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

Gail Davison, Martina Ann Kelly, Richard Conn, Andrew Thompson, Tim Dornan

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, Cumulative Index to Nursing and Allied Health Literature (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 inpatient CADs 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.

BACKGROUND
Children’s experiences, like patients’ experiences in general, are of fundamental importance in healthcare. 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. 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’. Accordingly, PCC has become the dominant ideology in healthcare design and delivery. 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. CADs, therefore, typically experience healthcare as part of a family unit.

Strengths and limitations of this study
► Our findings have advanced current evidence by providing a comprehensive overview of children’s and adolescents’ (CADs’) experiences of healthcare professionals, 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.
► 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.


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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.

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. Recent research shows, however, that even within the FCC framework, parents and professionals tend to predominate and CADs struggle to be true participants. 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.

[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.

While aspects of FCC and CCC may be pertinent in different clinical contexts, experts now advocate a move towards CCC, 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), and could improve how CADs experience healthcare.

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 prioritising tasks, ‘getting the job done’, and mitigating, rather than engaging with, CADs’ demands. Furthermore, HCPs’ communication strategies adopted for consulting CADs are largely underpinned and conceptualised by biomedical or psychosocial models, from the perspective of the nature of being (theory of the nature of knowledge). As in our previously published research, 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 while 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.

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). As in our previously published research, 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 while 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.

Study procedures

The research followed a published protocol (accessible at https://rdcu.be/b2FFk), 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 and O’Malley,35 Levac et al36 and Colquhoun et al,37 adhering to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews reporting guidance (included in online supplemental file 1).41

**Table 1** STARLITE summary of search strategy

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

CINAHL, Cumulative Index to Nursing and Allied Health Literature.

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 emphasising 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 used the STARLITE mnemonic (sampling strategy, type of study, approaches, range of years, limits, inclusion and exclusions, terms used, electronic sources) and designed a 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 supplemental 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, Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus and Web of Science from inception to 11 January 2019. We included other articles found by searching relevant reference lists or found opportunistically.

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.

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 and 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 (ie, 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; and the interpretive synthesis used verbatim quotations, whose

**Box 1** Screening questions

1. Are the participants children and adolescents (CADs <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?
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, eg, Tjaden et al48).

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.

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 supplemental file 3).49 50 GD immersed herself in the data, reviewing all quotations on Microsoft Excel, using NVivo V.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

<table>
<thead>
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<th>Table 2</th>
<th>Eligibility criteria for article selection</th>
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<tr>
<td></td>
<td>A. Provisional</td>
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<tr>
<td>Inclusion criteria:</td>
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<tr>
<td>1. CADs speaking about HCPs, through first-person direct quotations.</td>
<td>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.</td>
</tr>
<tr>
<td>2. HCP defined as a member of a healthcare team.</td>
<td>2. A 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.</td>
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<tr>
<td>3. CADs defined as &lt;18 years old, regardless of health status or illness type.</td>
<td>3. CADs defined as ≤18 years, regardless of health status or illness type.</td>
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<tr>
<td>Exclusion criteria:</td>
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<tr>
<td>1. Adults aged &gt;18 years included in the study.</td>
<td>1. Adult patients aged &gt;18 years included in the study with or without CADs (as defined above).</td>
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</tbody>
</table>

CADs, children and adolescents; HCP(s), healthcare professional(s).
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.

While 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 epitomise these important themes in ways that could encourage HCPs to emulate favourable behaviours, we present predominantly favourable behaviours, but provide negative counter-examples to emphasise the breadth of CADs’ experiences. As in previous research,34 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 doing X’.

Step 6: stakeholder consultations

As recommended by Levac et al.,36 GD, AT and RC (with different ethics and governance approvals) recruited CADs aged 8–16 from inpatient wards in the Royal Belfast Hospital for Sick Children to two focus groups whose aim was to consolidate and elaborate on findings. Participants and parents chose whether parents should attend. We audio-recorded discussions and decisions and their unfavourable experiences were generally towards the opposite pole.

Child’s favourable experiences were of HCPs forming trusted relationships and involving them in healthcare discussions and decisions and their unfavourable experiences were generally towards the opposite pole.

Results

We identified 1359 articles, excluding 1015 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, 4448 CADs, aged 11 months to 18 years, participated. Most studies included 8–50 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 supplemental file 4.

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 to 18 years (average 13); male and female participants were equally represented (see online supplemental file 5). All quotations extracted are available at https://doi.org/10.5061/dryad.t76hdr817; quotations presented below are cited in online supplemental 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’.

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. CAD, child and adolescent.
## Table 3  Study characteristics

<table>
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<tr>
<th>Study details</th>
<th>CAD participants</th>
<th>Design</th>
<th>Methodology/analytical approach</th>
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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.
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 min respectively. Their medical conditions included type 1 diabetes, coeliac disease, spina bifida, and spinal/brain surgery. No parents attended. Three authors (GD, AT, and 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.

**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, trust, and involvement, 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. Parents had a significant influence on HCPs’ experiences in our study too, by facilitating or impeding communication. Overcoming parental primacy, over-involvement, over-protectiveness, and wishes to withhold information remains a substantial challenge for HCPs.

**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 policy-makers. 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 characterised, and consider how best to respect CADs’ preferences when it goes against ‘best practice’.

**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. Our findings endorse the concept and importance of CCC, while 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, while obviously desirable, is often omitted from scoping reviews. 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.
Table 4  Stakeholder findings: focus group participants’ experiences mapped to overarching themes

<table>
<thead>
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<th>Overarching themes</th>
<th>Forming trusting relationships</th>
<th>Being involved in healthcare discussions and decisions</th>
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<td><strong>Favourable experiences</strong></td>
<td>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 &amp; 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 &amp; 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)</td>
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<td><strong>Unfavourable experiences</strong></td>
<td>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 &amp; 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 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 &amp; 619–622)</td>
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Note: Rachel, Laura, Sarah, and Darren are pseudonyms (participants aged 11–15 years).
Box 3  Take-home messages for healthcare professionals (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)

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Collaborators None.

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

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