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TITLE PAGE

Title: Parents' learning needs and preferences when sharing management of their child's long-term/chronic condition: A systematic review

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Title: Parents' learning needs and preferences when sharing management of their child's long-term/chronic condition: a systematic review

Abstract

Objective: This review aimed to 1) identify parents' learning needs and preferences when sharing the management of their child's long-term/chronic (long-term) condition and 2) inform healthcare professional support provided to parents across the trajectory.

Methods: We conducted a literature search in seven health databases from 1990–2013. The quality of included studies was assessed using a critical appraisal tool developed for reviewing the strengths and weaknesses of qualitative, quantitative and mixed methods studies.

Results: Twenty-three studies met our criteria and were included in the review. Three themes emerged from synthesis of the included studies: (1) parents' learning needs and preferences (2) facilitators to parents' learning, and (3) barriers to parents' learning.

Conclusion: Asking parents directly about their learning needs and preferences may be the most reliable way for healthcare professionals to ascertain how to support and promote individual parents' learning when sharing management of their child's long-term condition.

Practice Implications: With the current emphasis on parent-healthcare professional shared management of childhood long-term conditions, it is recommended that professionals base their assessment of parents' learning needs and preferences on identified barriers and facilitators to parental learning. This should optimise delivery of home-based care, thereby contributing to improved clinical outcomes for the child.

1. Introduction

Children and young people (children) with chronic or long-term conditions (hereafter referred to as LTCs) often require treatment and care regimens at home for which their parents assume responsibility. Some parents of children with LTCs readily accept the clinical care-giving role and adapt to it by developing competent management styles that minimise the intrusiveness of conditions; others, however, experience difficulties and LTCs remain an unwelcome focus of family life [1-4]. Some parents are reluctant to acknowledge comprehension difficulties in case healthcare professionals (HCPs) consider them to be incompetent; others find the relentless requirements of home-based clinical care-giving difficult to maintain [4, 5].

While managing the child's clinical care, HCPs also act as teachers as parents develop the skills and knowledge to manage their child's condition at home [6]. Parents, who sometimes feel isolated and overwhelmed often look to clinicians for help, but HCPs may struggle to meet their needs when faced with no standardised way of assessing parents' needs and, for example, if parents' first language is not English or they have limited health literacy [7]. Although studies acknowledge issues such as normalisation [2], parents' beliefs that professionals do not collaborate with them [8], the 'work' associated with parenting [9] and how families adjust, there is little guidance to help HCPs individualise parent-teaching. Therefore, HCPs tend to rely on intuition when assessing parents' learning needs [4, 10]. However, these aspects of clinicians' roles are rarely articulated in the literature, so little evidence

exists on which to base parent-teaching interventions. If parents are unsure about the tasks needed for their child's management, they may not maintain treatment regimens or recognise subtle clinical changes [11], so negative clinical outcomes may occur with significant emotional, physical and financial implications for families [4, 10] and financial implications for health services [12].

The literature therefore, supports the conclusion that parents learn in different ways, have differing support and information needs, and adopt different ways of responding to condition management. However, there is a dearth of rigorously developed and psychometrically validated interventions for HCPs to use when assessing and addressing parents' learning needs and preferences. Given the increasing clinical responsibilities assigned to parents of children with LTCs, further evidence-synthesis is needed to inform the development and evaluation of such interventions. This paper reports on a systematic review of primary research that identified and explored published qualitative, quantitative and mixed methods studies to address the question: 'What are parents' learning needs and preferences when sharing management of their child's LTC?' The impetus for our review was to inform: HCPs' day-to-day practice; the undergraduate curricula for educating novice HCPs; and rigorous development and evaluation of interventions to routinely determine parents' learning needs and preferences.

2. Methods

The review followed the NHS (National Health Service) Centre for Reviews and Dissemination [13] and Cochrane mixed method methodology guidance [14] and included empirical, peer-reviewed research papers whose primary focus was on the learning needs and preferences of parents of a child with a LTC. The review was registered on the PROSPERO international database of prospectively registered systematic reviews in health and social care, registration number: CRD42014014106.

2.1 Search strategy

A search of relevant databases (AMED, BNI, CINAHL, Cochrane Database of Systematic Reviews, Embase, Medline, PsycINFO) was conducted during November 2013-January 2014. Search results were limited to articles reporting on primary research studies, published in English from 1990-2013. The search strategy was constructed to take into account the population, intervention(s), comparator(s), outcomes and study design (PICOS) [13]. The study steering group provided advice on the search strategy. A combination of Medical Subject Headings (MeSH) terms and keywords were used including: (chronic illness* or long term condition* or chronic disease) and (parent training or parent education or information need* or communicat*). The search strategy was modified to fit each database. Reference lists of included papers were hand-searched for relevant articles. In this review the definition for primary research is 'the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods' [15]. The definition for 'long-term condition' is: a) it occurs in childhood 0-18 years; b) diagnosis is based on scientific knowledge and established using reproducible and valid methods; c) it is not (yet) curable; d) it has been present for longer than three months or it will, very probably, last longer than three months, or it has occurred three times or more during the past year and will probably reoccur [16].

Initial screening of titles and abstracts against the inclusion criteria was conducted by one author (RN); following this, two of the authors (RN and VS) reviewed the eligible articles to decide which papers to include in the systematic review. A key question used to decide on inclusion/exclusion was whether the primary focus of the article was on parents' learning needs and preferences when sharing management of their child's LTC. Lead authors of two of the studies [17, 18] were contacted to seek clarification that the studies they reported on were primary research rather than quality improvement. As a result of their responses, one study was included [17] and one excluded [18].

2.2 Data extraction

Included studies were classified by study design into three streams: qualitative, quantitative and mixed methods [14]. Deductive data extraction techniques were used based on a predesigned template developed by RN. This included the following headings: reference, research question, study design, setting context and main findings. Each study was assessed by RN. Due to time and resource limitations it was not possible for a second reviewer to independently complete data extraction or check the data extraction forms for accuracy and detail [13].

2.3 Quality assessment

The quality of included studies was assessed using a recognised critical appraisal tool [19]. This tool can be used for reviewing the strengths and weaknesses of qualitative, quantitative and mixed methods studies, has clear criteria and instructions and comprises nine items which enable an assessment of the methodological rigor of each study. Each item examines a different aspect (e.g. method and data, sampling) and outlines explicit criteria for what is 'good', 'fair', 'poor' and 'very poor'. **For example, to score 'good' in the method and data section, the paper needed to describe the method appropriately and clearly (e.g. include questionnaires), whereas a 'very poor' score was indicated when there was no mention of the method and/or the method was inappropriate and/or there were no details of the data.** Each of these nine sub-scores can be added together to calculate a summed score which defines the overall quality of the study (0- 9 = very poor; 10-18 = poor; 19-27 = fair; 28-36 = good). Clarification regarding calculating the summed score was sought and provided through email contact with one of the tool's authors [19].

One author of the current review (RN) assessed the quality of 22 of 23 studies, whilst the other authors (VS and SF) assessed 8 of the studies (VS [n = 5]; SF [n = 3]). As VS was the lead author of three of the included studies, and one of these was co-authored by RN, neither VS or RN conducted critical appraisal of these three studies. **Of the seven studies whose quality was assessed by two authors, there was very good agreement between pairs of raters on the total scores (ICC = 0.95, 95% CI 0.75 to 0.99) and perfect agreement in terms of the gradings of the total score (Cohen's kappa = 1.00), thus demonstrating excellent inter-rater reliability.**

2.4 Data synthesis

A narrative synthesis was deemed an appropriate **method to synthesise data** as the review question led to inclusion of a range of research designs, producing both quantitative and qualitative findings. Narrative synthesis adopts a textual approach to

summarise and explain synthesis findings [13]. Guidance for narrative synthesis developed by the European and Social Research Council Methods Programme [20] was used to guide data synthesis. This guidance provides a framework, tools and techniques to increase the rigor, transparency and trustworthiness of the synthesis process. The flow chart in Figure 1 shows how the narrative synthesis framework, tools and techniques were applied in this review. **For example, RN started by producing a descriptive paragraph on each included study (textural description), used tabulation and organised the studies into groups/clusters to start identifying patterns across studies. This led onto exploring relationships within and between studies which involved using diagrams and flow charts (idea/conceptual webbing), and looking at how emerging concepts could be translated across studies. Finally the robustness was assessed through the quality assessment process described in section 2.3, and by reflecting critically on the synthesis process.** Some aspects of the framework, tools and techniques (Figure 1) outlined in the guidance were not used as they were not appropriate to the aim of the systematic review or for the type of evidence being synthesised.

3. Results

3.1 Included and excluded studies

The search strategy produced 1190 references, most of which were not specifically relevant to the review question; **for example they did not look at parents, children, LTCs or were not primary research. Additionally, a number of studies were excluded as their primary focus was on issues such as social support or parenting experience, not on parents' learning needs and preferences when sharing management of their child's LTC.** After assessment and deletion of duplicates, 23 studies were included in the systematic review (see Figure 2). Tables 1-3 provide a summary of each of the included papers, involving qualitative (n = 11), quantitative (n = 5) and mixed methods (n = 7) designs. Using a critical appraisal tool [19] to assess the quality of included studies, ten studies were assessed as good, eleven as fair, and two as poor; none of the studies were excluded from the review based on their quality assessment.

3.2 Narrative synthesis

Through utilising the framework, tools and techniques outlined in narrative synthesis guidance [20], three key themes emerged from synthesis of the included studies. Figure 3 provides an overview of the review's findings. The following three themes were identified and offer new understanding of the way parents learn to share management of their child's LTC.

3.2.1. Parents' learning needs and preferences

Figure 3 illustrates how parents' learning needs and preferences can be viewed in terms of their information needs, communication preferences, motives for wanting information and the information source. Although parents received information from HCPs about their child's condition, including its cause, treatment and prognosis [21], gaps in information provision were identified including psychosocial issues [22, 23], the child's future including fertility and social development [24] and research into the condition [21].

Though the content of HCPs' information provision was explored in some of the studies, only limited research is available which explores the processes by which information is communicated to parents. However, research which has been undertaken suggests that parents value receiving information in a variety of formats. Parents identified a need for information provision in both individual and group formats [25], for opportunities to meet other parents of children with the same condition [26] including those from a similar ethnic background [27], and wanted access to positive role models [25]. Information from HCPs needed to be available in various formats, including verbal, written [25], visual [10] and online [26]; however, regardless of format, it is crucial that information is accurate, current and accessible [25].

Various reasons were found to explain why parents wanted information; Hummelinck and Pollock [28] suggested parents' priority was to learn about their child's condition, daily management and treatment, but that information could offer reassurance, help them adjust to the future and establish control. It appears many parents were motivated to seek information to be able to answer other people's questions; however parents who were dissatisfied with information provision, sought information to ensure HCPs covered all aspects of the condition and were following recent research and recommendations [29].

Although the majority of information was provided by HCPs, parents sought information from other sources. Thon and Ullrich [23] suggest that most parents found information from HCPs to be more helpful than from other sources whereas Tetzlaff [30] found that parents' preferred source depended on the nature of information needed. Additionally, parents' choice of source was found to be related to the situation, as well as parents' experience, knowledge and level of trust in the source [26].

All included studies either explicitly or implicitly reported on the significant variation that exists in parents' learning needs and preferences. Parents' learning needs varied between individuals and over time [30]; for example, learning needs were shaped by the level of confidence that parents had in sharing management of their child's condition [28] as relationships with HCPs changed and as parents gained knowledge and competency in caring for their child [31]. The point on the child's disease trajectory was found to impact on parents' learning needs [26]; for example, diagnosis and other points which can be particularly stressful were viewed by some as times when detailed information should be limited due to the effects of stress on retention of information [32, 33]. Parents' learning needs varied depending on their child's age and stage on the life-course, including starting school, puberty and transition to adult health care [26, 27]. In contrast, Collier et al [24] found there were no significant effects on parents' learning needs over time or when their child's treatment changed; however, the focus of this study was on the amount, rather than the content of information, sought by parents.

3.2.2 Facilitators to parents' learning

HCPs having the knowledge and skills to teach was seen as central in facilitating parents' learning. The importance of tailoring information provision and teaching to individual parents' requirements [32] means HCPs can be required to: elicit parents' individual concerns, learning needs and understanding on an ongoing basis [28];

take into account parents' previous experiences and knowledge [33]; and take an interest in the family's whole life situation [26]. Use of various teaching methods and tools to support parents' learning was believed to be effective [34, 35]. This included combining verbal, written and audio-visual materials [33, 36], using dummies and vignettes [37] and demonstration [4]. In some situations, for example where parents were learning a practical task such as giving their child medication, it was suggested that documenting and evaluating parents' learning progress and achievements could help facilitate their learning [33].

HCPs developing good working relationships with parents [34], combined with creating a reciprocal atmosphere where parents would feel able to ask questions and express opinions [33], facilitated the process of teaching. Povlsen et al [27:41] suggested that with ethnic minority families it was useful for HCPs to ascertain parents' understanding of their child's condition and its 'impact on the family within the context of their cultural reality'. HCPs and parents discussing, and where possible sharing, concepts of LTCs, self-care and shared management was thought to facilitate parents' learning [34]. Some parents reported benefiting from meeting other parents of children with the same LTC [25] and from HCPs sharing anecdotes and anonymous examples of other families' learning [10, 34].

3.2.3 Barriers to parents' learning

In some studies HCPs' communication styles and teaching skills were barriers to parents' learning [4, 28]. Examples of such barriers included HCPs lacking the ability to have a dialogue with parents, only providing information verbally when additional written information and/or demonstration was needed [33], or being unable to adjust their teaching to parents' needs [27]. The challenge for HCPs of assessing parents' learning needs and communication preferences was highlighted, especially as these changed over time [17]. This means HCPs may not be aware of parents' needs and preferences, especially in the initial stages following diagnosis [34] when information provision and the formation of relationships is critical. HCPs may rely on their own 'tacit knowledge' to help determine how to pitch information [34], which can result in HCPs misjudging (often underestimating) parents' learning and information needs [28].

Limited time and resources could negatively impact on teaching; for example, inadequate time in clinic appointments meant HCPs focused on the child's clinical status rather than providing psychosocial information [32], and having received information, parents were unable to reflect and formulate questions [27]. Concerns were expressed about multi-disciplinary team (MDT) and multi-agency working, with parents experiencing poor information provision due to lack of communication within the team [38], resulting in information either not being provided at all, being duplicated [21], or information overload [28]. However, MDT working in renal services facilitated parents' learning as it provided multiple opportunities for interaction between HCPs and parents and for HCPs to feedback to the team about parents' understanding of their child's condition [34]. This variation in findings may be a result of differing study designs or be specific to renal MDTs.

As well as the processes used to communicate information, the content and amount of information provided could also impede parents' learning. Where information provision was inadequate, due to lack of detail, incomprehensible explanations or

being available too late [28], this could result in parents feeling anxious and confused [38]. Parents expressed concerns about the poor availability of psychosocial information [21] and information which focused on the 'disease activity' rather than the child and parents as people [25]. Hummelinck and Pollock [28] reported how some parents felt overloaded with certain types of information, yet struggled to find answers to their specific questions; this corresponds with the idea that due to scientific limitations, HCPs are not always able to answer parents' questions fully or with certainty [21]. Some parents who did have questions for HCPs, were reluctant to ask as they were fearful that it would be viewed as 'imposing' on the HCP, and felt the question was too unimportant [30] .

Some studies suggested parents from ethnic minorities and lower socio-economic groups could be disadvantaged in how HCPs supported them to learn to share management. For example, a clash was observed between HCPs and parents from Turkish and Kurdish backgrounds regarding views on parenting and LTC management, and HCPs would avoid raising certain topics as they thought they were not culturally relevant despite being relevant to the LTC [27]. Some studies found parents from lower socio-economic groups were less likely to be provided with information [32], yet had higher information needs [24], and parents with limited education could experience communication and comprehension difficulties during their interactions with HCPs [21]. This could explain why parents with a lower level of education benefitted more from a formal education programme about their child's asthma [39] as parents with higher levels of education may be more able to gain information informally and from various sources. Hummelinck and Pollock [28] found that if parents were not knowledgeable about their child's LTC, HCPs potentially considered them incompetent and not interested, and were therefore less likely to provide them with further information. Moreover, socio-economic factors were not predictive of parents' learning needs and this made information provision more complex as information needed to be individualised to each parent rather than directed to the 'average' parent [31]. However, the study sample appeared relatively homogeneous which could explain the findings regarding socio-economic groups and learning needs.

4. Discussion and Conclusion

4.1. Discussion

This systematic review has demonstrated that a diverse evidence base exists within the field of parents' learning needs and preferences when sharing management of their child's LTC. Through utilising a narrative synthesis approach [20] it was possible to summarise and explain the findings of the 23 heterogeneous studies included in the review. Three themes were identified: parents' learning needs and preferences, facilitators to parents' learning and barriers to parents' learning.

As Figure 3 illustrated, parents' learning needs and preferences can be viewed in terms of their information needs, communication preferences, motives for wanting information and the information source; however, the ways HCPs decide what information to provide and how to teach parents is an under-researched area. As a result, it can be challenging for HCPs to know the most effective ways to facilitate each individual parent's learning. Some studies included in the review indirectly explored this issue.

An association was found in some studies between parents' learning needs and 'external' factors that may relate to either the child or parent; these included the child's disease trajectory and age, and parents' ethnicity, socio-economic status and level of education. This suggests that if HCPs are aware of these factors, they would have a better understanding of a parent's learning needs and be able to adjust their information provision accordingly. **However, awareness does not necessarily lead to understanding, and understanding does not necessarily lead to behaviour change (in this situation presenting information differently); to promote this behaviour change, HCPs' educational curricula need to emphasise this information.**

Although there was some association between these 'external' factors and parents' learning needs, other factors which could affect parents' needs are more difficult to assess. These factors suggest HCPs make judgements, use intuition or rely on their own tacit knowledge to help determine how to pitch their communication [5, 34]. As outlined in section 3.2.1, parents' learning needs were found to change as their knowledge and confidence in managing their child's condition and relationships with HCPs evolved; however, there is no indication that HCPs have a robust way to assess these factors and determine parents' learning needs.

As a result of the difficulties associated with HCPs relying on tacit knowledge, parents' needs can be misjudged. As outlined in section 3.2.3, HCPs are more likely to under-, rather than over-estimate parents' information needs, resulting in a gap between parents' needs and the information they actually receive [25]. Sobo [17] suggests that HCPs' bias may also impact on the judgements made about a parent's learning needs and preferences

Several of the studies either directly or indirectly explored the concept that parents could be categorised according to their learning needs and preferences. Two studies [28] and [25], found some parents wanted to know 'everything' in relation to their child's LTC; however, some parents in another study demonstrated ambivalence towards information, reporting they wanted to know 'everything' but did not want to hear anything negative [30]. Parents self-rating their typology of information-seeking behaviour as either 'wait and see', 'information-maximiser' or 'submit to medical advice' was found to closely correspond with their measured level of information needs [22]; this suggests that asking parents' directly about their learning needs and preferences may be the most reliable way that HCPs can ascertain how to provide information and teach individual parents.

The conclusion that information provision and teaching should be tailored to the needs of individual parents when they are learning to share management was evident in many of the studies. Recommendations were made that HCPs could help parents to identify the information they require [27] by developing a profile of their individual needs [31], or through using questionnaires [24] and assessment tools [33]. Sobo [17] developed and piloted a tool to assess patients' and parents' information needs and preferred role in decision-making; however, it was not validated in further research or used in practice. A recent study of parents' learning to share care of their child with a chronic kidney condition [34] found there was no standardised tool to assess parents' learning needs and preferences, and to our knowledge, no

rigorously developed, piloted and evaluated, MDT tool is used in supporting any LTCs.

There are some potential challenges with assessing parents' learning needs; for example, parents may want to know more about their child's condition but be unsure what there is to know or what information they might need to manage the condition [28]. Additionally, some parents find it difficult to identify and predict their learning needs [40], because some needs can only be identified retrospectively or a certain amount of knowledge is required to understand what is unknown and to formulate questions [28]. HCPs differ in their own preferences for information-giving, even when parents' needs and preferences are known, so some HCPs may be reluctant, or require training, to adjust their teaching strategies [17]. Additionally, organisational barriers may prevent HCPs from adopting teaching approaches identified as helpful by parents [17]. **However, it is acknowledged that HCPs find it difficult to change their practice patterns without the support of the system in which they work [41]. Therefore, strategic attempts to change the wider health care systems may be needed to stimulate, facilitate and reinforce HCPs' understanding of the importance of assessing parents' learning needs and preferences.**

Despite these potential challenges, findings from an assessment of parents' learning needs and preferences could be used by HCPs to tailor their teaching to parents' individual needs. HCPs have expressed concerns that if parents are unsure about the information and skills required to share management of their child's LTC, they may not maintain treatment regimens or recognise subtle clinical changes [11], potentially resulting in poor outcomes for the child. This emphasises the importance of HCPs being able to base their information provision and teaching interventions on a robust assessment of parents' needs.

The quality of reviewed studies was variable, although the majority (21/23 studies) were assessed as either fair or good with only two scored as poor. Common limitations identified in the qualitative studies included unclear sampling strategies, limited descriptions of data analysis and poor consideration of ethical issues and bias. Among the five included quantitative studies, identified weaknesses included limited consideration of the existing evidence base, failing to identify gaps in knowledge and not adequately addressing ethical issues. The two studies given a poor rating used a mixed methods design; limitations included inadequate description of the methods used, inappropriate sampling strategies, and analysis methods which appeared to lack rigor. However, as four of the seven mixed methods studies aimed to develop and pilot an intervention relating to parents' learning needs, it is possible the focus of reporting was on evaluation, rather than intervention development. This highlights the issue raised by Hawker et al [19] that published papers reporting on primary research rarely provide enough details about study methods, resulting in quality assessment becoming a judgement on the quality of reporting.

At a review level, 22 of the 23 studies are from the UK, North America or Europe, suggesting there could have been bias towards western cultures, although one study explicitly examined the support and information needs of Turkish and Kurdish parents [27]. Cultural impacts on parents' learning needs and preferences is an area

where further research is needed. Many of the studies examined specific LTCs which may limit the generalizability and transferability of the findings; however, through using a narrative synthesis approach in our review, it was possible to explore the relationships between studies and identify common concepts [20].

Another potential bias is that only one author (RN) conducted initial screening and data extraction. To allay this limitation, other authors were involved in reviewing eligibility (VS) and quality assessment (VS and SF), with any discrepancies being resolved through discussion. The review was the first stage of a research study utilising a phased approach to develop and pre-pilot a complex intervention [42] to help paediatric renal MDTs individualise parent-teaching strategies; this potentially could have introduced bias into the review process as RN was simultaneously engaged in some aspects of the review whilst collecting data. However, this 'cross-fertilisation' could be viewed as a strength as it means the review, synthesis process and data collection builds on current knowledge. Though the search for eligible studies was systematic and thorough, as this is not a well-indexed field of research, it is possible that some relevant studies were not included. In addition, as database searches only focused on studies written in English, some relevant non-English studies may have been omitted.

4.2. Conclusion

This article presents a **systematic review** of qualitative, quantitative and mixed methods studies on parents' learning needs and preferences when sharing management of their child's LTC. **Three themes emerged from this review. First, parents' learning needs and preferences can be viewed in terms of information needs, communication preferences, source of information and motives for wanting information. Next, facilitators to parents' learning include HCPs skills in teaching and information provision, relationships with parents and tailoring teaching to the individual. Finally, barriers to parents' learning include HCPs lacking teaching skills, limited time and resources, HCPs not being aware of parents' needs and preferences, and too much or too little information being made available.**

Further research which explores the facilitators and barriers to parents' learning, how parents' learning needs change over time and the impact of 'external' factors such as the child's age, families' ethnicity and socio-economic status on parents' learning needs and preferences, would be beneficial. Future studies are needed which develop and evaluate interventions to assess parents' learning needs and preferences, with detailed reporting on both the development and evaluation processes to inform HCPs and researchers.

4.3 Practice Implications

To ensure that support provided to parents across the childhood LTC trajectory is based on the current evidence, the undergraduate and continuing professional development curricula for HCPs should be informed by the findings from this review. For example, HCPs may be better able to tailor support to parents' individual needs if they are aware of the importance of having a dialogue with parents and of providing written information or demonstration. Based on this review HCPs can be encouraged to elicit parents' individual concerns, learning needs and understanding on an ongoing basis,

taking into account parents' previous experiences and knowledge. In addition, the evidence presented here reinforces the importance of taking an interest in the family's whole life situation, thereby encouraging a family-centred approach and ensuring equitable support for parents who have developed competent management styles as well as those who experience difficulties with this.

Conflict of interest: The authors declare that they have no conflict of interest.

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Figure 1. Narrative synthesis process [20]

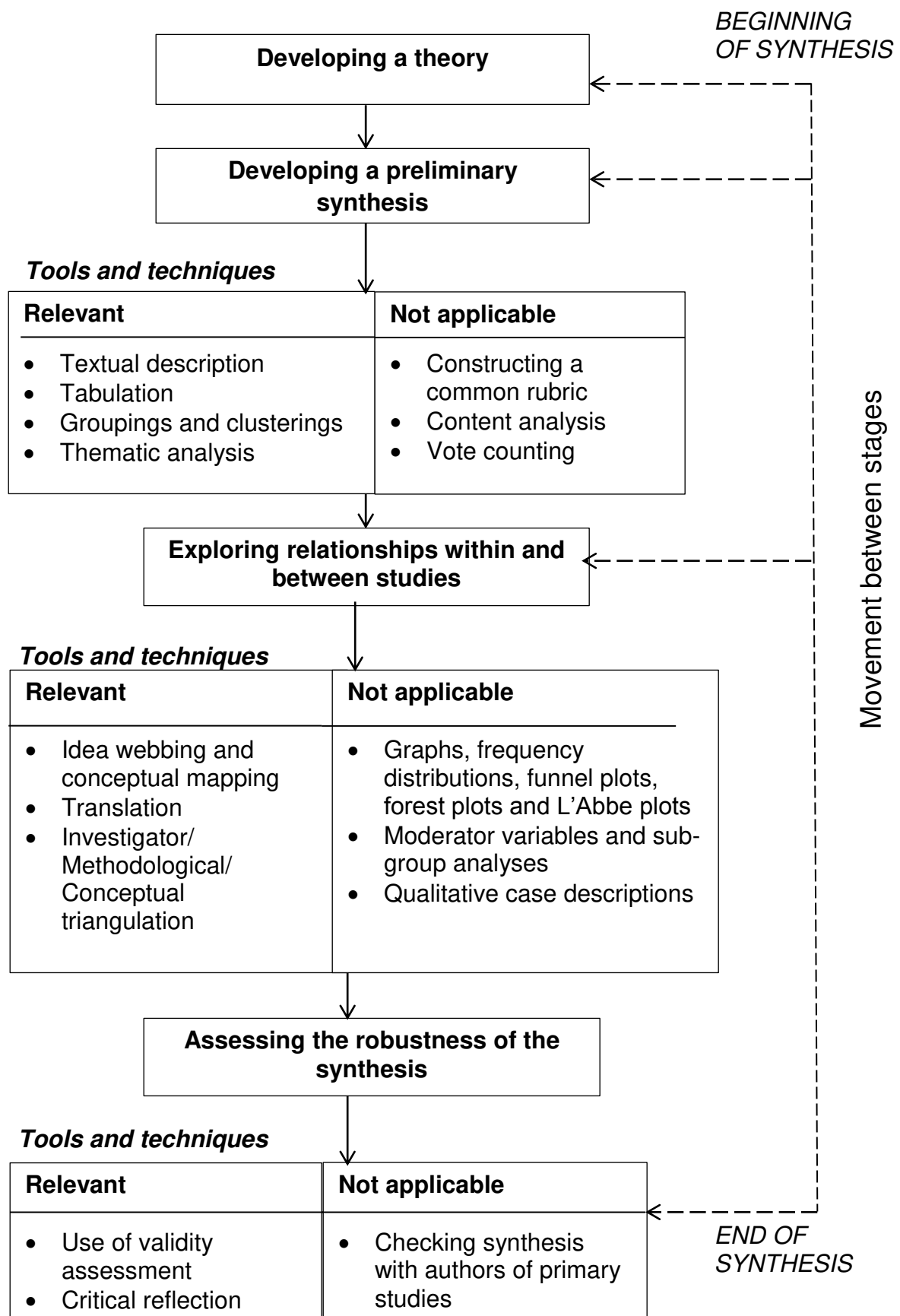


Figure 2. Study selection process

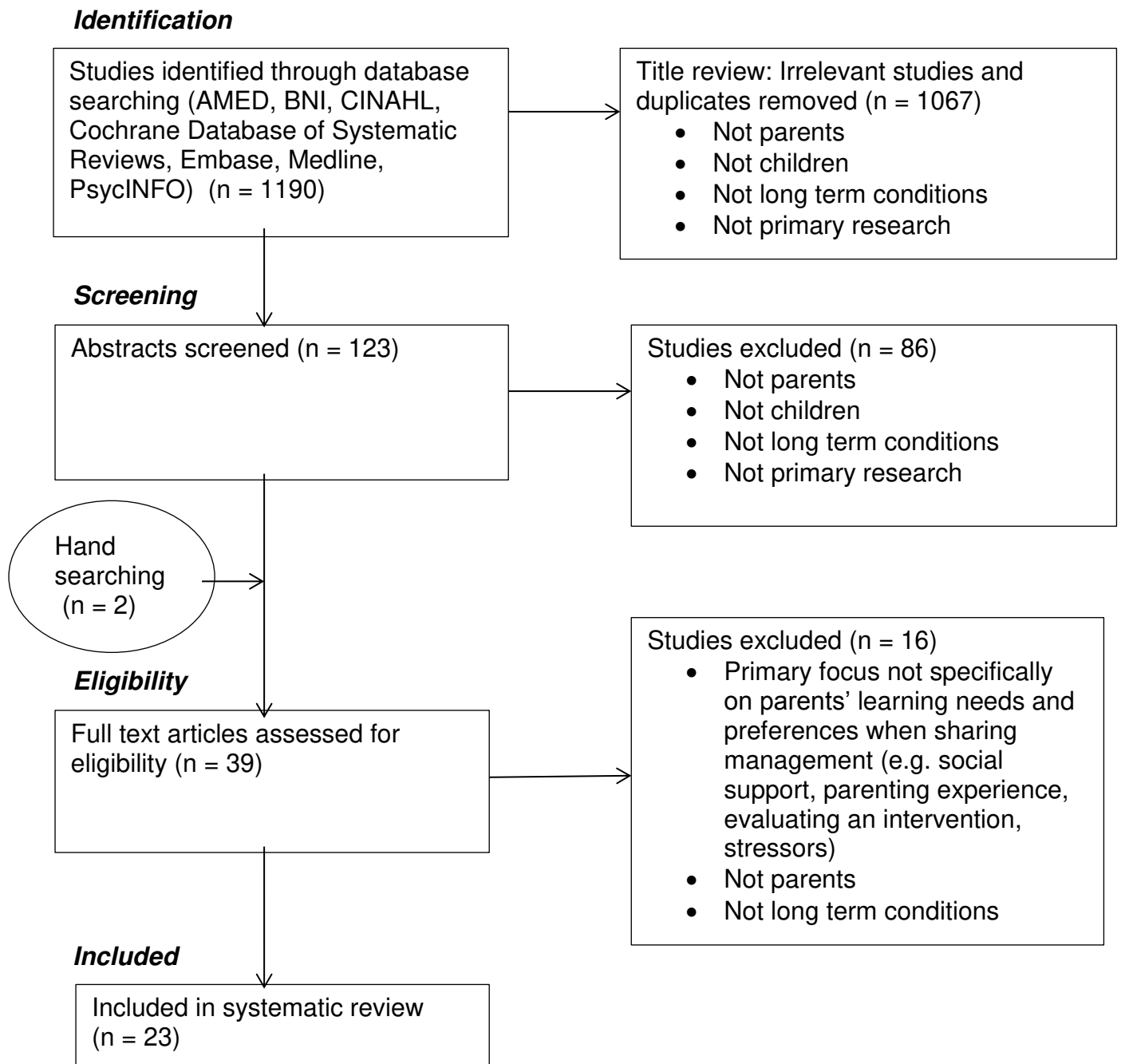


Figure 3. Overview of review's findings: parents' learning to share management of their child's long-term condition

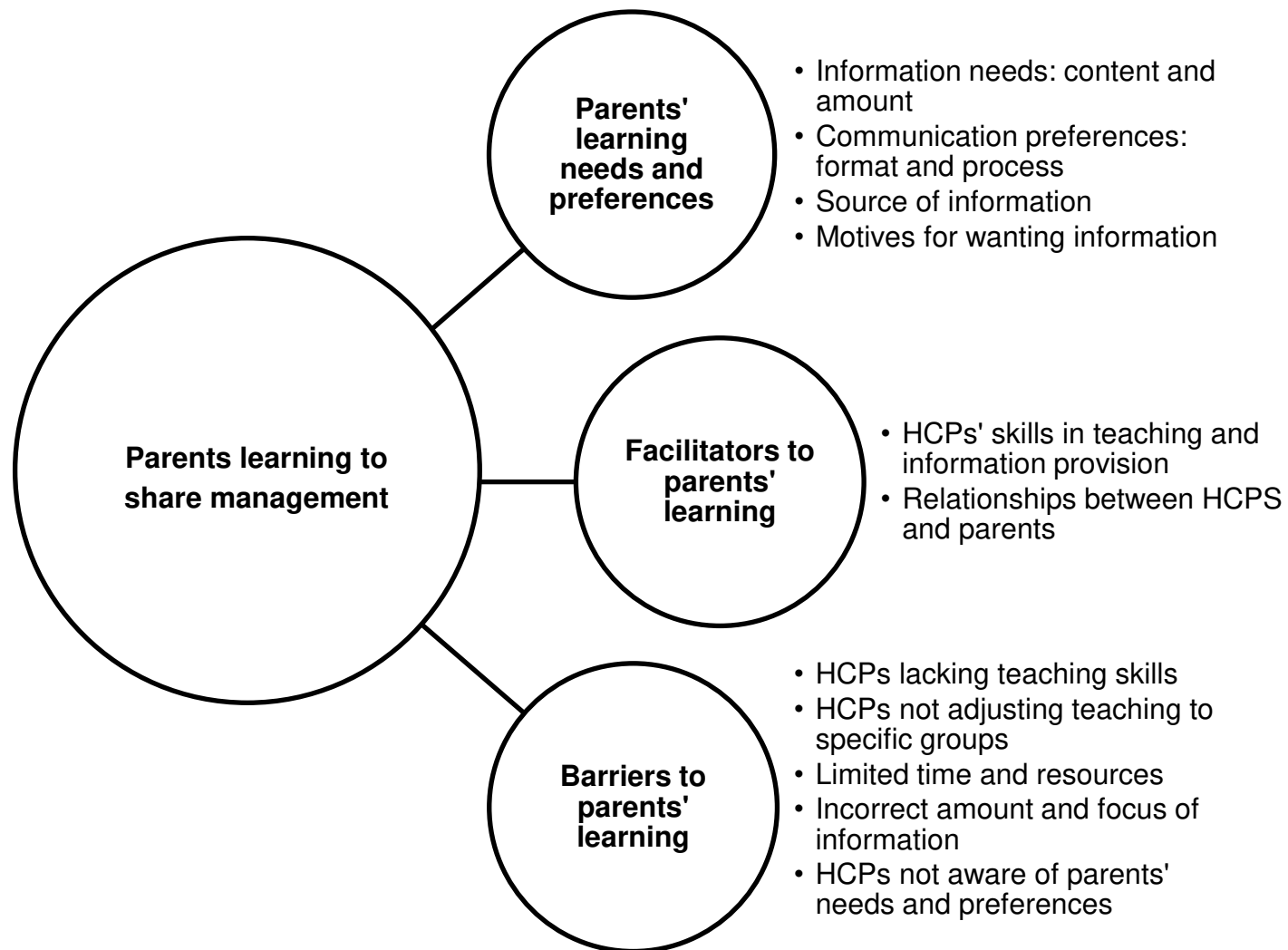


Table 1. Summary table of included qualitative studies

Reference	Research question	Study design	Setting context	Main findings
Barlow et al [25]	To gain insight into the needs and preferences of children and their parents, and examine how psycho-educational interventions may address these	Focus groups with a) 10 children b) 13 parents c) 7 HCPs	Juvenile chronic arthritis UK	Greater availability, easier access and more comprehensive psycho-educational interventions wanted. Education should be tailored to match disease severity, developmental age and stage in life course.
Hummelinck and Pollock [28]	To explore parents' information needs and how current information provision is evaluated	Qualitative individual interviews with 27 parents	Range of chronic conditions UK	Need for information varied between individuals and over time. Parents' varied information needs not always appreciated by HCPs.
Kelo et al [33]	To explore the elements of significant patient education events during hospital visits described by children and their parents	Qualitative individual interviews with 12 children and 19 parents	Type 1 diabetes, asthma, allergy, epilepsy Finland	Nurses require competence in 3 areas when providing education 1) nursing 2) didactic 3) interpersonal.
Mitchell and Sloper [38]	To investigate parents' definitions of good information provision and work with them to develop a model of good practice	Focus groups with a) 27 parents b) 5 health and social care professionals	Range of disabilities and chronic illnesses UK	Parents view good information practice as 3-dimensional and personally interactive; a combination of personal guidance/ information 'keyworkers', in-depth booklets and shorter leaflets/summaries.
Niedel et al	To examine how HCPs	Audio-recording of 55	Type 1 diabetes	HCPs use 4 strategies to enable parental self-

[35]	guide parents' acquisition of knowledge and develop expertise	consultations between parents and HCPs	UK and USA	management and development of expertise 1) setting expectations 2) trial and error 3) pattern recognition 4) pro-active management.
Nordfelt et al [26]	To explore parents' perceptions of their information-seeking, communication needs and internet use	Focus groups with 27 parents	Type 1 diabetes Sweden	Parents' information seeking varied greatly, associated with their life situation, child's development phases and disease trajectory. Trust in source of information was significant.
Povlsen et al [27]	To analyse how Turkish and Kurdish parents and HCPs perceive education provided and assess what was required to improve collaboration between families and professionals to optimise self-care	Case study design (11 families) 1) Individual interviews and focus groups with parents of 8 children 2) Focus group with 3 HCPs 3) Individual interview with 1 interpreter 4) Observation of educative group session with 3 children/ their parents 5) Review of 11 medical records	Diabetes Denmark	Useful to adjust education to promote better understanding of concepts of chronic illness and self-care. Need to ensure content of education is understood, implemented and maintained.
Starke and Moller [29]	To increase understanding of parents' need for knowledge regarding the medical condition of	Qualitative individual interviews with 44 parents	Turner Syndrome Sweden	All parents sought information to learn more about the condition; however, some parents motives for seeking information were to control HCPs actions or explain the condition to others.

their child

Swallow et al [4]	To explore how families learn to share management during the early stages of childhood chronic kidney disease	Family study design (6 families) 1) 36 qualitative interviews with children, parents and HCPs 2) 21 case-note reviews 3) 4 child/ family learning diaries	Chronic kidney disease UK	3 learning stages identified 1) dependent 2) co-dependent 3) independent. HCPs used various strategies to support parents' learning.
Swallow et al [10]	To explore nurses' contribution to families learning about shared management in childhood chronic kidney disease	Family study design (5 families) 1) 30 qualitative interviews with children, parents and nurses 2) 19 case-note reviews 3) 4 child/ family learning diaries	Chronic kidney disease UK	Nurses demonstrated 5 teaching activities 1) assessing learning needs 2) creating learning opportunities 3) implementing teaching strategies 4) acting as interpreters and ambassadors 5) assessing learning progress.
Weichler [40]	To explore the information needs of mothers of children who have had liver transplants	Qualitative individual interviews with 8 mothers	Liver transplants USA	Information needs change according to stage of transplant process and mothers' emotional response to situation.

Table 2. Summary table of included quantitative studies

Reference	Research question	Study design	Setting context	Main findings
Collier et al [24]	To evaluate information needs of parents	Survey repeated on 7 occasions over 2 years to 67 parents. Total of 302 questionnaires completed	End stage renal failure Diabetes UK	Need for information depends on child's age and parents occupation/ socio-economic status. Change in treatment mode had no effect on information needs.
Henley and Hill [32]	To assess global and specific disease-related information needs of children and their families	Cross-sectional survey with 114 parents, 18 children and 29 siblings	Cystic Fibrosis South Africa	Most family members wanted complete and comprehensive information about the condition (regardless of whether good/bad) and more about psychosocial issues.
Pyke-Grimm et al [31]	To determine parents' information needs and preferences for participating in treatment decision making	Cross-sectional survey with 58 parents	Cancer Canada	Concrete informational needs took precedence over information regarding emotional issues, family impact or pain. Socio-demographic, disease and treatment factors were not predictive of information needs.
Thon and Ullrich [23]	To explore parents' information needs	Cross-sectional survey with 116 parents	Juvenile idiopathic arthritis/ rheumatic diseases Germany	Parents' interest in further information was high, irrespective of amount of prior information provided.
Thon and Ullrich [22]	To explore parents' information needs and intervening factors such	Cross-sectional survey with 116 parents	Juvenile idiopathic arthritis/ rheumatic diseases	Parents identified deficits in information provision regarding psychosocial impact. Neither disease impact on the family nor the

as disease-related or
disease-unrelated
strain

Germany

presence and number of disease-unrelated
stressors had any influence on parents'
information needs.

Table 3. Summary table of included mixed methods studies

Reference	Research question	Study design	Setting context	Main findings
Mesters et al [39]	To develop and pilot a health education programme for parents of children with asthma	1) Focus groups with parents 2) Needs assessment study with HCPs 3) Pilot study to test education programme with 50 parents	Asthma Netherlands	Developing an education program which included various elements (e.g. providing written information, verbal discussion, checking understanding) was found to improve parents' knowledge, attitude, self-efficacy and self-management behaviours.
Patistea and Babatsikou [21]	To examine parents' perceptions of information provided to them about their child's leukaemia	Researcher administered questionnaire consisting of closed and open-ended questions with 71 parents	Leukaemia Greece	Parents wanted more information regarding psychosocial issues. Parents' level of education and previous experience with cancer correlated with amount of information received and satisfaction with it.
Sobo [17]	To develop a tool for HCPs to gauge parent's communication preferences	1) Focus groups with HCPs to review tool 2) 21 parents asked to complete tool and interviewed 3) Pilot study of tool with 79 parents/young people 4) Tool utility test: nurses asked to attribute answers to 51 parents/young people	Cancer USA	Challenge for HCPs of assessing parents' communication preferences especially as they change over time. The majority of nurses misjudged parents' communication preferences, and often underestimated parents' information desires.
Sullivan-	To evaluate the use of	1) Predevelopment	Type 1 diabetes	Learning self-management was a 2-phase

Bolyai et al [37]	a human patient simulator to teach parents' diabetes management for their child	group discussion with parents, HCPs and researcher (n = 6) 2) Focus groups with 13 parents 3) Pilot studies a) 1-group study with 10 parents b) 2-group study with 16 parents	USA	process 1) mechanical/ survival mode 2) more complex and abstract. Using a human patient simulator along with other strategies as part of parent education sessions was effective in increasing parent knowledge, self-efficacy etc.
Swallow et al [34]	To obtain an understanding of the way multi-disciplinary teams (MDT) support parents to undertake clinical care at home	1) Telephone survey to map 12 MDTs' parent-educative activities 2) Qualitative individual interviews and focus groups with 12 HCPs 3) 6 ethnographic case studies	Chronic kidney disease UK	Challenge for HCPs of how to share tacit knowledge. 3 patterns of patient-educative activity common across MDTs 1) engaging parents in shared practice 2) knowledge exchange and role negotiation 3) promoting common ground. HCPs used repertoire of tools to support negotiation with parents that helped them accomplish common ground.
Tetzlaff [30]	To explore the informatic requirements of parents in the home care of their child	1) Questionnaire sent to 14 HCPs and 10 parents 2) 2 nd questionnaire sent to 101 parents 3) Observations and video-taping of 6 sessions where a nurse teaches parents how to complete a dressing change 4) Observations of 6 parents using computer training and support system	Leukaemia USA	Parents seek information to solve problems and provide emotional support, which may create conflict of interest if material is threatening. Parents prefer live interaction to video, which was preferred to text when receiving information. The person they preferred to receive information from depended on the nature of the information.

Weichler [36]	To identify the information needs and concerns of parents of children who have had a renal or liver transplant	Questionnaire consisting of closed and open-ended questions with 21 parents	Liver and renal transplants USA	Parents' need for information varied depending on the phase of transplantation.
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