, or telling them nothing, so that CADs could not understand. HCPs neglecting to ask CADs or asking in a tokenistic way prevented them ‘having a say’: ‘they [HCPs] might ask me “is that ok” […] in such a way that I kind of feel like I don’t have any other option but [to] agree with them’. HCPs and parents side-lined CADs by talking behind the curtains so CADs could not hear or sticking them ‘in the middle’ of a conversation where they could not interrupt. Some parents told CADs to keep quiet or dominated conversations: ‘you try to say something but then your parents just say shhhhh! […] They come out and say, […] did you understand that, you say no, they say, you should have asked them, and then you say, oh you didn’t let me, they say rubbish!’

Not trusting people or understanding what was happening made CADs fearful. HCPs who made CADs feel ‘rejected’ and objectified, ‘like a piece of machinery’, enraged them. CADs found it ‘hard to talk’, disengaged in conversations, and left the talking to their parents. Not trusting in HCPs or being uninvolved meant some CADs hated hospital or clinic, they objected to attending, and sought information or guidance from other sources.

Stakeholder consultations

Two CAD inpatients participated in each of two focus groups (3 females and 1 male, aged 11-15 years) lasting 67 and 93 minutes respectively. Their medical conditions included type 1 diabetes, coeliac disease, spina bifida, and spinal/brain surgery. No parents attended. Three authors (GD, AT, & RC) attended both consultations and a hospital play specialist attended the first consultation. Participants identified with the provisional findings and elaborated on them (table

4). All wanted some degree of involvement in their own care though the amount of information and level of participation they wanted depended on their age, what was being discussed, and individual preferences. Box 3 offers take-home messages for HCPs.

Table 4 Stakeholder findings: Focus group participants’ experiences mapped to overarching themes

Overarching themes	Forming trusting relationships	Being involved in healthcare discussions and decisions
Favourable experiences	Rachel, a young girl with diabetes, described having a very good relationship with the diabetic team and ward staff: *‘Hm, it’s just the nurses really like nice. Like, the first night I was staying over they were staying it's a sleepover and stuff.’* (Rachel, FG1, line 746 & 747) She acknowledged how continuity of care helped her become more familiar with the staff: *‘they’re always in the clinic when I am there’*. (Rachel, FG1, line 678) She commented on how the diabetic team got to know her, by chatting casually and taking an interest in her wider life: *‘they like asked me what school I’m going to this year’ and about ‘my baby sister and stuff’*. (Rachel, FG1, line 815-819) Participants experienced some HCPs as being easier to talk to than others. Rachel felt that she could talk to the diabetic team: *‘[…] I can talk to them more ‘cos you know them.’* (Rachel, FG1, line 621) From the perspective of Laura, a young girl with a recent diagnosis of diabetes, a caring nature was an important factor: *‘[HCPs who] make you feel as if they care [were easier to talk to]’*. (Laura, FG2, line 432)	Laura was well informed by her hospital consultant, who had seen her when she was first diagnosed with diabetes: *‘My consultant like came the day before […] and he explained the whole thing in detail.’* (Laura, FG2, line) Laura’s experience of being well informed resembled Rachel’s: *‘The doctor like normally tells me everything that I need to know anyway and they put it in like ways that I like, know.’* (Rachel, FG1, line 657 & 658) Sarah, an adolescent with spina bifida and scoliosis, felt she had some control over her treatment: *‘Uhm, I might have to get the surgery on my back, because I’ve got scoliosis, em, so if it gets like really, it’s not too bad but if it gets worse I have to have surgery so I feel as if I have like a choice because I don’t have to have it, and I don’t want it. […] I don’t want to have it.’* (Sarah, FG2, line 743-748) Although all participants wanted to be informed, the oldest participant, Darren, a young boy with spina bifida and epilepsy, preferred his parents to ask and answer questions, and doctors to make decisions on his behalf: *‘GD: Do you ever have any questions [Darren]?* *Darren: Ah...don't think so.* *AT: Are you happy for your parents to ask the questions?* *Darren: Yeah.* *AT: And you just listen?* *Darren: Yeah [smiling and laughing].’* (Verbatim excerpt, FG1, line 555-560)
Unfavourable experiences	Sarah found it difficult to trust HCPs who were uncaring: *‘Well yesterday I had to get a line [cannula] in and there was four different doctors that tried […] and I thought like the doctors didn’t really care, they were just gonna get it in, they didn’t really care what I was thinking. […] Well I know they needed to do it. But they didn’t care, […] they didn’t care if they hurt me.’* (Sarah, FG2, line 438-441 & 512)	During her cannulation experience, Sarah felt angry because HCPs failed to grant her wishes: *‘I always tell them to put it, try my feet first because I don’t have any feeling in my feet […] I told the doctor not to put it in there and they still did it. […] I was really cross after it because I thought all that pain.’* (Sarah, FG2, line 460-465) Sarah spoke about feeling excluded when a doctor spoke discretely to her mother: *‘No but it does happen to people like they feel they’re left out. […] Today, […] a doctor was explaining something to me and he was just about to leave and when he was just about to leave he said to my mum, “If you want to ask a question I can come back” so I kind of thought is he doing that because he doesn’t want me to hear my mother asking the question.’* (Sarah, FG2, line 612 & 619-622)

Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

Box 3 Take-home messages for HCPs

Focus group participants provided take-home messages about how HCPs, could deliver high-quality child-centred care:

1. *'Explain.'* (Laura, FG2, line 409) *'Explain it in a child friendly way.'* (Sarah, FG2, line 411) *'Because if the child is really young it has to be explained in a different way. At an age you're able to understand [or HCPs will] scare them.'* (Sarah, FG2, line 658-663)
2. *'They should explain what they are going to do before they do it, and like […] always say who they are and what they're gonna do […] [and at] what time […], and explain what was gonna happen and why […].'* (Rachel, FG1, line 498-510)
3. *'I think just tell everyone together. […] Because like telling your mum and dad first you'll see the expression on their face and then you're already gonna know.'* (Laura, FG2, line 651-654)
4. *'Always like ask [children] do you have any questions […] ask [to check understanding].'* (Sarah, FG2, line 388 & 416-417)
5. *'Whenever [children] come in, try and treat them like nicer, em.'* (Darren, FG1, line 992) *'Like treat them the same as everybody else so they all feel the same.'* (Rachel, FG1, line 993)

Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

DISCUSSION

CADs' experiences were influenced by HCPs forming relationships and involving them: engendering trust and involving CADs satisfied them, made them happier when undergoing procedures and treatments, and better able to confide. HCPs did this by being personable, wise, and sincere, relating at a personal level, bringing CADs into conversations and decisions, and speaking in child-friendly ways. Conversely, not relating to or involving CADs, communicating ineffectively by using inappropriately technical language or positioning CADs as 'piggy-in-the-middle' between HCPs and parents resulted in CADs being fearful, angry, resistant, and disengaged.

These findings add to earlier studies, which identified intimate relationships,[77,110,150] trust,[77] and involvement,[47,151] as important ingredients of caring well for CADs. They corroborate a recent systematic review of decision-making experiences, which found that HCPs (and parents) made adolescents feel fearful, anxious, and depersonalised when they withheld information or denied involvement.[151] Parents had a significant influence on HCPs' experiences in our study too, by facilitating or impeding communication. Overcoming parental primacy, over-involvement, over-protectiveness,[47,77,151] and wish to withhold information remains a substantial challenge for HCPs.[77]

Strengths and limitations

Our synthesis advances understanding of CADs' experiences of HCPs because of its comprehensiveness, analysis of interrelationships between the nature, origins, and effects of trust and involvement, and its advocacy for CADs' autonomy. It provides a blueprint for CCC, which has, until now, largely depended on theory and expert consensus rather than empirical evidence.[8] Our findings endorse the concept and importance of CCC, whilst showing how much work is needed to put this principle into practice. Our review was innovative in the way it used phenomenology, a theory that is highly relevant to the topic, to inform a rigorous interpretive synthesis. This allows us to go beyond cataloguing publications and draw empirically supported conclusions about how HCPs could care more effectively for CADs. This, we suggest, is a significant contribution to the scholarship of evidence synthesis.

As with most qualitative syntheses, we present a broad overview, whose findings are potentially transferable across a range of clinical contexts. We took an iterative approach to article selection and ensured adequate time for rigorous interpretive analysis; while some evidence may have been published since we searched the databases, this is an inherent limitation in research that goes to such lengths to analyse a huge evidence-base and synthesise information. We doubt that this materially affects our conclusions since the nature of human relationships are unlikely to change in 12 months. Consulting with stakeholders, whilst obviously desirable, is often omitted from scoping reviews.[152] Our consultation sample was admittedly small and relatively homogenous, but participants spoke informatively about their experiences, which helped consolidate and authenticate the findings.

Our conclusions are susceptible to both publication and interpretation bias because more emotive material tends to attract greater attention. This limitation is partially offset by our rigorous adherence to methodological standards. Another limitation, imposed by the non-specific nature of studies and inexplicit reporting of metadata by primary authors, is that we could not analyse how different types of HCP, or participants' ages or illnesses, affected CADs' experiences. Restricting the scope to English language publications excluded non-English speaking children from distinct cultural groups.[40] This is an important topic for future study.

Implications for policy, research, and practice

Our findings add impetus to the movement to design, deliver, and further characterise child-centred healthcare which has important implications for HCPs, educators, researchers, and policymakers.[153] Our empirical augmentation of this conceptual model supports these initiatives. To achieve the vision of CCC, there is a need for communication strategies, training, assessments, and feedback (from CADs, specifically) at both the undergraduate and postgraduate levels of health professions education. Further research will be needed to address the long-term sustainability and effectiveness of CCC. Evidence on how healthcare policy, practice, and legislation can influence child-centred approaches is long overdue. Further research could also examine how age, illness, gender, and the cultures of different professions influence the drive for CCC. Further implications for practice include the need for HCPs to examine how professional boundaries between themselves and CADs are characterized, and consider how best to respect CADs' preferences when it goes against 'best practice'.

ABBREVIATIONS

CADs- Children and adolescents

CCC- Child-centred care

CINAHL- Cumulative Index to Nursing and Allied Health Literature

FCC- Family-centred care

HCPs- Healthcare professionals

PCC- Patient-centred care

RBHSC- Royal Belfast Hospital for Sick Children

DECLARATIONS

Ethics approval and consent to participate

Ethical approval for focus groups was obtained from the Office for Research Ethics Committees Northern Ireland (reference: 19/NI/0070), while research governance was obtained from the Belfast Health and Social Care Trust, Northern Ireland.

Consent for publication

Consent for publication was gained.

Availability of data and materials

All data are available in this article, or supplementary materials and open access repositories.

Supplementary materials

The content has been supplied by the authors.

Competing interests

None declared.

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Authors’ contributions

GD conceived the review, sought approvals, secured funding, led the execution, and led the write-up. GD, AT & RC completed the focus groups. MK, RC, AT & TD assisted with data selection, analyses, and manuscript revision. All authors read and approved the final manuscript.

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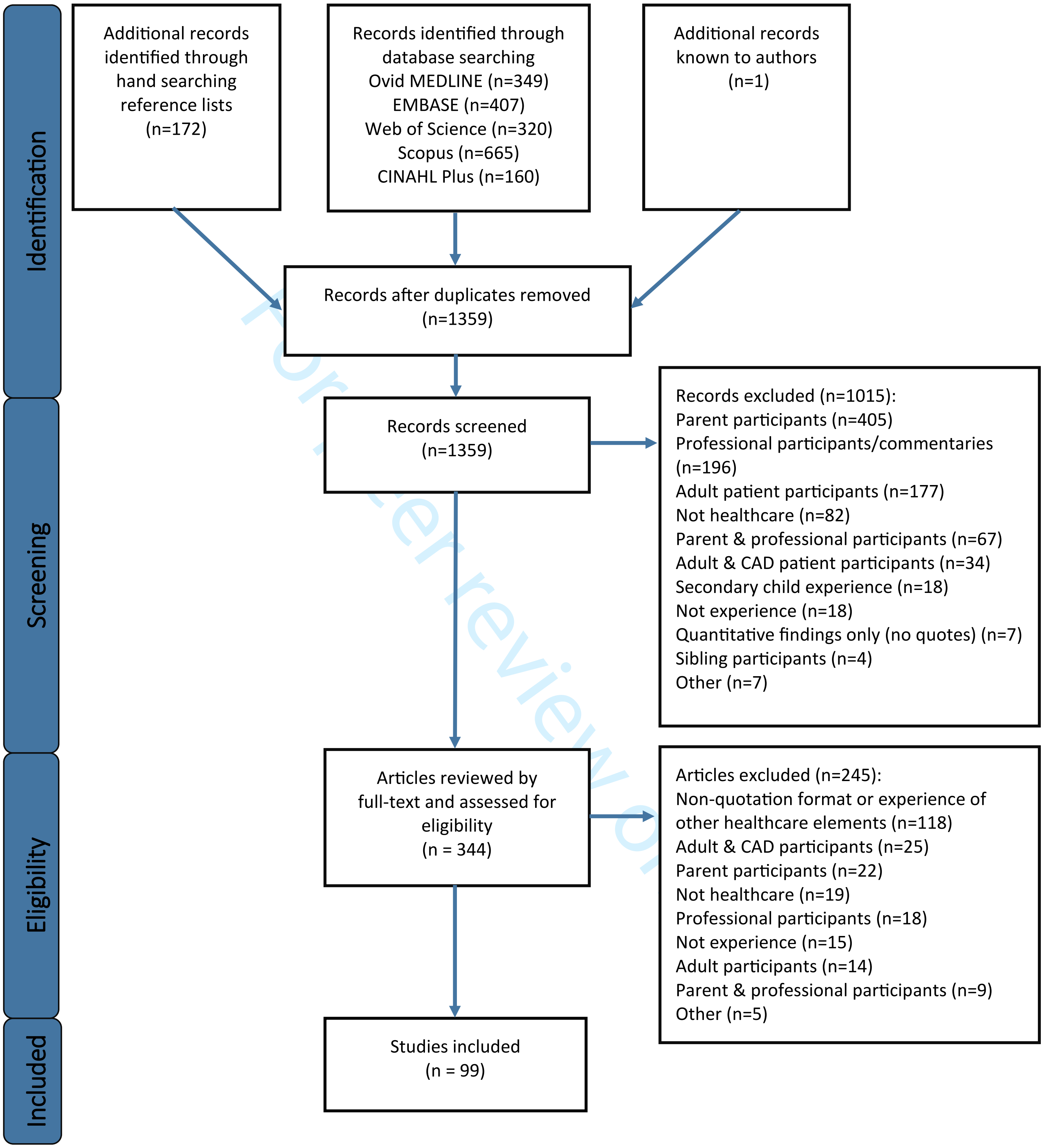
FIGURE CAPTIONS

Figure 1 PRISMA flow diagram



Note ‘Other’ (n=12) reasons for excluding records/articles included: participants’ ages unclear (n=4); no full-text available or unobtainable in English (n=7); same study as included article (n=1).

PRISMA-ScR Checklist

This supplementary information includes the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (1).

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
TITLE			
Title	1	Identify the report as a scoping review.	p.1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	p.3-4, background not required in abstract as per journal guidance
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	p.6-8
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	p.8 & 9
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	p.9 and reference list. Not registered.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	p.9-12 (Table 2)
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	p. 9 & 10 (Table 1)
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	p. 9 & 10, Supp file 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	p. 10 & 11
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	p. 13 (box 2)
Data items	11	List and define all variables for which data were	p. 13

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
		sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Critical appraisal not done. Rationale on p.11
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	p. 13-15
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	p. 15 (Figure 1)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	p. 15 (Table 2)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	p. 15 (Table 2) & Dryad data
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	p. 15, 16, 23-26, & supp file 4.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	p. 29-30
Limitations	20	Discuss the limitations of the scoping review process.	P. 30-31
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	p. 31
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	p. 32

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

REFERENCE:

1. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. Ann Intern Med. 2018;169(7):467–73. doi: 10.7326/M18-0850.

MEDLINE search
1. health?care.mp.
2. Hospitals/
3. Community Mental Health Services/ or Mental Health Services/ or Community Health Services/ or Community Health Nursing/
4. School Health Services/
5. 1 or 2 or 3 or 4
6. Stress, Psychological/
7. Emotions/
8. emotion*.mp.
9. experienc*.mp.
10. 6 or 7 or 8 or 9
11. 5 and 10
12. limit 11 to "all child (0 to 18 years)"
13. ((child* or infant* or adolescen* or teen?age* or boy* or girl* or toddler*) adj5 (view* or opinion* or feeling* or emotion* or experience* or perception* or first?hand* or their* or say?in or decision* or choice* or choos* or autonomon* or interview* or art or "art* therap*")).mp.
14. 12 and 13
15. Qualitative Research/
16. 14 and 15

key: mp, multi-purpose search; adj5, search within adjacent 5 words.

Braun & Clarke 15-point Thematic Analysis Checklist

Process	No.	Criteria	Response
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'	Both focus group transcripts transcribed to an appropriate level of detail and checked against tapes.
Coding	2	Each data item has been given equal attention in the coding process	We reviewed all quotations to generate coding.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive	Themes, and the findings described herein, were developed from a complete coding process of the entire dataset. The coding process was thorough, inclusive and comprehensive, as all quotations were used to generate codes, and develop themes. Each theme was developed based on numerous codes gathered across a range of articles and participants quotations.
	4	All relevant extracts for all each theme have been collated	Yes.
	5	Themes have been checked against each other and back to the original data set	Yes.
	6	Themes are internally coherent, consistent, and distinctive	Yes.
Analysis	7	Data have been analysed- interpreted, made sense of- rather than just paraphrased or described	Yes, evident from the results.
	8	Analysis and data match each other- the extracts illustrate the analytic claims	The analysis and findings from it closely match the data set.
	9	Analysis tells a convincing and well-organised story about the data and topic	Yes.
	10	A good balance between analytical narrative and illustrative extracts is provided	Yes. Illustrative extracts have been used within the results section.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly	Yes.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated	Yes, stated in the methods section.
	13	There is good fit between what you claim you do, and what you show you have done- i.e. described method and reported analysis are consistent	Yes.

	14	The language and concepts used in the report are consistent with the epistemological position of the analysis	Yes.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'	Yes.

REFERENCE:

1. Braun V, Clarke V. Successful qualitative research: a practical guide for beginners. London: SAGE Publications Ltd; 2013.

Additional Scoping Review Results: Basic numerical analysis and figures

This supplementary information includes additional findings and graphical illustrations from basic numerical analysis.

Trend in study publications over time

On average, four studies were published each year and the rate of publication rose progressively, increasing to 11 per year in 2018 (as shown in Figure 1).

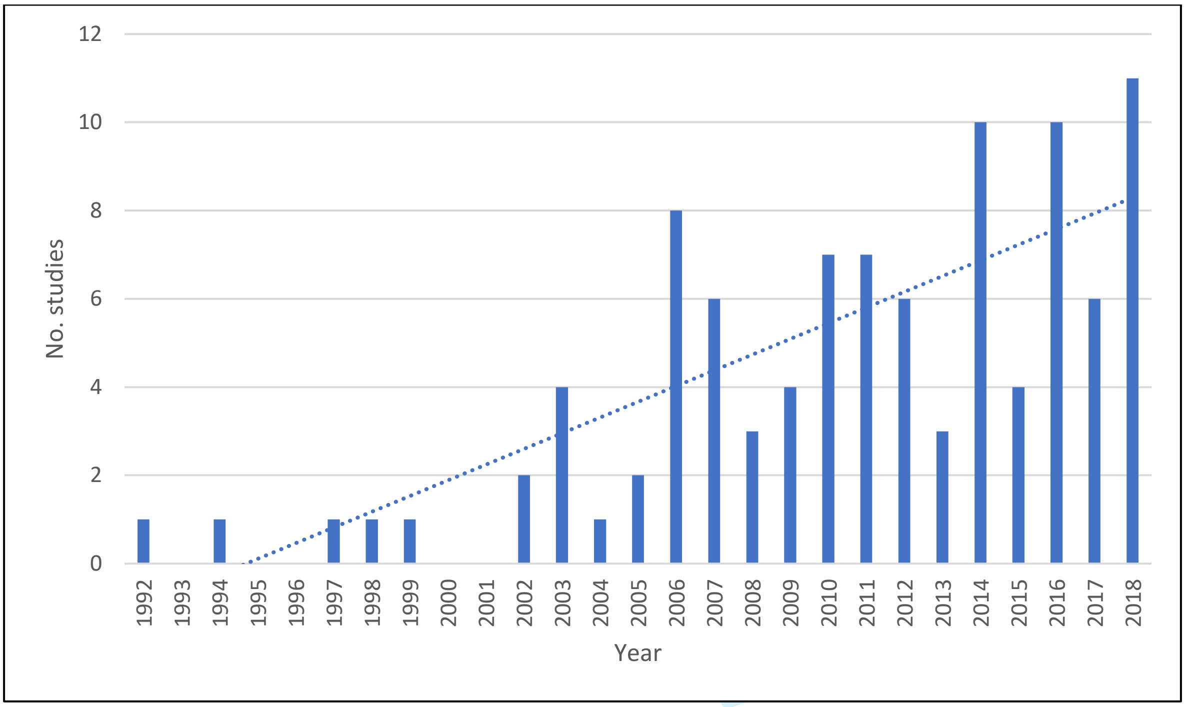


Figure 1 Years of publications

Countries of origin

Figure 2 illustrates the geographical distribution of included studies on the world map and figure 3 lists countries of origin (n=21) including the number of studies pertaining to each country. Eighty-eight studies originated in western or more developed countries of which the UK (n=26), Canada (n=15), Ireland (n=9), Sweden (n=9), and the United States (n=9) were most common.

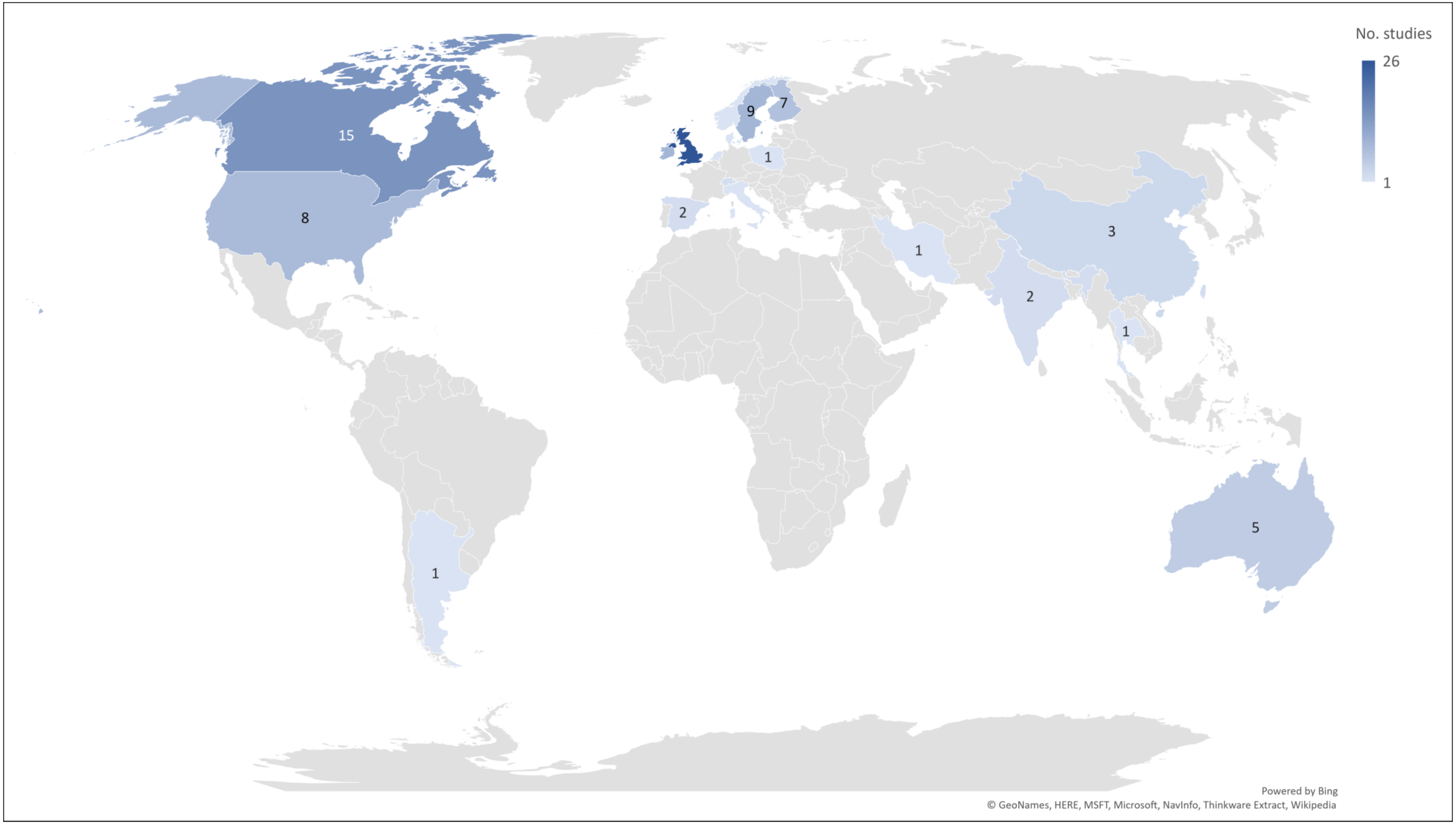


Figure 2 Map of geographical distribution of studies

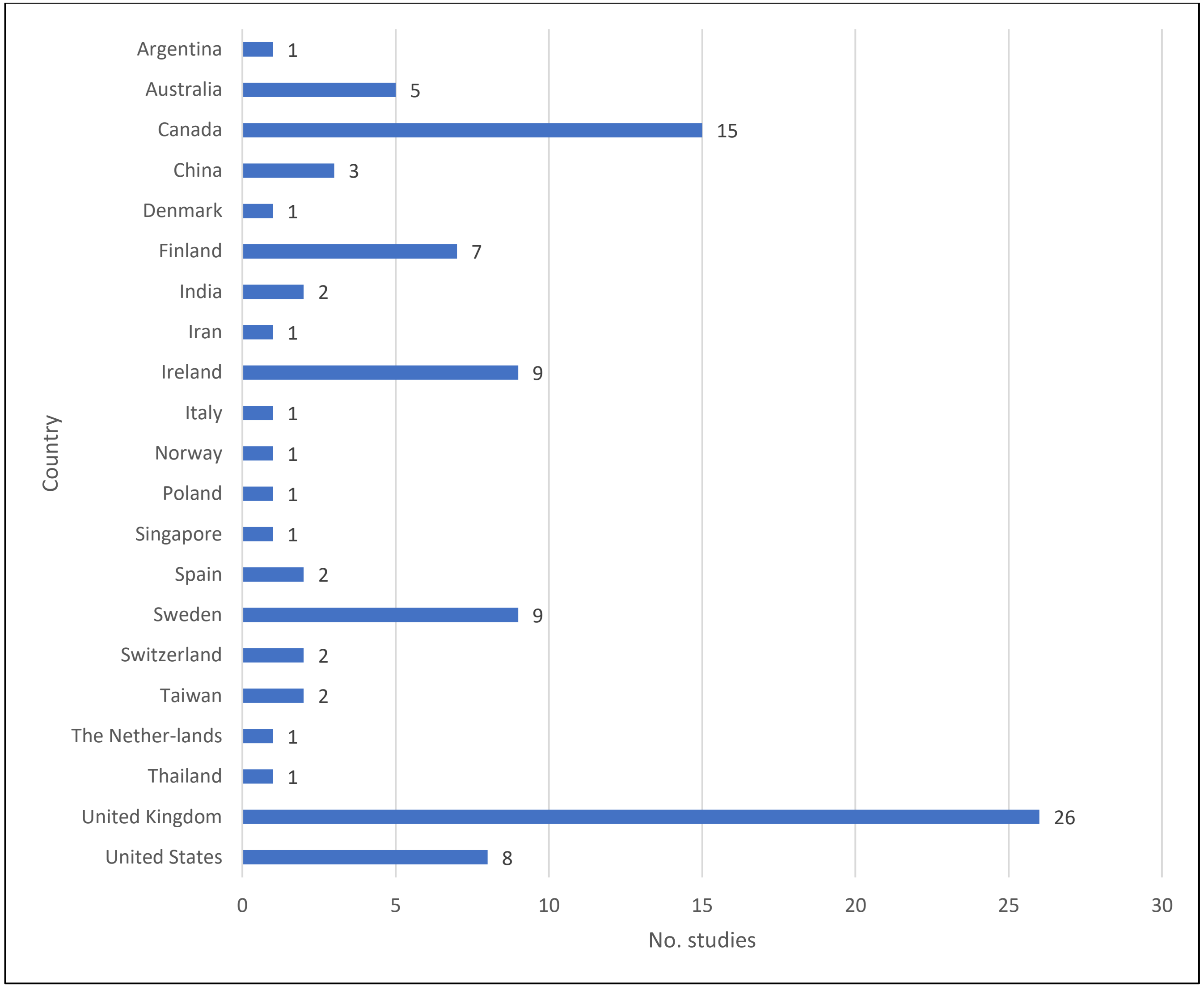


Figure 3 Number of studies per country

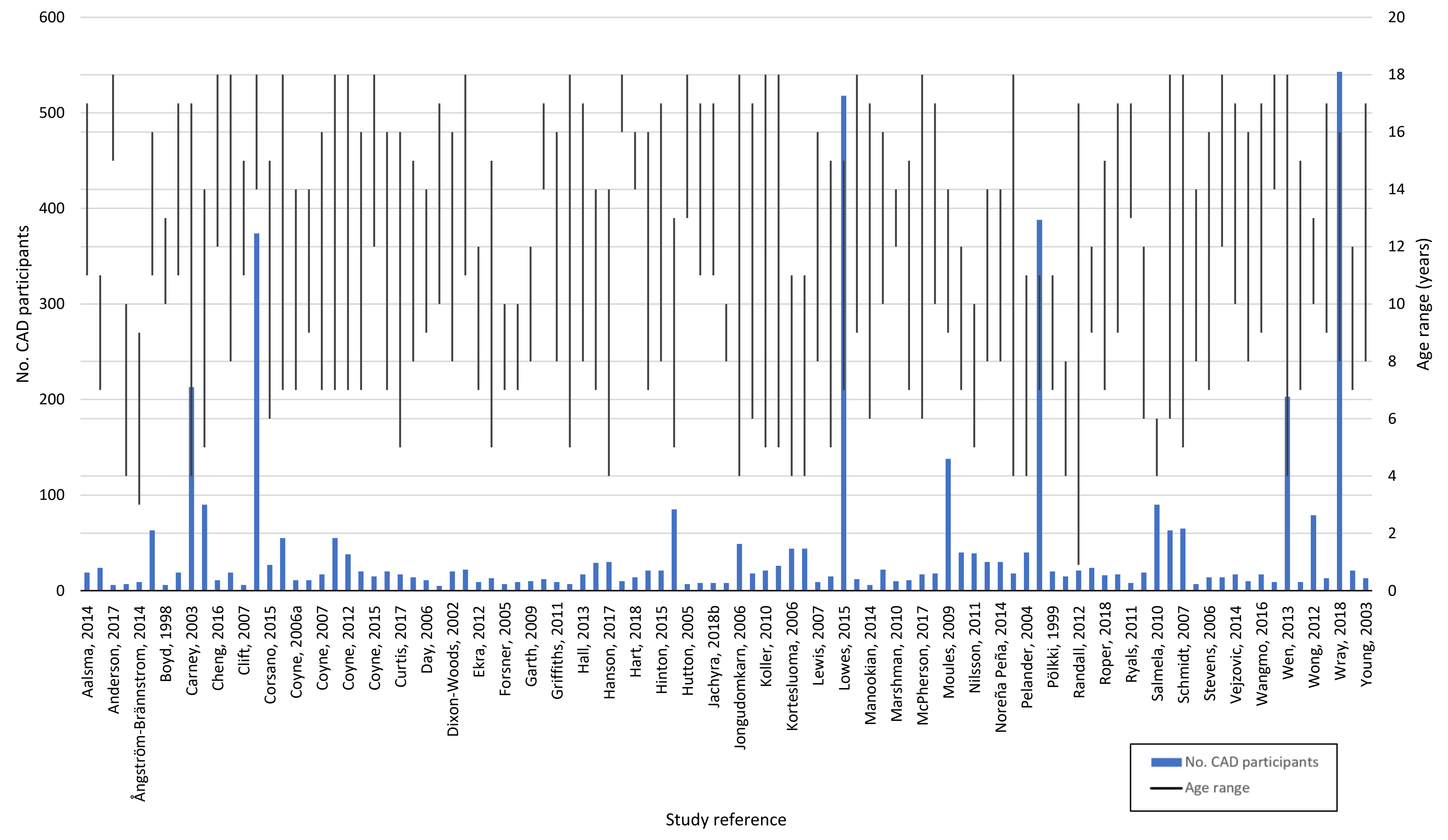


Figure 4 Number of CAD participants per study and age ranges

CAD participants

The number of CAD participants per study and age ranges are illustrated in figure 4. Age ranges varied, however, most studies recruited CAD participants aged 6-17 years. Studies tended to recruit between 8 to 50 participants; seven studies recruited over 100.

Additional participants

Most studies recruited CADs only (n=72). Some studies recruited other participants (n=27); who were parents, HCPs, and teachers (figure 5).

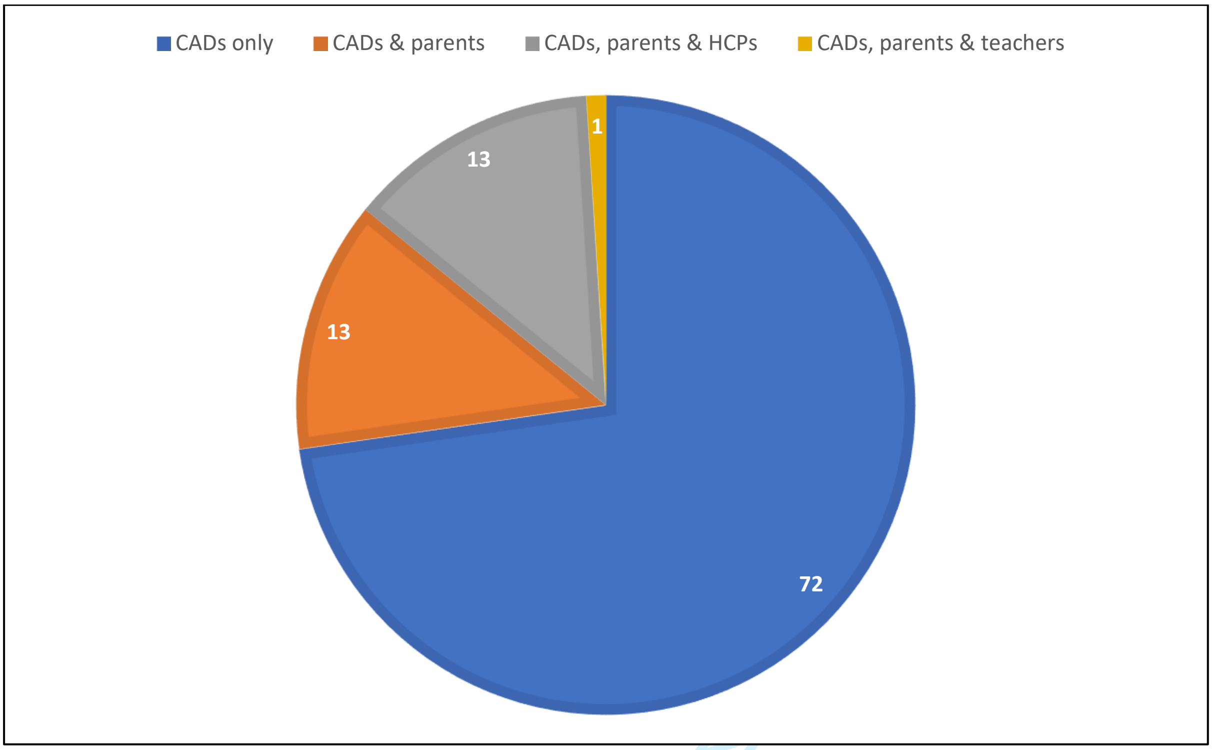


Figure 5 Study participants

Study methods

Most studies used a single method; interviews were most prevalent, followed by focus groups, free-text questionnaires, and workshops (figure 6). Twenty-nine studies used 2 or 3 methods; commonly, interviews combined with observation or focus groups (figure 7).

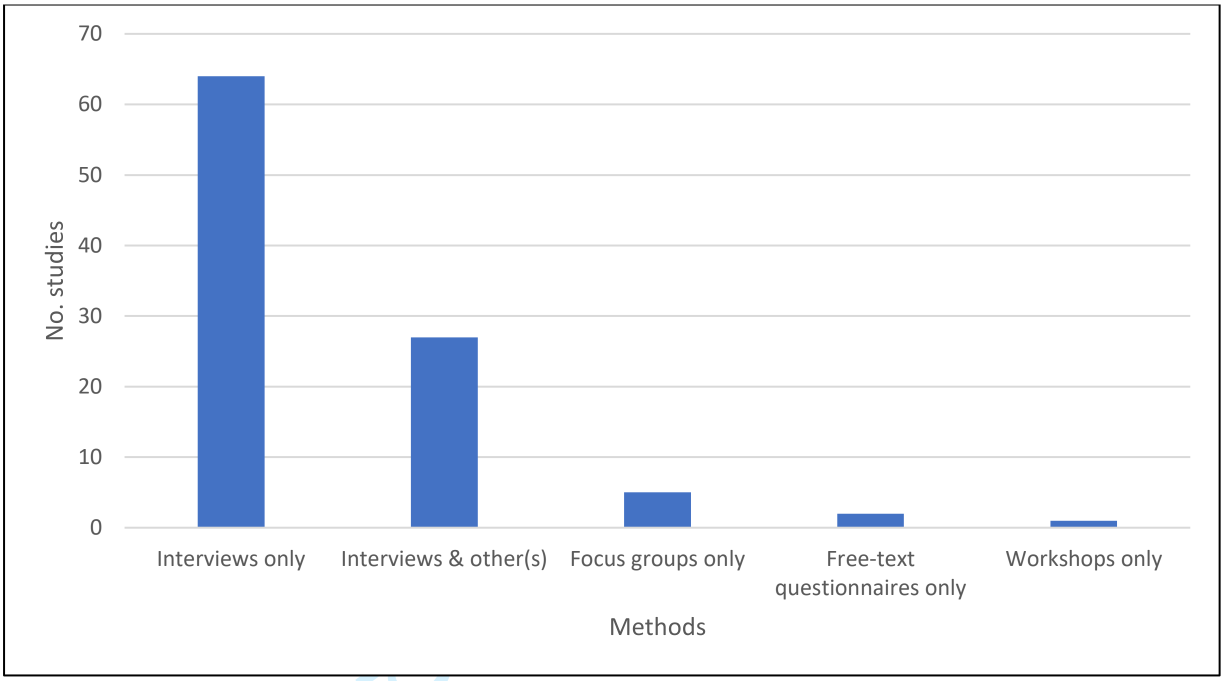


Figure 6 Methods classification

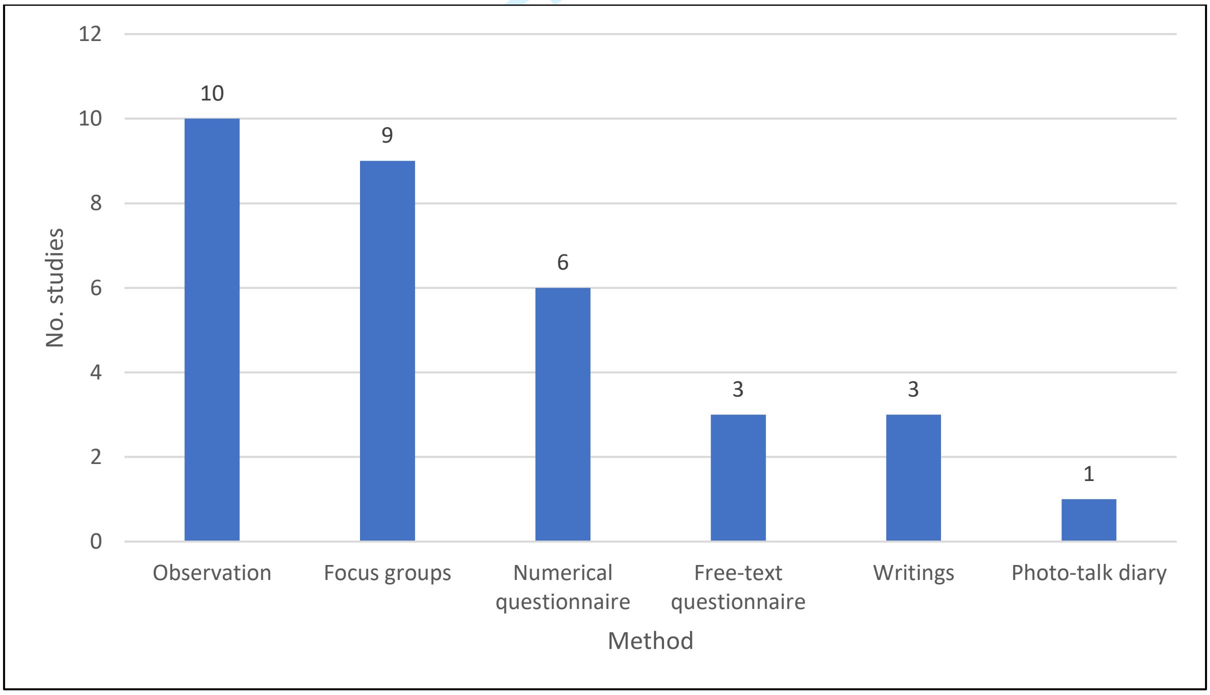


Figure 7 Methods conducted with interviews

CADs’ ages and genders from extracted quotes

Figure 1 illustrates the age distribution of quotations extracted. CADs aged 11-14 were more commonly quoted, while those aged 5-8 years were quoted less. Many quotations referenced CADs’ ages (n=379, 56.7%) and genders (n=390, 58.3%); of which 52% were female.

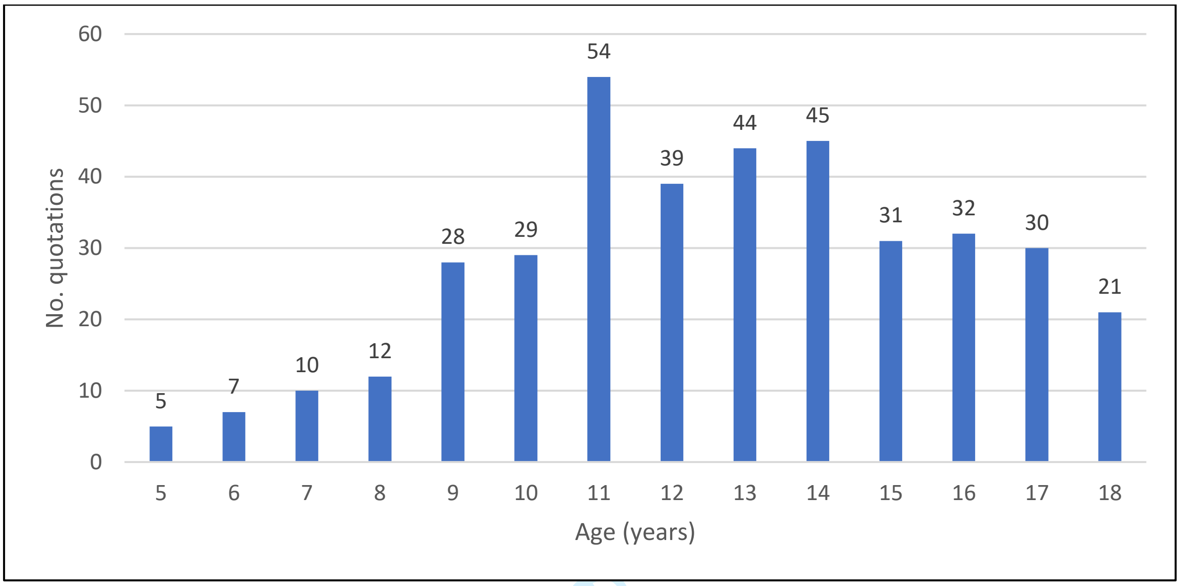


Figure 1 CAD participant ages, from extracted quotes

Quotations presented in results section

The full quotations extracted from articles are accessible using the Dryad unique identifier https://doi.org/10.5061/dryad.z08kprrc2

Quote no.	Quote as written in results section	Quote reference (first author, year, quote no.)
1	‘bond’	Ryals, 2011(49)
2	‘emotional attachment’	Brown et al., 2014(04)
3	‘best friend’	Ryals, 2011(33)
4	‘relate to’	Ryals, 2011(32)
5	‘good care’	Ångström-Brännström et al., 2008(05)
6	‘strangers’	Coyne et al., 2015(02)
7	‘As time passed, […] we created that bond.’	Ryals, 2011(29)
8	‘very smart’	Coyne et al., 2014(02)
9	‘experienced’	Hodgins et al., 1997(02)
10	‘[knew] what to do’	Day et al., 2006(04)
11	‘[took] care’	Noreña Peña, 2011(21)
12	‘everything the best they [could]’	Boyd, 1998(03)
13	‘truthful’	Brown et al., 2014(15)
14	100% with you'	Brown et al., 2014(15)
15	‘just [told] you straight up.’	Brown et al., 2014(15)
16	‘not tell children any lies’	Koller et al., 2010(02)
17	‘nothing [was] hidden’	Coyne et al., 2016(01)
18	‘really nice’	Clift et al., 2007(06)
19	‘nurturing, caring and helpful people who [were] there for you’	Schmidt et al., 2007(01)
20	‘good sense of [humour]’	Schmidt et al., 2007(15)
21	‘she knew what I was talking about, she knew what I was feeling, she knew how I was feeling.’	Ryals, 2011(20)
22	‘took time to get to know’	Brown et al., 2014(06)
23	‘real conversations, not just [HCP]-patient discussions’	Schmidt et al., 2007(31)
24	‘down to earth’	Ryals, 2011(45)
25	‘a lot in common’	Ryals, 2011(22)
26	‘you gotta have trust.’	Ryals, 2011(42)
27	‘satisfied’	Wangmo et al. 2016(05)
28	‘happy’	Corsano et al. 2015(04)
29	‘good memories’	Manookian et al, 2014(03)
30	‘open up’	Ryals, 2011(42)
31	‘tell anything’	Beresford et al, 2003(06)
32	‘cure [the] illness’	Han et al, 2011(01)
33	‘whatever happens I let them [HCPs] do what they have to do to help me get better.’	Boyd & Hunsberger, 1998(01)
34	‘individually [they’re] all heroes.’	Anderson et al., 2017(04)
35	‘Because you can save people […] I’m going to be a children’s doctor.’	Olausson et al., 2006(01)
36	‘everything [was] always clear’	Schalkers et al., 2014(04)
37	‘together’	Dell’Api et al., 2007(07)
38	‘seriously’	Clift et al., 2007(05)
39	‘as an equal’	Clift et al., 2007(05)

40	‘into all the conversations’	Coyne et al., 2011(15)
41	‘as much as they [talked to the] parents’	Edgecombe et al., 2010(03)
42	‘[breaking] the words down in an easier explanation’	Coyne et al., 2006(13)
43	‘listening’	Coyne et al., 2006(03)
44	‘I tell them I don’t want this and they … understand’	Coyne et al., 2006(03)
45	‘me because I know my own body, my parents because they know what’s best for me […] and the paediatrician because they are qualified.'	Garth et al., 2009(02)
46	‘most important, as in the end it is about [them]’	Schalkers et al., 2014(04)
47	‘brilliant’	Moules, 2009(01)
48	‘interesting and informational’	Lowes et al., 2015(02)
49	‘learn something new’	Lowes et al., 2015(03)
50	‘comfortable and confident’	Lowes et al., 2015(02)
51	‘make better decisions’	Coyne & Kirwan, 2012(23)
52	‘fully informed’	Coyne & Kirwan, 2012(23)
53	‘I’m asking the doctor more questions myself than having my Dad do it.’	Coyne et al., 2006(15)
54	‘nasty’	McPherson et al., 2018(03)
55	‘[seeming] that concerned’	Coyne, 2006b(02)
56	‘too busy’	Coyne et al., 2006(28)
57	‘big words’	Coyne et al., 2006(16)
58	‘they [HCPs] might ask me “is that ok” and they ask me in such a way that I kind of feel like I don’t have any other option but [to] agree with them’	Coyne et al., 2015(01)
59	‘behind the curtains’	Coyne et al., 2011(20)
60	‘in the middle’	Coyne et al., 2006(18)
61	‘you try to say something but then your parents just say shhhhh! […] They come out and say, […] did you understand that, you say no, they say, you should have asked them, and then you say, oh you didn’t let me, they say rubbish!’	Hawthorne et al., 2011(04)
62	‘rejected’	Coyne et al., 2006(17)
63	‘like a piece of machinery’	Coyne, 2006b(04)
64	‘hard to talk’	Anderson et al., 2017(01)

BMJ Open

How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis

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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Paediatrics, Communication, Ethics, Patient-centred medicine
Keywords:	PAEDIATRICS, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

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TITLE PAGE

How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis

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Word count: 4,143

ABSTRACT

Objective

Explore children's and adolescents' (CADs') lived experiences of healthcare professionals (HCPs).

Design

Scoping review methodology provided a six-step framework to, first, identify and organise existing evidence. Interpretive phenomenology provided methodological principles for, second, an interpretive synthesis of the life-worlds of CADs receiving healthcare, as represented by verbatim accounts of their experiences.

Data Sources

Five key databases (Ovid MEDLINE, Embase, Scopus, CINAHL Plus, and Web of Science), from inception through to January 2019, reference lists, and opportunistically identified publications.

Eligibility criteria

Research articles containing direct first-person quotations by CADs (aged 0-18 years inclusive) describing how they experienced HCPs.

Data extraction and synthesis

Tabulation of study characteristics, contextual information, and verbatim extraction of all 'relevant' (as defined above) direct quotations. Analysis of basic scope of the evidence-base. The research team worked reflexively and collaboratively to interpret the qualitative data and construct a synthesis of children's experiences. To consolidate and elaborate the interpretation, we held two focus groups with CAD inpatients in a children's hospital.

Results

669 quotations from 99 studies described CADs' experiences of HCPs. Favourable experiences were of forming trusting relationships and being involved in healthcare discussions and decisions; less favourable experiences were of not relating to or being unable to trust HCPs and/or being excluded from conversations about them. HCPs fostered trusting relationships by being personable, wise, sincere, and relatable. HCPs made CADs feel involved by including them in conversations, explaining medical information, and listening to CADs' wider needs and preferences.

Conclusion

These findings strengthen the case for making CADs partners in healthcare despite their youth. We propose that a criterion for high-quality child-centred healthcare should be that HCPs communicate in ways that engender trust and involvement.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Our findings have advanced current evidence by providing a comprehensive overview of CADs' experiences of HCPs, while providing a blueprint for the child-centred care conceptual model.
- In addition to completing a scoping review in line with a published protocol, this article reports an interpretive phenomenological synthesis of the evidence-base
- Restricting included articles to the English language limited the scope of our review
- Limitations in the metadata provided by primary researchers prevented subgroup analyses
- The subjectivity of interpretive synthesis is both a limitation and a strength: a limitation, because it does not meet quantitative, experimental standards of proof; and a strength because we used our subject position as clinicians to help fellow clinicians earn the trust of CADs.

BACKGROUND

Children's experiences, like patients' experiences in general, are of fundamental importance in healthcare.[1–3] Research consistently shows that favourable experiences are associated with a wide range of positive health outcomes, including adherence to recommended treatments, uptake of preventive care, and utilisation of healthcare resources.[3] Exploring, understanding, and adapting to patients' experiences, particularly those concerning interpersonal communication, is the hallmark of patient-centred care (PCC), which is what patients 'strongly want'.[4,5] Accordingly, PCC has become the dominant ideology in healthcare design and delivery.[6]

In the case of children, however, it has proven more difficult to establish a model of PCC. Children and adolescents (CADs) are distinct from adults; they are developing physically, intellectually, and emotionally, and they occupy different positions in society and by law.[7] CADs, therefore, typically experience healthcare as part of a family unit, accompanied by parents or guardians who often act on their behalf. These factors affect the roles that CADs occupy within healthcare settings – how they interact and communicate with others – and predispose them to asymmetric relationships with adults. To address this, two specific theoretical models of care – family-centred care (FCC) and child-centred care (CCC) – have been developed for use in paediatric practice, based on the principles of PCC but incorporating modified conceptualisations of centredness.[8]

In FCC, the family is the central unit of care, with the aspiration of an equal partnership between healthcare professionals (HCPs) and families. FCC, which first originated in the 1950s, was an important conceptual advance because, up to this point, no framework existed to involve parents in their children's care.[7] Recent research shows, however, that even within the FCC framework, parents and professionals tend to predominate and CADs struggle to be true participants.[9] In contrast, the newer concept of CCC situates CADs at the centre of healthcare practice, giving primacy to their voices and experiences. Rather than being guided by outsider perspectives of children's best interests, CCC compels HCPs to consciously perceive and understand children's conditions, experiences, and priorities, as viewed through their eyes:[8,10,11]

> "[CCC] requires providers to critically consider the child's perspective in every situation while ensuring collaboration with the family who the [child] is part of."[8]

While aspects of FCC and CCC may be pertinent in different clinical contexts,[12] experts now advocate a move towards CCC,[13] arguing that it better upholds values laid down by the UN Convention on the Rights of the Child and governing bodies (such as the General Medical Council),[14,15] and could improve how CADs experience healthcare.[8,13]

Adopting the CCC approach, however, requires a major shift in thinking and practice. Research suggests that HCPs' realities are incompatible with CADs', with HCPs focused on prioritizing tasks, 'getting the job done', and mitigating, rather than engaging with, CADs' demands.[16] Furthermore, HCPs' communication strategies adopted for consulting CADs are largely underpinned and conceptualized by biomedical or psychosocial models, from the clinical gaze,[17] with little or no input from CADs.[18,19] And while CADs' healthcare experiences overall are generally positive, large-scale studies have identified shortcomings in how HCPs interact and communicate,[20–22] impacting on CADs' ability to manage their conditions and participate in decision-making.[23] HCPs, too, continue to find communicating with CADs challenging, supporting a change in thinking and practice.[19]

To achieve the vision of CCC, then, HCPs need greater insight into the experiences of sick children.[11] This reflects a wider drive towards co-production (providers and service users working in equal partnership to effect change) in children's healthcare;[24,25] and also complements the present impetus to acknowledge and examine CADs' *own* experiences, opinions, and priorities, within research,[26,27] quality improvement,[28–30] and standard setting.[31] To date, however, most research and surveys examining experiences in paediatric settings have relied on parents' accounts, while CADs have participated less, if at all.[32] Nevertheless, the few studies that have explored CADs' own experiential accounts have found them to be informative and distinct from parents'.[23,33] At present, these accounts are widely dispersed, yet if compiled, synthesised, and interpreted, these could provide a rich account of CADs' lived experiences of how they encounter HCPs.

This study aimed to explore how CADs experience HCPs within interpersonal interactions, in order to provide practitioners, organisations, and policymakers with evidence that could promote child-centred communication. First, we conducted a scoping literature review to systematically gather evidence on CADs' experiences of HCPs. Second, we interpreted CADs' extracted quotations from the perspective of phenomenology. This well-established methodological tradition, grounded in philosophy, enables researchers to produce valid interpretations by examining and interpreting participants' verbatim accounts of their lived experience.[34] Finally, we organised the interpretation into a synthetic account of how CADs experience their interactions with HCPs.

METHODS

Methodological orientation

Scoping review methodology has a pragmatic orientation in the sense that it sets out to map existing published evidence on a topic but it is adaptable in the sense that the usefulness of its procedures is not tied to any one specific epistemology (theory of the nature of knowledge).[35–37] As in our previously published research,[38] this review augments scoping review procedures with interpretive phenomenology. The latter has an ontology (theory of the nature of being) derived from the philosophy of Husserl, according to which the lived experience of research participants is a legitimate topic of qualitative inquiry. Interpretive phenomenology helps researchers respond reflexively to spoken or written words and arrive at valid, subjective interpretations. Phenomenologists typically take a reflexive stance that consciously sets aside strong a priori preconceptions whilst allowing their own experiences (such as, in our case, having experience of caring for sick children) to help them construct an informative interpretation.[34] The quality of a constructivist interpretation is to be judged by its trustworthiness, authenticity, and ability to catalyse action – which, in this case, would be to improve future children's healthcare experiences.[39]

Study procedures

The research followed a published protocol (accessible at https://rdcu.be/b2FFk),[40] which proposed to supplement traditional scoping review procedures with an interpretive synthesis, the distinction between which is explained in the previous paragraph. The scoping component followed the 6-step framework outlined by Arksey & O'Malley,[35] Levac et al.,[36] and Colquhoun et al.,[37] adhering to PRISMA-ScR reporting guidance (included in online supplementary file 1).[41]

Step 1: Defining the research question

This was: *'What is known about children's and adolescents' experiences of healthcare professionals, from their present perspective?'*, the final phrase emphasizing our commitment to CADs' contemporaneous accounts of their experiences expressed in their own words, rather than parents' descriptions or adults describing childhood memories.

Step 2: Identifying relevant articles

We designed a STARLITE search strategy (summarised in table 1) to identify all published articles containing CADs' experiences of HCPs expressed as first-person direct quotations.[42] A subject librarian constructed a database search (included in online supplementary file 2), using the population, context, and concept framework,[43] combining the terms ‘children’ or ‘adolescents’, ‘healthcare’, and ‘experience’ (and synonyms), limiting it to English language articles, ‘qualitative research’, and ‘0 to 18 years’, and then running it on Ovid MEDLINE, Embase, Scopus, CINAHL Plus, and Web of Science from inception to 11th January 2019. We included other articles found by searching relevant reference lists or found opportunistically.

Table 1 STARLITE summary of search strategy[42]

Sampling strategy	Comprehensive: attempting to identify all published materials
Types of studies	Any published study contributing to the research question: qualitative (with or without other methodologies (i.e., mixed method)); primary or secondary sources
Approaches	Electronic database searching; manual searching of reference lists; articles found opportunistically
Range of years	From database inception until 11th January 2019
Limits	Articles published in English language; ‘qualitative research’; children aged 0-18 years (inclusive)
Inclusion and exclusion criteria	See table 2 and Step 3: Study selection
Terms used	See online supplementary file 2
Electronic databases	Ovid MEDLINE; Embase; Scopus; CINAHL Plus; Web of Science

Step 3: Study selection

Refinement of selection criteria

As is customary in scoping review, the process iterated between searching, selecting, extracting data, and refining the research question. To enhance the rigour of this process, and in keeping with our interpretive stance, we responded reflexively to the accumulating evidence, discussing our interpretations, and articulating a clear rationale for each refinement. All records were imported to Mendeley Reference Manager, duplicates removed, titles and abstracts screened against five screening questions (Box 1), and full texts of those that screened positive reviewed against eligibility criteria.

Box 1 Screening questions

1. Are the participants CADs ($\leq$ 18 years)?
2. Is the study examining an aspect of health, illness, or healthcare?
3. Are CADs participating as recipients of healthcare?
4. Are participants aged > 18 years excluded from the study?
5. Do children or adolescents describe experiences?

These criteria, at first provisional (table 2A), were progressively refined in response to the heterogeneity of evidence. Table 2B shows final criteria. GD led the process of first-screening, annotating, sorting, and collating articles. MK & TD supported her by second-screening 10% of records, discussing results, assessing articles whose eligibility was in doubt, and responding to the often-imprecise details given by researchers. Any ambiguities (i.e., lack of age ranges) during screening led to full-text review and a final decision about eligibility against criteria. To optimise validity of the selection process, GD rescreened all records and annotations after each refinement and, finally, after definitive criteria had been set.

Rationale for criteria

We included children up to and including 18 years because late adolescents are increasingly cared for in paediatric settings.[44,45] Our age range conforms, also, with the United Nations' influential definition of adolescence.[46] We included articles that contained verbatim quotations irrespective of methodology. Judgement of methodological quality was not a criterion for three reasons: it is not standard practice in scoping reviews; it is notoriously difficult to judge qualitative research categorically;[47] and the interpretive synthesis used verbatim quotations, whose validity does not depend on what the primary researchers did with CADs' words. Because authors often failed to report the exact age of patient participants they quoted, we excluded any study that included patient participants aged > 18 years (see, for example, Tjaden et al. [48]).

Table 2 Eligibility criteria for article selection

A. Provisional	B. Definitive
Inclusion criteria:	
1. CADs speaking about HCPs, through first-person direct quotations. 2. HCP defined as a member of a healthcare team. 3. CADs defined as ≤ 18 years old, regardless of health status or illness type.	1. CADs speaking about one or more HCPs, on one or more instances, from any experience, through first-person direct quotation(s), where there had been direct contact between the two parties, and where CADs were the persons receiving healthcare. 2. An HCP defined as a member of a healthcare team with professional qualifications and training, such as a qualified doctor, nurse, therapist, psychologist, or social workers, regardless of grade. 3. CADs defined as ≤ 18 years, regardless of health status or illness type.
Exclusion criteria:	
1. Adults aged >18 years included in the study. 2. Non-English language publications.	1. Adult <u>patients</u> aged >18 years included in the study with or without CADs as defined above. 2. Non-English language publications. 3. CADs speaking about HCP(s) not from memory of personal experience as a patient; for example, third-party description (e.g., parent). 4. Age range of CAD participants unclear. 5. No full-text manuscript available; only an abstract available, or unobtainable by searching online, directly emailing authors, or by university librarians requesting inter-library loans.

Step 4: Charting the data

GD and MK piloted a spreadsheet to chart study characteristics, contextual information, and all CADs' verbatim quotations on 10 articles; this resulted in the final dataset shown in box 2, which GD then used to extract data on the remaining articles.

Box 2 Data extracted

Study characteristics:
- First author
- Year published
- Country of origin
- No. CAD participants
- Age range of CAD participants
- Male to female (or non-binary) ratio
- Other participants (e.g., parents)
- Methods
- Methodology (or analytical approach)

Contextual information:
- Study focus (the experience being explored)
- Health setting
- Health condition
- Length of healthcare encounter being explored

CADs' quotations:
- All first-person direct quotations, where CADs are talking about HCPs
- Age and gender referenced to each quotation

When key information was missing or unclear, we sought clarification from primary authors. All authors independently reviewed the extracted information for its fitness to address the aims and purpose of the study, subsequently conferring to optimise the validity of the dataset.

Step 5: Collating, summarising, and reporting the results

We first analysed the basic characteristics of included studies. We then identified themes in the verbatim quotations following Braun and Clarke's method of thematic analysis as defined by their checklist (included in online supplementary file 3).[49,50] GD immersed herself in the data, reviewing all quotations on Microsoft Excel, using NVivo 12 qualitative analysis software to support generation of codes and construction of themes.[51] Other team members supported her interpretation, by reviewing quotations first individually, and then collectively. We systematically interrogated the data for themes that had meaning in relation to the research question, revising candidate themes periodically (with the aid of a visual thematic map) to ensure these were coherent, distinctive, complementary, and relevant. The ensuing thematic structure had central concepts, which we used to organise subordinate themes and their associated codes. Throughout this process, we constantly compared our evolving interpretation against the original data, including a final 'quality control' check of the synthesis against all quotations.[49,50]

In keeping with our interpretive stance, we used our different subject positions as paediatricians, a family doctor, and an adult internist to interpret CADs' words reflexively and arrive at 'beyond-surface insights', so that the themes were amenable to an additional stage of phenomenological synthesis.[34,50] As we did this, the gamut of emotional content in CADs' words became an increasingly compelling influence on our interpretation. CADs' emotional expressions tended to have quite distinct 'valence' (defined as the attractiveness [positive valence] or averseness [negative valence] of the emotions described) which linked in recurring ways to HCPs' reported behaviours.[52,53] So, for example, a HCP who related well to a child might engender trust, while an HCP who related poorly might engender mistrust.

Whilst crude dichotomies between positive/negative emotions and behaviours do not reflect the subtlety of interpretive research, links between these contrasting behaviours were so clearly present that they offered a parsimonious way of presenting our results. The Results section uses the terms 'favourable' and 'unfavourable' to specify what are, in reality, nuanced polarities. To epitomize these important themes in ways that could encourage HCPs to emulate favourable behaviours, we present predominantly favourable behaviours, but provide negative counter-examples to emphasize the breadth of CADs' experiences. As in previous research,[54] we used CADs' own words, as far as possible, to construct a narrative of findings that was as true as possible to the phenomena experienced and narrated by children. We use the wording 'HCPs did X' as a shorthand for the more correct wording, 'CADs experienced HCPs as doing X'.

Step 6: Stakeholder consultations

As recommended by Levac et al.,[36] GD, AT, and RC (with research ethics and governance approvals) recruited CADs aged 8-16 from inpatient wards in the Royal Belfast Hospital for Sick Children (RBHSC) to two focus groups whose aim was to consolidate and elaborate on findings. Participants and parents chose whether parents should attend. We presented candidate themes along with exemplar quotations and facilitated discussions, asking participants to comment on provisional findings and provide suggestions for practice. We audio-recorded sessions and transcribed recordings verbatim. We reviewed transcripts alongside the provisional findings to authenticate, build upon, and summarise a final narrative of results. Participants' identities are pseudonymised in the results section.

Patient and public involvement

The essence of this research was to involve children, albeit as expressed verbatim by other researchers. The stakeholder consultation further fulfilled the patient and public involvement component of the research by ensuring findings disseminated were intelligible and relevant.

RESULTS

We identified 1,359 articles, excluding 1,015 by screening and 245 by reviewing full texts, and categorised reasons for exclusion on a PRISMA flow diagram (shown in figure 1).

Overview of included studies

Table 3 presents an overview of included studies (n=99), published between 1992 and 2018. In total, 4,448 CADs, aged 11 months to 18 years, participated. Most studies included 8 to 50 participants (n=73), aged 7 or older (n=70), and used interviews only (n=64). Studies commonly included CADs with chronic and potentially debilitating or life-threatening conditions (such as asthma and cancers), explored long-term experiences (over months to years), and focused on hospital care. Further descriptive findings and figures are presented in online supplementary file 4.

Table 3 Study characteristics

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Aalsma *et al.*, 2014[55]	US	19	11-17	12:7	INT	Qualitative	CAMHS	Non-specific	Mental health illness	Long-term	5
Alex MR, 1992[56]	Canada	24	7-11	13:11	INT, Q	Content analysis	Pain	Hospital	Surgical (post-op)	Short-term	4
Anderson *et al.*, 2017[57]	England	6	15-18	3:3	INT	Interpretative phenomenological analysis	Lung transplantation	Hospital	Post-lung transplantation	Long-term	6
Ångström-Brännström *et al.*, 2008[58]	Sweden	7	4-10	3:4	INT (PT)	Thematic analysis	Being comforted	Hospital	Chronic	Short-term	6
Ångström-Brännstrom *et al.*, 2014[59]	Sweden	9	3-9	5:4	INT	Content analysis	Comfort during cancer treatment	Hospital	Cancer	Long-term	3
Beresford *et al.*, 2003[60]	England	63	11-16	27:36	INT, FG (PT)	Framework method	Communicating	Hospital	Chronic	Long-term	14
Boyd *et al.*, 1998[61]	Canada	6	10-13	2:4	INT (PT), WT	Grounded theory	Hospital and coping strategies	Hospital	Surgical (chronic)	Long-term	3
Brown *et al.*, 2014[62]	US	19	11-17	12:7	INT	Grounded theory	Therapeutic alliances	Hospital	Mental health illness	~	16
Carney *et al.*, 2003[63]	Scotland	213	4-17	115:98	INT, FTQ	Thematic analysis	Healthcare	Hospital	Non-specific	Non-specific	9
Cheng *et al.*, 2003[64]	Taiwan	90	5-14	45:45	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Cheng *et al.*, 2016[65]	Taiwan	11	12-18	7:4	INT	Content analysis	Cancer recovery	Hospital	Cancer	Long-term	1
Christofides *et al.*, 2016[66]	Canada	19	8-18	7:12	INT	Thematic analysis	Research participation	Hospital	Cystic fibrosis	Long-term	3
Clift *et al.*, 2007[67]	Wales	6	11-15	3:3	INT	Qualitative	Emergency admission	Hospital	Non-specific	Short-term	7
Colver *et al.*, 2018[68]	England	374	14-18	219:155	INT, Q, OBS	Constant comparison	Transition	Hospital	Medical	Long-term	2
Corsano *et al.*, 2015[69]	Italy	27	6-15	12:15	INT	Qualitative	Emotional events	Hospital	Cancer/ blood disorders	Long-term	4
Coyne *et al.*, 2006[70]	Ireland	55	7-18	30:25	INT, FG	Constant comparison analysis	Participating/ decision-making	Hospital	Non-specific	Non-specific	52
Coyne, 2006a[71]	Ireland	11	7-14	~	INT	Grounded theory	Hospitalisation	Hospital	Non-specific	~	1
Coyne, 2006b[72]	Ireland	11	9-14	~	INT (PT), FTQ, OBS	Grounded theory	Participating	Hospital	Non-specific	~	4
Coyne *et al.*, 2007[73]	Ireland	17	7-16	~	INT	Qualitative	Hospitalisation	Hospital	Non-specific	Non-specific	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Coyne *et al.*, 2011[74]	Ireland	55	7-18	31:24	INT, FG	Qualitative	Communicating/ decision-making	Hospital	Non-specific	Non-specific	20
Coyne *et al.*, 2012[75]	Ireland	38	7-18	~	INT (PT)	Content analysis	Hospital and HCPs	Hospital	~	~	24
Coyne *et al.*, 2014[76]	Ireland	20	7-16	11:9	INT (PT)	Constant comparison analysis	Participating/ decision-making	Hospital	Cancer	Long-term	2
Coyne *et al.*, 2015[77]	Ireland	15	12-18	6:9	INT, FG	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	6
Coyne *et al.*, 2016[78]	Ireland	20	7-16	11:9	INT	Grounded theory	Communicating	Hospital	Cancer	Long-term	6
Curtis *et al.*, 2017[79]	England	17	5-16	~	INT (PT), OBS	Ethnographic	Single/ shared rooms	Hospital	~	~	3
Das *et al.*, 2017[80]	India	14	8-15	~	FG	Qualitative	Living with HIV	Non-specific	HIV	Long-term	1
Day *et al.*, 2006[81]	England	11	9-14	5:6	FG	Thematic Analysis	CAMHS	Non-specific	Mental health illness	Long-term	13
Dell’Api *et al.*, 2007[82]	Canada	5	10-17	2:3	INT	Qualitative	Interacting with HCPs	Hospital	Non-specific	Long-term	19
Dixon-Woods *et al.*, 2002[83]	England	20	8-16	9:11	INT	Constant comparison analysis	Asthma services	Community	Asthma	Long-term	12
Edgecombe *et al.*, 2010[84]	England	22	11-18	16:6	INT	Thematic analysis	Asthma services	Hospital	Asthma	Long-term	5
Ekra *et al.*, 2012[85]	Norway	9	7-12	5:4	INT, OBS (PT)	Hermeneutic phenomenology	Hospitalisation	Hospital	TIDM	Long-term	2
Engvall *et al.*, 2016[86]	Sweden	13	5-15	6:7	INT (PT)	Content Analysis	Radiotherapy	Hospital	Cancer	Long-term	2
Forsner *et al.*, 2005[87]	Sweden	7	7-10	4:3	INT	Thematic analysis	Illness	Hospital	~	Short-term	4
Forsner *et al.*, 2009[88]	Sweden	9	7-11	2:7	INT, OBS	Hermeneutic phenomenology	Fear	Hospital	Non-specific	Short-term	4
Garth *et al.*, 2009[89]	Australia	10	8-12	3:7	INT	Grounded theory	Participating	Non-specific	Cerebral palsy	Long-term	3
Gill *et al.*, 2016[90]	England	12	14-17	2:10	INT	Thematic analysis	CAMHS inpatient ward	Non-specific	Mental health illness	Long-term	2
Griffiths *et al.*, 2011[91]	Australia	9	8-16	~	INT	Interpretative phenomenological analysis	Living with cancer	Non-specific	Cancer	Long-term	3
Haase *et al.*, 1994[92]	US	7	5-18	3:4	INT (PT)	Colaizzi’s method of phenomenological analysis	Completing cancer treatment	Non-specific	Cancer	Long-term	6
Hall *et al.*, 2013[93]	England	17	8-17	~	INT	Thematic analysis	Life with repaired cleft lip/ palate	Non-specific	Cleft lip/ palate	Long-term	1

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Han *et al.*, 2011[94]	China	29	7-14	16:13	INT	Content analysis	Cancer	Hospital	Cancer	Long-term	2
Hanson *et al.*, 2017[95]	US	30	4-14	16:14	INT	Narrative analysis	Pain	Hospital	Fractured arm	Short-term	5
Harper *et al.*, 2014[96]	England	10	16-18	3:7	INT	Interpretative phenomenological analysis	CAMHS	Non-specific	Mental health illness	Long-term	8
Hart *et al.*, 2018[97]	England	14	14-16	~	INT	Thematic analysis	CAMHS	Non-specific	Mental health illness	Long-term	2
Hawthorne *et al.*, 2011[98]	England	21	7-16	12:9	FG	Thematic analysis	Diabetes services	Hospital	T1DM	Long-term	8
Hinton *et al.*, 2015[99]	England	21	8-17	6:15	INT (PT)	Constant comparison analysis	A multiple sclerosis diagnosis	Non-specific	Multiple sclerosis	Long-term	3
Hodgins *et al.*, 1997[100]	Canada	85	5-13	38:41	INT, Q	Mixed-method	Venepuncture	Hospital	Non-specific	Short-term	3
Hutton, 2005[101]	Australia	7	13-18	3:4	INT (PT)	Qualitative	Adolescent wards	Hospital	Cystic fibrosis/ asthma	Long-term	3
Jachyra *et al.*, 2018a[102]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	6
Jachyra *et al.*, 2018b[103]†	Canada	8	11-17	4:4	INT	Interpretative phenomenological analysis	Talking about weight	Non-specific	ASD	Long-term	4
Jensen *et al.*, 2012[104]	Denmark	8	8-10	5:3	INT (PT)	Thematic analysis	Acute hospitalisation	Hospital	Medical	Short-term	6
Jongudomkarn *et al.*, 2006[105]	Thailand	49	4-18	31:18	INT, FG, OBS, PT	Content analysis	Pain	Non-specific	Non-specific	Long-term	1
Kluthe *et al.*, 2018[106]	Canada	18	6-17	11:7	INT	Content analysis	IBD diagnosis	Hospital	IBD	Long-term	1
Koller *et al.*, 2010[107]	Canada	21	5-18	12:9	INT (PT)	Grounded theory	Hospitalisation during SARS	Hospital	Non-specific	Long-term	2
Koller, 2017[108]	Canada	26	5-18	11:15	INT (PT)	Thematic analysis	Medical education/ participating	Hospital	Chronic	Long-term	10
Kortesluoma *et al.*, 2006[109]†	Finland	44	4-11	~	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	1
Kortesluoma *et al.*, 2008[110]†	Finland	44	4-11	27:17	INT	Content analysis	Pain	Hospital	Non-specific	Non-specific	7
Lewis *et al.*, 2007[111]	Australia	9	8-16	5:4	INT	Cognitive mapping	Receiving care	Hospital	~	~	5
Livesley *et al.*, 2013[16]	England	15	5-15	3:2	INT (PT), OBS	Critical ethnography, constant comparison analysis	Hospitalisation	Hospital	Surgical	Long-term	4
Lowes *et al.*, 2015[23]	Wales	518	7-15	~	FTQ	Qualitative descriptive analysis	Life with T1DM and services	Hospital	T1DM	Long-term	8

Study details		CAD participants			Design		Contextual information				Data
First author, year	**Country**	**n**	**Age (yrs)**	**M:F**	**Methods**	**Methodology/analytical approach**	**Study focus (experience of)**	**Health setting**	**Health condition**	**Length of encounter**	**Quotes (n)**
Macartney *et al.*, 2014[112]	Canada	12	9-18	6:6	INT	Content analysis	Life after a brain tumour	Non-specific	Brain tumour	Long-term	1
Manookian *et al.*, 2014[113]	Iran	6	6-17	3:3	INT	Interpretative phenomenological analysis	Stem cell transplantation	Hospital	Cancer & blood disorders	Long-term	4
Marcinowicz *et al.*, 2016[114]	Poland	22	10-16	8:14	INT	Content analysis	Nurse relationships and wards	Hospital	~	~	7
Marshman *et al.*, 2010[115]	England	10	12-14	5:5	INT, Q	Framework analysis	Malocclusion treatment	Non-specific	Malocclusion	Long-term	1
McNelis *et al.*, 2007[116]	India	11	7-15	6:5	FG	Thematic analysis	Living with epilepsy	Non-specific	Epilepsy	Long-term	2
McPherson *et al.*, 2017[117]	Canada	17	6-18	8:9	INT	Phenomenology, thematic analysis	Talking about weight	Hospital	Spina Bifida	Long-term	3
McPherson *et al.*, 2018[118]	Canada	18	10-17	9:9	INT, FG	Thematic analysis	Talking about weight	Hospital	Non-specific	Long-term	3
Moules, 2009[119]	England	138	9-14	82:56	INT (PT)	Framework analysis	Hospital care	Hospital	~	~	3
Nguyen *et al.*, 2010[120]	Sweden	40	7-12	~	INT, Q, vital signs	Content analysis	Music therapy for lumbar puncture	Hospital	Cancer	Short-term	1
Nilsson *et al.*, 2011[121]	Sweden	39	5-10	32:7	INT	Content analysis	Pain	Hospital	Skin trauma	Short-term	4
Noreña Peña *et al.*, 2011[122]†	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	24
Noreña Peña *et al.*, 2014[123]†	Spain	30	8-14	13:17	INT, OBS	Critical incident technique	Communicating with nurses	Hospital	Surgical	~	22
Olausson *et al.*, 2006[124]	Sweden	18	4-18	8:10	INT	Hermeneutic phenomenology	Life after transplantation	Non-specific	Post- transplant	Long-term	6
Pelander *et al.*, 2004[125]	Finland	40	4-11	28:12	INT	Content analysis	Nursing care	Hospital	Chronic (T1DM & other)	Long-term	3
Pelander *et al.*, 2010[126]	Finland	388	7-11	198:188 *	FTQ	Content analysis	Hospitalisation	Hospital	Non-specific	Non-specific	2
Pölkki *et al.*, 1999[127]	Finland	20	7-11	~	INT, WT	Content analysis	Pain	Hospital	Non-specific	~	1
Pope *et al.*, 2018[128]	Australia	15	4-8	11:4	INT (PT)	Thematic analysis	Pain and nurses' roles	Hospital	Trauma	Short-term	1
Randall, 2012[129]	England	21	0.9-17	8:12 *	INT, FG (PT), PTD	Colaizzi's method of phenomenological analysis	Community children's nursing	Community	Non-specific	Long-term	4
Rankin *et al.*, 2018[130]	Scotland	24	9-12	13:11	INT (PT)	Thematic analysis	Managing T1DM	Non-specific	T1DM	Long-term	1
Roper *et al.*, 2018[27]	England	16	7-15	9:7	INT	Qualitative	Research participation/ consent	Hospital	Asthma or anaphylaxis	Short-term	7

Study details		CAD participants			Design		Contextual information				Data
First author, year	Country	n	Age (yrs)	M:F	Methods	Methodology/analytical approach	Study focus (experience of)	Health setting	Health condition	Length of encounter	Quotes (n)
Ruhe *et al.*, 2016[131]	Switzerland	17	9-17	11:6	INT	Thematic analysis	Participating	Hospital	Cancer	Long-term	1
Ryals, 2011[132]	US	8	13-17	6:2	INT	Phenomenology	Therapeutic relationships	Non-specific	Mental health illness	Long-term	59
Saarikoski *et al.*, 2018[133]	Finland	19	6-12	7:12	FG	Content analysis	Therapeutic intervention	Community (school)	Enuresis	Long-term	1
Salmela *et al.*, 2010[134]	Finland	90	4-6	~	INT	Colaizzi's method of phenomenological analysis	Hospital related fears	Hospital	~	~	4
Schalkers *et al.*, 2014[135]	The Netherlands	63	6-18	31:32	INT (PT), WT	Action research	Hospital care	Hospital	Non-specific	~	8
Schmidt *et al.*, 2007[136]	US	65	5-18	34:31	INT, FTQ	Thematic analysis	Nurses in hospital	Hospital	Non-specific	Non-specific	45
Spalding *et al.*, 2016[137]	England	7	8-14	2:5	WS (PT)	Action research, thematic analysis	Good doctors	Hospice	Palliative	Long-term	3
Stevens *et al.*, 2006[138]	Canada	14	7-16	9:5	INT	Content analysis	Home chemotherapy	Community (home)	Cancer	Long-term	1
Taylor *et al.*, 2010[139]	England	14	12-18	~	INT	Framework analysis	Life after transplantation	Non-specific	Liver transplant	Long-term	6
Vejzovic *et al.*, 2014[140]	Sweden	17	10-17	5:12	INT	Content analysis	Preparing for colonoscopy	Hospital	Suspected IBD	Short-term	4
Vindrola-Padros, 2012[141]	Argentina	10	8-16	5:5	INT (PT)	Narrative analysis	Living with cancer	Non-specific	Cancer	Long-term	4
Wangmo *et al.*, 2016[142]	Switzerland	17	9-17	11:6	INT	Qualitative	Cancer services and treatment	Hospital	Cancer	Long-term	5
Watson *et al.*, 2009[143]	US	9	14-18	7:1:1#	INT	Grounded theory	Accessing CAMHS & mental illness	Non-specific	Mental health illness	Long-term	1
Wen *et al.*, 2013[144]§	Singapore	203	4-18	~	INT, OBS	Thematic analysis	Pain	Non-specific	Surgical (post-op)	Non-specific	15
Wise, 2002[145]	US	9	7-15	~	INT (PT)	Hermeneutic phenomenology	Transplantation	Non-specific	Liver transplant	Long-term	7
Wong *et al.*, 2012[146]	China	79	10-13	54:25	FG	Qualitative	Weight-loss program	Community (school)	Obesity	Long-term	1
Woodgate, 2008[147]	Canada	13	9-17	7:6	INT	Constant comparison analysis	Cancer symptoms	Non-specific	Cancer	Long-term	1
Wray *et al.*, 2018[148]	England	543	8-16	~	INT, FG, Q	Framework Analysis	Healthcare	Hospital	~	~	5
Xie *et al.*, 2016[149]	China	21	7-12	12:9	INT	Content Analysis	Lumbar puncture	Hospital	ALL	Short-term	15
Young *et al.*, 2003[150]	England	13	8-17	8:5	INT	Constant comparison analysis	Communicating	Hospital	Cancer	Long-term	7

Note:

Non-specific, not focusing on a certain type or area; ALL, acute lymphoblastic leukaemia; ASD, autism spectrum disorder; CAMHS, child and adolescent mental health service; HIV, human immunodeficiency virus; IDB, inflammatory bowel disease; SARS, severe acute respiratory syndrome; T1DM, type 1 diabetes mellitus. FG, focus groups; FTQ, free-text questionnaires; INT, interviews; OBS, observations; PT, participatory techniques employed; PTD, photo talk diaries; Q, quantitative questionnaires; WS, workshops; WT, writings; ~, unable to ascertain; *, numerical inconsistency detected in source article; †, same study with different quotations presented; §, qualitative systematic review; #, non-binary gender.

Children's and adolescents' experiences

Six-hundred and sixty-nine quotations referred to CADs' experiences of HCPs, most of whom were doctors or nurses. CADs also spoke about their experiences with counsellors, psychologists, social workers, and dentists. CADs' ages (available for 397 quotations), ranged from 5-18 years (average 13); male and female participants were equally represented (see supplementary file 5). All quotations extracted are available at doi:10.5061/dryad.z08kprrc2; quotations presented below are cited in online supplementary file 6.

CADs' favourable experiences were of HCPs forming trusting relationships and involving them in healthcare discussions and decisions and their unfavourable experiences were generally towards the opposite pole.

Forming trusting relationships

Their nature

Being in a trusting relationship was feeling a 'bond', having an 'emotional attachment', or having a 'best friend'. CADs and HCPs knew each other, could 'relate to' each other, and really understood each other. There was openness, transparency, and there was trust. CADs trusted in HCPs to provide 'good care', knowing they would do everything necessary, and do it right.

Their origins

At first, HCPs were 'strangers'; CADs did not know the HCPs, who they were, and how they were. HCPs, likewise, did not know CADs, their histories, or their personalities. Repeated contact and dialogue built and reinforced relationships: 'As time passed, […] we created that bond.'

HCPs engendered trusting relationships by demonstrating positive attributes, including being able to empathise. CADs trusted in HCPs who were 'very smart', 'experienced', '[knew] what to do', '[took] care', and did 'everything the best they [could]'. They trusted HCPs who were 'truthful', '100% with you', and 'just [told] you straight up.' Such HCPs did 'not tell children any lies'; 'nothing [was] hidden'. CADs built trusting relationships with HCPs who were 'really nice', 'nurturing, caring, and helpful people who [were] there for you', and had a 'good sense of [humour]'.

HCPs related to CADs by understanding them: 'she knew what I was talking about, she knew what I was feeling, she knew how I was feeling.' HCPs 'took time to get to know' CADs and had 'real conversations, not just [HCP]-patient discussions', in which they shared experiences and got to know each other personally. CADs could better relate to HCPs who were 'down to earth' and had 'a lot in common'.

Their effects

Trust was vital: 'you gotta have trust.' Trusting relationships improved CADs' healthcare experiences by promoting positive emotions. CADs felt 'satisfied' and 'happy'. They enjoyed their time with HCPs and had 'good memories'. CADs were more able to 'open up' or 'tell anything' to HCPs whom they trusted. Trusting relationships gave CADs hope that HCPs could 'cure [the] illness' or help lessen the pain. CADs who trusted HCPs submitted themselves more willingly to recommended treatments: 'whatever happens I let them [HCPs] do what they have to do to help me get better.' And they consciously chose to remain with or seek out HCPs they trusted. CADs admired trustworthy HCPs: 'individually [they're] all heroes.' And they aspired to be like them: 'Because you can save people […] I'm going to be a children's doctor.'

Being involved in healthcare discussions and decisions

The nature of involvement

CADs who were fully involved in healthcare discussions felt they knew everything; ‘everything [was] always clear’ to them. They had a seat at the table to discuss issues that affected them and felt acknowledged as key stakeholders. CADs worked ‘together’ with HCPs and parents; they felt as though they were respected, taken ‘seriously’, and treated ‘as an equal’.

Its origins

HCPs involved CADs by including them in conversations, sharing information, providing opportunities to ask questions, taking time to answer, and listening to their wider needs and preferences. HCPs who promoted involvement used simple words, communicated in a timely way, gave accurate information at the right pace, and explained things so that CADs understood. These HCPs brought CADs ‘into all the conversations’ by talking to CADs ‘as much as they [talked to the] parents’. Parents facilitated CADs’ involvement in the presence of HCPs or afterwards by ‘[breaking] the words down in an easier explanation’. HCPs promoted participation by ‘listening’ to and respecting CADs’ requests: ‘I tell them I don’t want this and they … understand’. For more complex decisions, CADs took a joint approach: ‘me because I know my own body, my parents because they know what’s best for me […] and the paediatrician because they are qualified.’

Its effects

CADs viewed involvement as ‘most important, as in the end it is about [them]’. CADs enjoyed being involved; it was ‘brilliant’, and they looked forward to their next visit. CADs were more satisfied with healthcare; they found it ‘interesting and informational’. Getting to ‘learn something new’ made them feel ‘comfortable and confident’. CADs could ‘make better decisions’ because they were ‘fully informed’. This promoted self-advocacy and self-efficacy: ‘I’m asking the doctor more questions myself than having my Dad do it.’

Not forming trusting relationships or being involved

CADs described unfavourable experiences, which broadly *mirrored* favourable ones. For instance, trust was undermined by HCPs getting things wrong, being ‘nasty’, and not ‘[seeming] that concerned’. HCPs being unfamiliar to CADs because they were ‘too busy’ or because HCPs or CADs moved to other services prevented trusting relationships forming. HCPs excluded CADs by using ‘big words’, speaking too fast, or telling them nothing, so that CADs could not understand. HCPs neglecting to ask CADs or asking in a tokenistic way prevented them ‘having a say’: ‘they [HCPs] might ask me “is that ok” […] in such a way that I kind of feel like I don’t have any other option but [to] agree with them’. HCPs and parents side-lined CADs by talking behind the curtains so CADs could not hear or sticking them ‘in the middle’ of a conversation where they could not interrupt. Some parents told CADs to keep quiet or dominated conversations: ‘you try to say something but then your parents just say shhhhh! […] They come out and say, […] did you understand that, you say no, they say, you should have asked them, and then you say, oh you didn’t let me, they say rubbish!’

Not trusting people or understanding what was happening made CADs fearful. HCPs who made CADs feel ‘rejected’ and objectified, ‘like a piece of machinery’, enraged them. CADs found it ‘hard to talk’, disengaged in conversations, and left the talking to their parents. Not trusting in HCPs or being uninvolved meant some CADs hated hospital or clinic, they objected to attending, and sought information or guidance from other sources.

Stakeholder consultations

Two CAD inpatients participated in each of two focus groups (3 females and 1 male, aged 11-15 years) lasting 67 and 93 minutes respectively. Their medical conditions included type 1 diabetes, coeliac disease, spina bifida, and spinal/brain surgery. No parents attended. Three authors (GD, AT, & RC) attended both consultations and a hospital play specialist attended the first consultation. Participants identified with the provisional findings and elaborated on them (table

4). All wanted some degree of involvement in their own care though the amount of information and level of participation they wanted depended on their age, what was being discussed, and individual preferences. Box 3 offers take-home messages for HCPs.

Table 4 Stakeholder findings: Focus group participants' experiences mapped to overarching themes

Overarching themes	Forming trusting relationships	Being involved in healthcare discussions and decisions
Favourable experiences	Rachel, a young girl with diabetes, described having a very good relationship with the diabetic team and ward staff: *'Hm, it's just the nurses really like nice. Like, the first night I was staying over they were staying it's a sleepover and stuff.'* (Rachel, FG1, line 746 & 747) She acknowledged how continuity of care helped her become more familiar with the staff: *'they're always in the clinic when I am there'*. (Rachel, FG1, line 678) She commented on how the diabetic team got to know her, by chatting casually and taking an interest in her wider life: *'they like asked me what school I'm going to this year'* and about *'my baby sister and stuff'*. (Rachel, FG1, line 815-819) Participants experienced some HCPs as being easier to talk to than others. Rachel felt that she could talk to the diabetic team: *'[…] I can talk to them more 'cos you know them.'* (Rachel, FG1, line 621) From the perspective of Laura, a young girl with a recent diagnosis of diabetes, a caring nature was an important factor: *'[HCPs who] make you feel as if they care [were easier to talk to]'*. (Laura, FG2, line 432)	Laura was well informed by her hospital consultant, who had seen her when she was first diagnosed with diabetes: *'My consultant like came the day before […] and he explained the whole thing in detail.'* (Laura, FG2, line) Laura's experience of being well informed resembled Rachel's: *'The doctor like normally tells me everything that I need to know anyway and they put it in like ways that I like, know.'* (Rachel, FG1, line 657 & 658) Sarah, an adolescent with spina bifida and scoliosis, felt she had some control over her treatment: *'Uhm, I might have to get the surgery on my back, because I've got scoliosis, em, so if it gets like really, it's not too bad but if it gets worse I have to have surgery so I feel as if I have like a choice because I don't have to have it, and I don't want it. […] I don't want to have it.'* (Sarah, FG2, line 743-748) Although all participants wanted to be informed, the oldest participant, Darren, a young boy with spina bifida and epilepsy, preferred his parents to ask and answer questions, and doctors to make decisions on his behalf: *'GD: Do you ever have any questions [Darren]?* *Darren: Ah...don't think so.* *AT: Are you happy for your parents to ask the questions?* *Darren: Yeah.* *AT: And you just listen?* *Darren: Yeah [smiling and laughing].'* (Verbatim excerpt, FG1, line 555-560)
Unfavourable experiences	Sarah found it difficult to trust HCPs who were uncaring: *'Well yesterday I had to get a line [cannula] in and there was four different doctors that tried […] and I thought like the doctors didn't really care, they were just gonna get it in, they didn't really care what I was thinking. […] Well I know they needed to do it. But they didn't care, […] they didn't care if they hurt me.'* (Sarah, FG2, line 438-441 & 512)	During her cannulation experience, Sarah felt angry because HCPs failed to grant her wishes: *'I always tell them to put it, try my feet first because I don't have any feeling in my feet […] I told the doctor not to put it in there and they still did it. […] I was really cross after it because I thought all that pain.'* (Sarah, FG2, line 460-465) Sarah spoke about feeling excluded when a doctor spoke discretely to her mother: *'No but it does happen to people like they feel they're left out. […] Today, […] a doctor was explaining something to me and he was just about to leave and when he was just about to leave he said to my mum, "If you want to ask a question I can come back" so I kind of thought is he doing that because he doesn't want me to hear my mother asking the question.'* (Sarah, FG2, line 612 & 619-622)

Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

Box 3 Take-home messages for HCPs

Focus group participants provided take-home messages about how HCPs, could deliver high-quality child-centred care:

1. *'Explain.'* (Laura, FG2, line 409) *'Explain it in a child friendly way.'* (Sarah, FG2, line 411) *'Because if the child is really young it has to be explained in a different way. At an age you're able to understand [or HCPs will] scare them.'* (Sarah, FG2, line 658-663)
2. *'They should explain what they are going to do before they do it, and like […] always say who they are and what they're gonna do […] [and at] what time […], and explain what was gonna happen and why […].'* (Rachel, FG1, line 498-510)
3. *'I think just tell everyone together. […] Because like telling your mum and dad first you'll see the expression on their face and then you're already gonna know.'* (Laura, FG2, line 651-654)
4. *'Always like ask [children] do you have any questions […] ask [to check understanding].'* (Sarah, FG2, line 388 & 416-417)
5. *'Whenever [children] come in, try and treat them like nicer, em.'* (Darren, FG1, line 992) *'Like treat them the same as everybody else so they all feel the same.'* (Rachel, FG1, line 993)

Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11-15 years)

DISCUSSION

CADs' experiences were influenced by HCPs forming relationships and involving them: engendering trust and involving CADs satisfied them, made them happier when undergoing procedures and treatments, and better able to confide. HCPs did this by being personable, wise, and sincere, relating at a personal level, bringing CADs into conversations and decisions, and speaking in child-friendly ways. Conversely, not relating to or involving CADs, communicating ineffectively by using inappropriately technical language or positioning CADs as 'piggy-in-the-middle' between HCPs and parents resulted in CADs being fearful, angry, resistant, and disengaged.

These findings add to earlier studies, which identified intimate relationships,[78,111,151] trust,[78] and involvement,[48,152] as important ingredients of caring well for CADs. They corroborate a recent systematic review of decision-making experiences, which found that HCPs (and parents) made adolescents feel fearful, anxious, and depersonalised when they withheld information or denied involvement.[152] Parents had a significant influence on HCPs' experiences in our study too, by facilitating or impeding communication. Overcoming parental primacy, over-involvement, over-protectiveness,[48,78,152] and wishes to withhold information remains a substantial challenge for HCPs.[78]

Strengths and limitations

Our synthesis advances understanding of CADs' experiences of HCPs because of its comprehensiveness, analysis of interrelationships between the nature, origins, and effects of trust and involvement, and its advocacy for CADs' autonomy. It provides a blueprint for CCC, which has, until now, largely depended on theory and expert consensus rather than empirical evidence.[8] Our findings endorse the concept and importance of CCC, whilst showing how much work is needed to put this principle into practice. Our review was innovative in the way it used phenomenology, a theory that is highly relevant to the topic, to inform a rigorous interpretive synthesis. This allows us to go beyond cataloguing publications and draw empirically supported conclusions about how HCPs could care more effectively for CADs. This, we suggest, is a significant contribution to the scholarship of evidence synthesis.

As with most qualitative syntheses, we present a broad overview, whose findings are potentially transferable across a range of clinical contexts. We took an iterative approach to article selection and ensured adequate time for rigorous interpretive analysis; while some evidence may have been published since we searched the databases, this is an inherent limitation in research that goes to such lengths to analyse a huge evidence-base and synthesise information. We doubt that this materially affects our conclusions since the nature of human relationships are unlikely to change in 12 months. Consulting with stakeholders, whilst obviously desirable, is often omitted from scoping reviews.[153] Our consultation sample was admittedly small and relatively homogenous, but participants spoke informatively about their experiences, which helped consolidate and authenticate the findings.

Our conclusions are susceptible to both publication and interpretation bias because more emotive material tends to attract greater attention. This limitation is partially offset by our rigorous adherence to methodological standards. Another limitation, imposed by the non-specific nature of studies and inexplicit reporting of metadata by primary authors, is that we could not analyse how different types of HCP, or participants' ages or illnesses, affected CADs' experiences. Restricting the scope to English language publications excluded non-English speaking children from distinct cultural groups. This is an important topic for future study.

Implications for policy, research, and practice

Our findings add impetus to the movement to design, deliver, and further characterise child-centred healthcare,[154] which has important implications for HCPs, educators, researchers, and policymakers. Our empirical augmentation of this conceptual model supports these initiatives. To achieve the vision of CCC, there is a need for communication strategies, training, assessments, and feedback (from CADs, specifically) at both the undergraduate and postgraduate levels of health professions education. Further research will be needed to address the long-term sustainability and effectiveness of CCC. Evidence on how healthcare policy, practice, and legislation can influence child-centred approaches is also long overdue. Further research could also examine how age, illness, gender, and the cultures of different professions influence the drive for CCC. Further implications for practice include the need for HCPs to examine how professional boundaries between themselves and CADs are characterized, and consider how best to respect CADs' preferences when it goes against 'best practice'.

ABBREVIATIONS

CADs- Children and adolescents

CCC- Child-centred care

CINAHL- Cumulative Index to Nursing and Allied Health Literature

FCC- Family-centred care

HCPs- Healthcare professionals

PCC- Patient-centred care

RBHSC- Royal Belfast Hospital for Sick Children

DECLARATIONS

Ethics approval and consent to participate

Ethical approval for focus groups was obtained from the Office for Research Ethics Committees Northern Ireland (reference: 19/NI/0070), while research governance was obtained from the Belfast Health and Social Care Trust, Northern Ireland. Queen's University Belfast (QUB) sponsored the study in accordance with the UK Policy Framework for Health and Social Care.

Consent for publication

Consent for publication was gained.

Availability of data and materials

All data are available in this article, or supplementary materials and open access repositories.

Supplementary materials

The content has been supplied by the authors.

Competing interests

None declared.

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Authors' contributions

GD conceived the review, sought approvals, secured funding, led the execution, and led the write-up. GD, AT & RC completed the focus groups. MK, RC, AT & TD assisted with data selection, analyses, and manuscript revision. All authors read and approved the final manuscript.

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Data availability

Extra data can be accessed via the Dryad data repository at http://datadryad.org/ with the doi: 10.5061/dryad.t76hdr817

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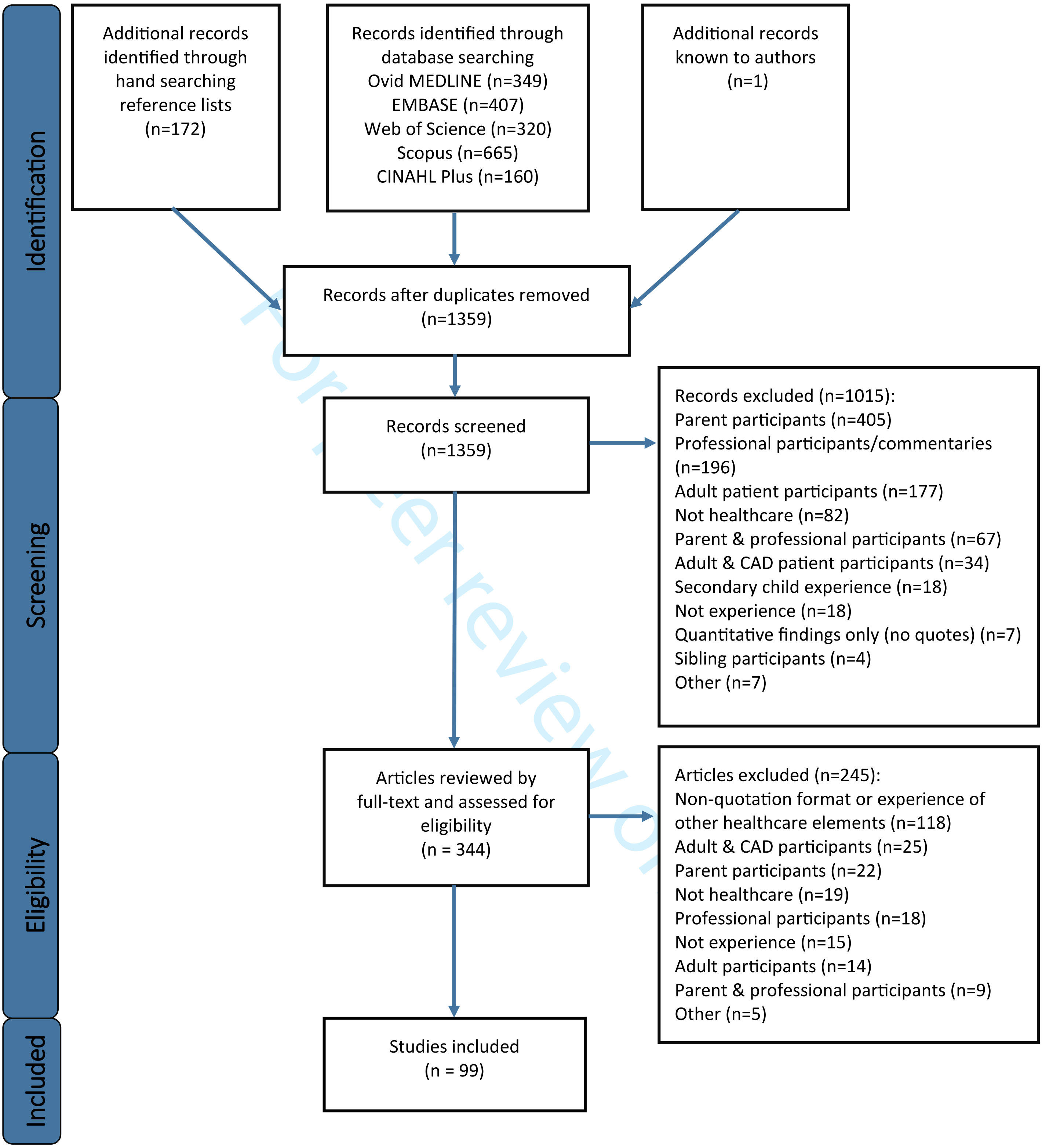
FIGURE CAPTIONS

Figure 1 PRISMA flow diagram



Note 'Other' (n=12) reasons for excluding records/articles included: participants' ages unclear (n=4); no full-text available or unobtainable in English (n=7); same study as included article (n=1).

PRISMA-ScR Checklist

This supplementary information includes the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (1).

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
TITLE			
Title	1	Identify the report as a scoping review.	p.1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	p.3-4, background not required in abstract as per journal guidance
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	p.6-8
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	p.8 & 9
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	p.9 and reference list. Not registered.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	p.9-12 (Table 2)
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	p. 9 & 10 (Table 1)
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	p. 9 & 10, Supp file 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	p. 10 & 11
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	p. 13 (box 2)
Data items	11	List and define all variables for which data were	p. 13

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE # (untracked version)
		sought and any assumptions and simplifications made.	
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Critical appraisal not done. Rationale on p.11
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	p. 13-15
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	p. 15 (Figure 1)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	p. 15 (Table 2)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	p. 15 (Table 2) & Dryad data
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	p. 15, 16, 23-26, & supp file 4.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	p. 29-30
Limitations	20	Discuss the limitations of the scoping review process.	P. 30-31
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	p. 31
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	p. 32

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

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MEDLINE search
1. health?care.mp.
2. Hospitals/
3. Community Mental Health Services/ or Mental Health Services/ or Community Health Services/ or Community Health Nursing/
4. School Health Services/
5. 1 or 2 or 3 or 4
6. Stress, Psychological/
7. Emotions/
8. emotion*.mp.
9. experienc*.mp.
10. 6 or 7 or 8 or 9
11. 5 and 10
12. limit 11 to "all child (0 to 18 years)"
13. ((child* or infant* or adolescen* or teen?age* or boy* or girl* or toddler*) adj5 (view* or opinion* or feeling* or emotion* or experience* or perception* or first?hand* or their* or say?in or decision* or choice* or choos* or autonomon* or interview* or art or "art* therap*")).mp.
14. 12 and 13
15. Qualitative Research/
16. 14 and 15

key: mp, multi-purpose search; adj5, search within adjacent 5 words.

Braun & Clarke 15-point Thematic Analysis Checklist

Process	No.	Criteria	Response
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'	Both focus group transcripts transcribed to an appropriate level of detail and checked against tapes.
Coding	2	Each data item has been given equal attention in the coding process	We reviewed all quotations to generate coding.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive	Themes, and the findings described herein, were developed from a complete coding process of the entire dataset. The coding process was thorough, inclusive and comprehensive, as all quotations were used to generate codes, and develop themes. Each theme was developed based on numerous codes gathered across a range of articles and participants quotations.
	4	All relevant extracts for all each theme have been collated	Yes.
	5	Themes have been checked against each other and back to the original data set	Yes.
	6	Themes are internally coherent, consistent, and distinctive	Yes.
Analysis	7	Data have been analysed- interpreted, made sense of- rather than just paraphrased or described	Yes, evident from the results.
	8	Analysis and data match each other- the extracts illustrate the analytic claims	The analysis and findings from it closely match the data set.
	9	Analysis tells a convincing and well-organised story about the data and topic	Yes.
	10	A good balance between analytical narrative and illustrative extracts is provided	Yes. Illustrative extracts have been used within the results section.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly	Yes.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated	Yes, stated in the methods section.
	13	There is good fit between what you claim you do, and what you show you have done- i.e. described method and reported analysis are consistent	Yes.

	14	The language and concepts used in the report are consistent with the epistemological position of the analysis	Yes.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'	Yes.

REFERENCE:

1. Braun V, Clarke V. Successful qualitative research: a practical guide for beginners. London: SAGE Publications Ltd; 2013.

Additional Scoping Review Results: Basic numerical analysis and figures

This supplementary information includes additional findings and graphical illustrations from basic numerical analysis.

Trend in study publications over time

On average, four studies were published each year and the rate of publication rose progressively, increasing to 11 per year in 2018 (as shown in Figure 1).

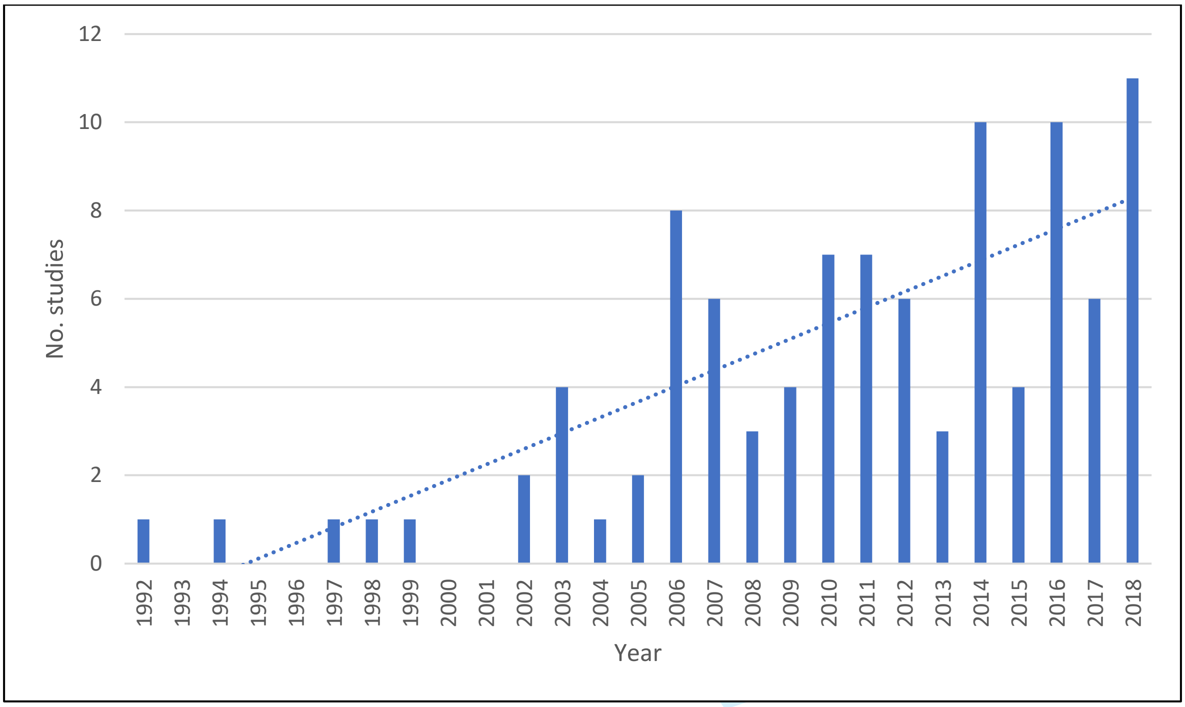

Figure 1 Years of publications

Countries of origin

Figure 2 illustrates the geographical distribution of included studies on the world map and figure 3 lists countries of origin (n=21) including the number of studies pertaining to each country. Eighty-eight studies originated in western or more developed countries of which the UK (n=26), Canada (n=15), Ireland (n=9), Sweden (n=9), and the United States (n=9) were most common.

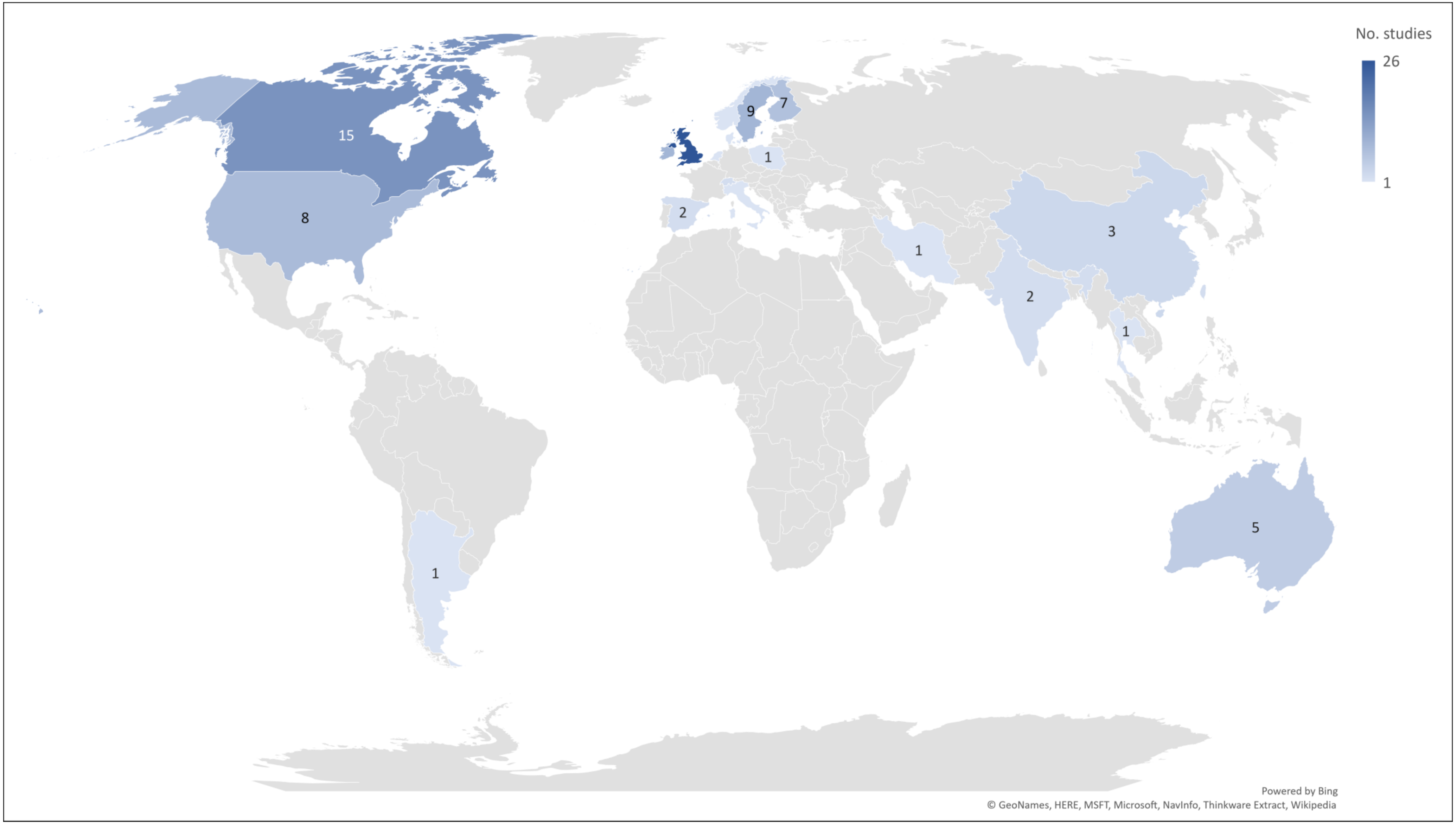

Figure 2 Map of geographical distribution of studies

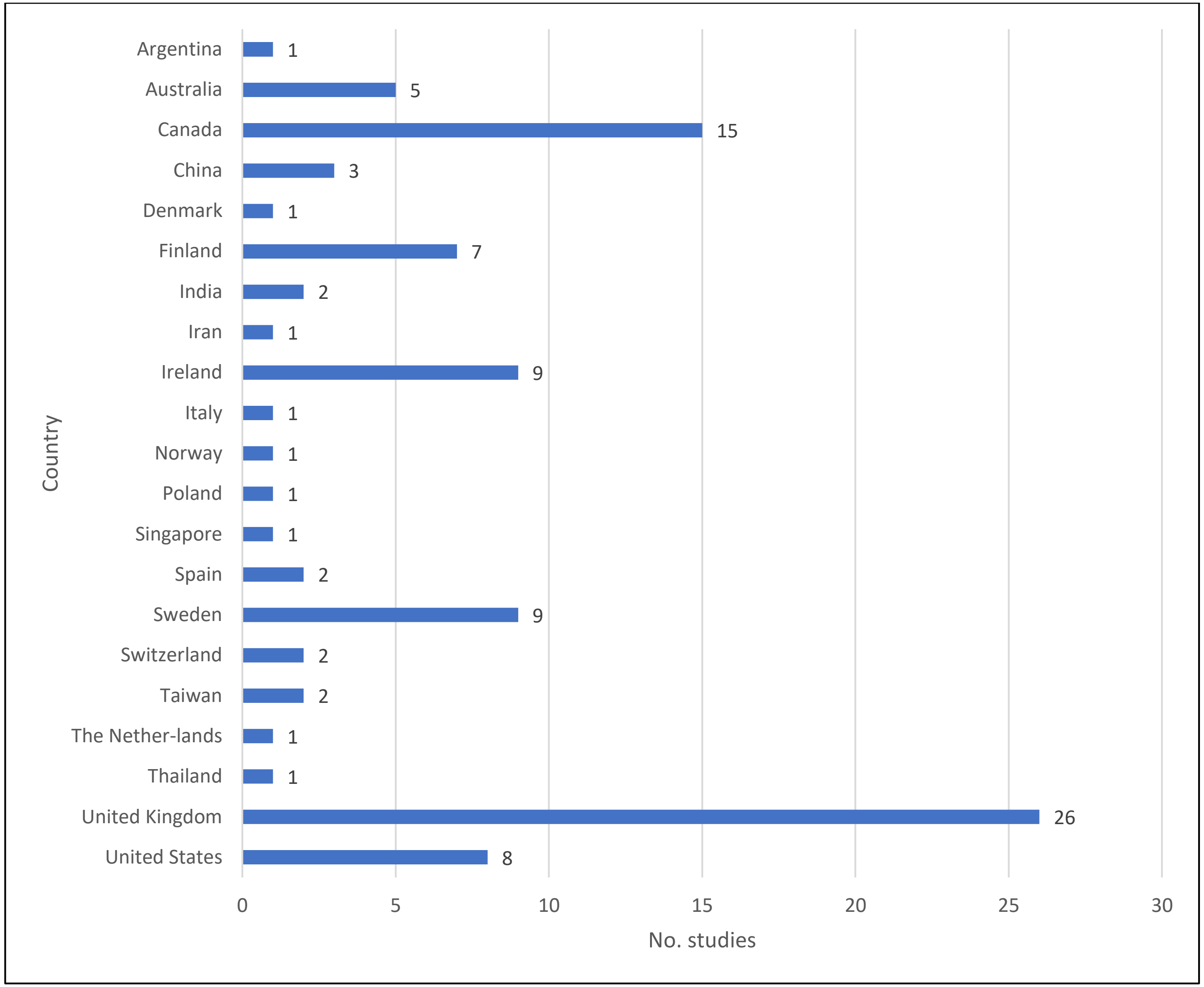

Figure 3 Number of studies per country

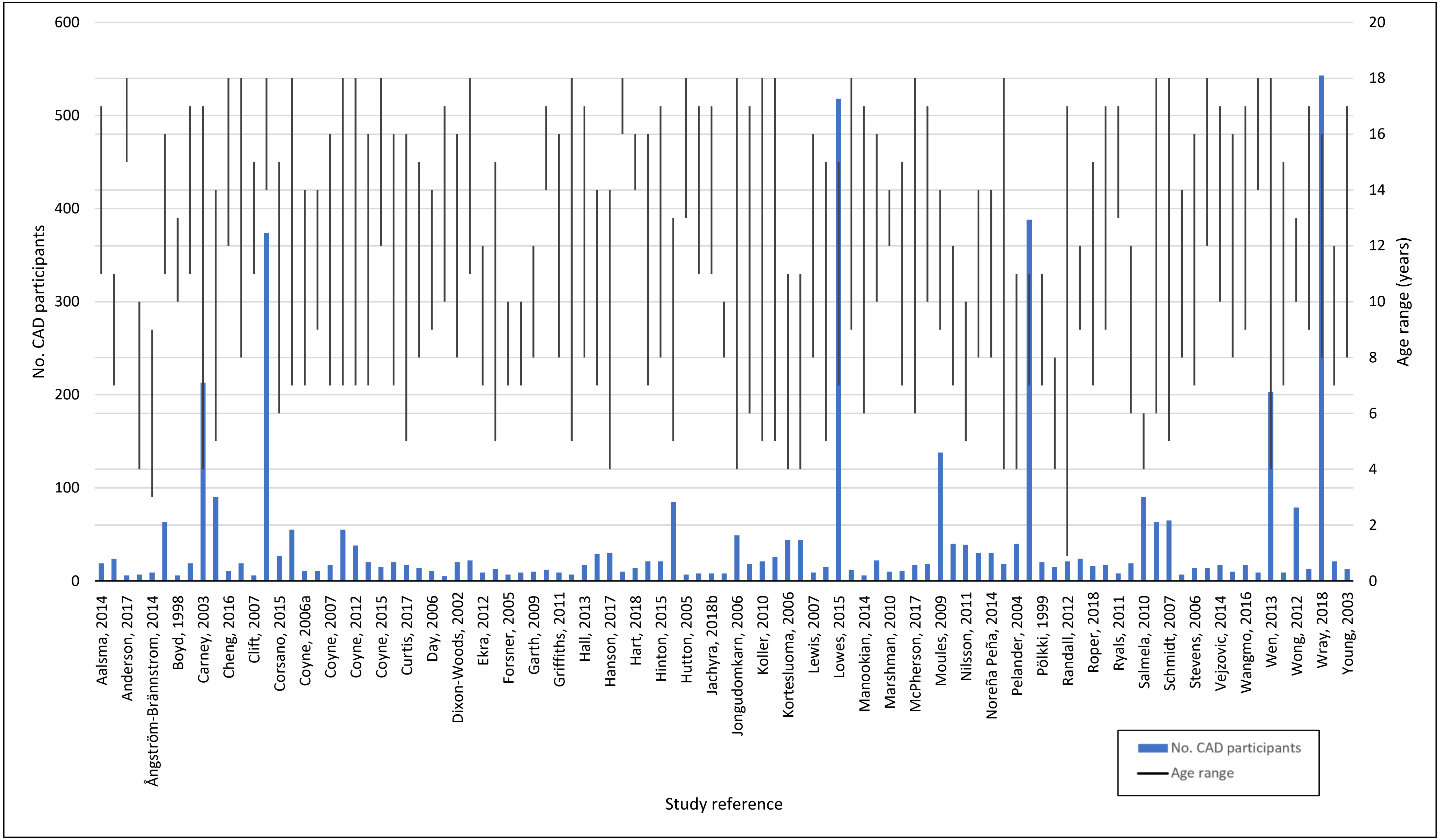

Figure 4 Number of CAD participants per study and age ranges

CAD participants

The number of CAD participants per study and age ranges are illustrated in figure 4. Age ranges varied, however, most studies recruited CAD participants aged 6-17 years. Studies tended to recruit between 8 to 50 participants; seven studies recruited over 100.

Additional participants

Most studies recruited CADs only (n=72). Some studies recruited other participants (n=27); who were parents, HCPs, and teachers (figure 5).

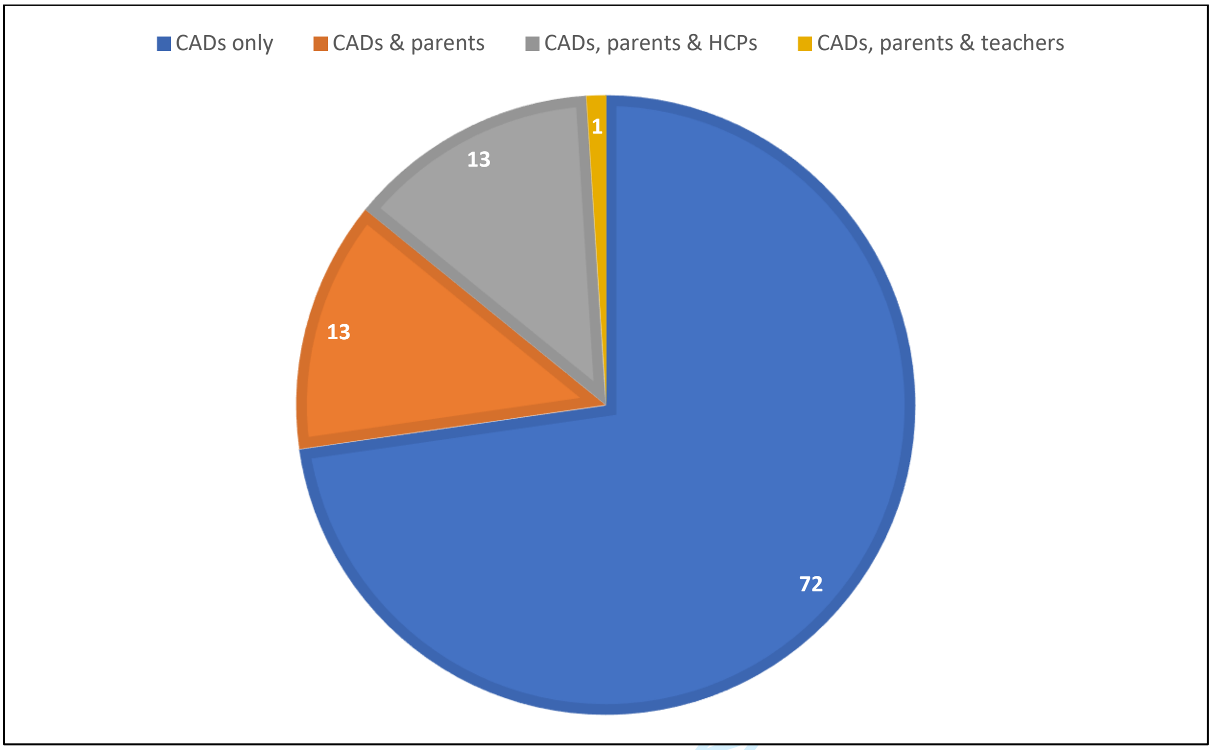

Figure 5 Study participants

Study methods

Most studies used a single method; interviews were most prevalent, followed by focus groups, free-text questionnaires, and workshops (figure 6). Twenty-nine studies used 2 or 3 methods; commonly, interviews combined with observation or focus groups (figure 7).

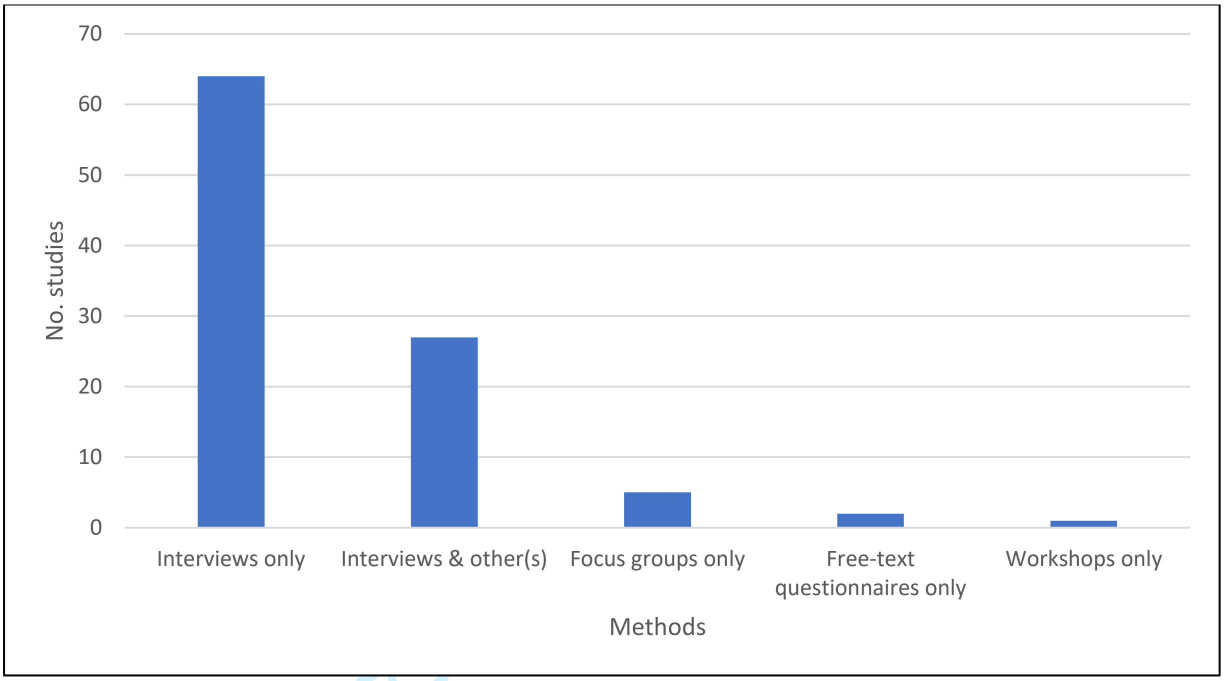

Figure 6 Methods classification

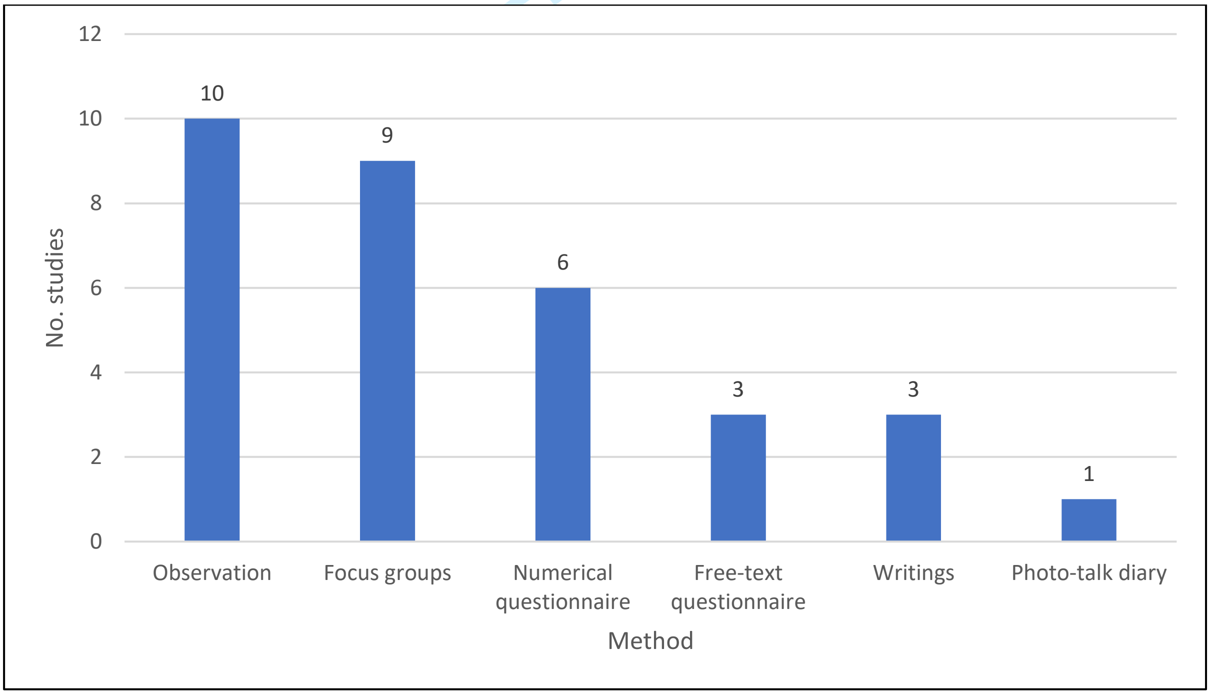

Figure 7 Methods conducted with interviews

CADs’ ages and genders from extracted quotes

Figure 1 illustrates the age distribution of quotations extracted. CADs aged 11-14 were more commonly quoted, while those aged 5-8 years were quoted less. Many quotations referenced CADs’ ages (n=379, 56.7%) and genders (n=390, 58.3%); of which 52% were female.

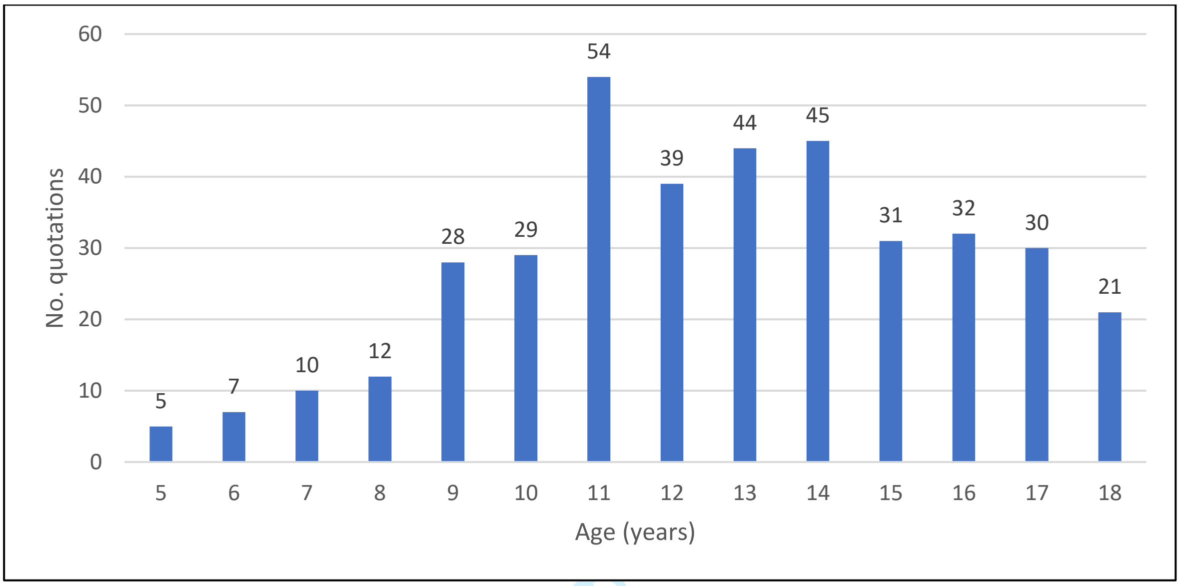

Figure 1 CAD participant ages, from extracted quotes

Quotations presented in results section

The full quotations extracted from articles are accessible using the Dryad unique identifier https://doi.org/10.5061/dryad.z08kprrc2

Quote no.	**Quote as written in results section**	**Quote reference (first author, year, quote no.)**
1	'bond'	Ryals, 2011(49)
2	'emotional attachment'	Brown et al., 2014(04)
3	'best friend'	Ryals, 2011(33)
4	'relate to'	Ryals, 2011(32)
5	'good care'	Ångström-Brännström et al., 2008(05)
6	'strangers'	Coyne et al., 2015(02)
7	'As time passed, […] we created that bond.'	Ryals, 2011(29)
8	'very smart'	Coyne et al., 2014(02)
9	'experienced'	Hodgins et al., 1997(02)
10	'[knew] what to do'	Day et al., 2006(04)
11	'[took] care'	Noreña Peña, 2011(21)
12	'everything the best they [could]'	Boyd, 1998(03)
13	'truthful'	Brown et al., 2014(15)
14	100% with you'	Brown et al., 2014(15)
15	'just [told] you straight up.'	Brown et al., 2014(15)
16	'not tell children any lies'	Koller et al., 2010(02)
17	'nothing [was] hidden'	Coyne et al., 2016(01)
18	'really nice'	Clift et al., 2007(06)
19	'nurturing, caring and helpful people who [were] there for you'	Schmidt et al., 2007(01)
20	'good sense of [humour]'	Schmidt et al., 2007(15)
21	'she knew what I was talking about, she knew what I was feeling, she knew how I was feeling.'	Ryals, 2011(20)
22	'took time to get to know'	Brown et al., 2014(06)
23	'real conversations, not just [HCP]-patient discussions'	Schmidt et al., 2007(31)
24	'down to earth'	Ryals, 2011(45)
25	'a lot in common'	Ryals, 2011(22)
26	'you gotta have trust.'	Ryals, 2011(42)
27	'satisfied'	Wangmo et al. 2016(05)
28	'happy'	Corsano et al. 2015(04)
29	'good memories'	Manookian et al, 2014(03)
30	'open up'	Ryals, 2011(42)
31	'tell anything'	Beresford et al, 2003(06)
32	'cure [the] illness'	Han et al, 2011(01)
33	'whatever happens I let them [HCPs] do what they have to do to help me get better.'	Boyd & Hunsberger, 1998(01)
34	'individually [they're] all heroes.'	Anderson et al., 2017(04)
35	'Because you can save people […] I'm going to be a children's doctor.'	Olausson et al., 2006(01)
36	'everything [was] always clear'	Schalkers et al., 2014(04)
37	'together'	Dell'Api et al., 2007(07)
38	'seriously'	Clift et al., 2007(05)
39	'as an equal'	Clift et al., 2007(05)

40	‘into all the conversations’	Coyne et al., 2011(15)
41	‘as much as they [talked to the] parents’	Edgecombe et al., 2010(03)
42	‘[breaking] the words down in an easier explanation’	Coyne et al., 2006(13)
43	‘listening’	Coyne et al., 2006(03)
44	‘I tell them I don’t want this and they … understand’	Coyne et al., 2006(03)
45	‘me because I know my own body, my parents because they know what’s best for me […] and the paediatrician because they are qualified.'	Garth et al., 2009(02)
46	‘most important, as in the end it is about [them]’	Schalkers et al., 2014(04)
47	‘brilliant’	Moules, 2009(01)
48	‘interesting and informational’	Lowes et al., 2015(02)
49	‘learn something new’	Lowes et al., 2015(03)
50	‘comfortable and confident’	Lowes et al., 2015(02)
51	‘make better decisions’	Coyne & Kirwan, 2012(23)
52	‘fully informed’	Coyne & Kirwan, 2012(23)
53	‘I’m asking the doctor more questions myself than having my Dad do it.’	Coyne et al., 2006(15)
54	‘nasty’	McPherson et al., 2018(03)
55	‘[seeming] that concerned’	Coyne, 2006b(02)
56	‘too busy’	Coyne et al., 2006(28)
57	‘big words’	Coyne et al., 2006(16)
58	‘they [HCPs] might ask me “is that ok” and they ask me in such a way that I kind of feel like I don’t have any other option but [to] agree with them’	Coyne et al., 2015(01)
59	‘behind the curtains’	Coyne et al., 2011(20)
60	‘in the middle’	Coyne et al., 2006(18)
61	‘you try to say something but then your parents just say shhhhh! […] They come out and say, […] did you understand that, you say no, they say, you should have asked them, and then you say, oh you didn’t let me, they say rubbish!’	Hawthorne et al., 2011(04)
62	‘rejected’	Coyne et al., 2006(17)
63	‘like a piece of machinery’	Coyne, 2006b(04)
64	‘hard to talk’	Anderson et al., 2017(01)