**Towards understanding problems in the parent-practitioner relationship when a child has cancer: meta-synthesis of the qualitative literature**

(Short title: Parent-practitioner relationship: meta-synthesis of the literature)

Sarah Davies[[1]](#footnote-1), Bridget Young[[2]](#footnote-2) and Peter Salmon2

**Abstract**

*Objective:* This review aimed to synthesise qualitative research on problems in the parent-practitioner relationship in childhood cancer, to understand how these problems arise, how they are conceptualised and how they might be resolved.

*Methods:* A systematic search of five electronic databases identified 2,863 articles. After screening, 81 full text papers were assessed for eligibility, and four were included in the review. Six further papers were identified through searching reference lists and citation tracking. Synthesis of these 10 papers drew on the meta-study approach, involving analysis, comparison and integration of findings, methods and theoretical influences.

*Results:* All papers but one conceptualised problems in the parent-practitioner relationship as conflict or relational problems, attributing these to differences between parents and practitioners in roles and perspectives, or in power and authority. The remaining paper focussed on parents’ emotional needs as the basis for relationship problems. Our approach to synthesis exposed researchers’ prior assumptions and the influence of these on the methods, analysis and findings of the studies.

*Conclusions:*

The current literature gives little attention to how interpersonal problems with practitioners may reflect the emotional needs of parents. Understanding these problems as an expression of the distress and fear parents experienced because of their child’s condition may offer new ways of helping parents. Future research needs to address the limitations of previous studies, including ensuring that the study design and analysis allow contextual factors and intrapersonal factors to be explored, and that researchers are open to their perspectives being altered by their data.

Key words: parent-practitioner relationship, cancer, oncology, problems, trust.

**BACKGROUND**

Research has highlighted the importance of relationships between parents and health care practitioners in the care of children with cancer [[1](#_ENREF_1)]. Difficulties in the relationship between parents and practitioners can complicate the child’s treatment and adversely affect parents during treatment and in the years that follow [[2-4](#_ENREF_2)]. Improved understanding of problems within the parent-practitioner relationship could contribute towards improving the experience of parents and their children during treatment for childhood cancer.

Parents of children diagnosed with serious illnesses have a distinctive role in clinical care contexts, with legal frameworks and social norms affording them the responsibility to adjudicate aspects of their child’s care [[5](#_ENREF_5)]. Compared to adult cancer patients, parents of children with cancer are twice as likely to prefer an active or collaborative role in treatment decision-making [[6](#_ENREF_6)]. Parents also have an important emotional role as the central source of comfort for children [[7](#_ENREF_7)], whilst needing to manage their own emotions at this time of crisis. The profound shock of diagnosis of cancer in a child and the accompanying fear that the child may die, combined with the demands of caring for the child, can impair parental mental health and quality of life [[8](#_ENREF_8)]. Some parents experience symptoms of posttraumatic stress following their child’s diagnosis of cancer, which can make it difficult for them to make treatment decisions and to provide emotional support for their child [[9](#_ENREF_9)].

Relationships with health care practitioners are important in supporting parents through their child’s treatment [[10](#_ENREF_10)]. Findings from a recent review of qualitative studies suggested that health care professionals do this by providing information, fostering a sense of control, individualising care, giving emotional and practical support, and recognising and addressing the particular needs of fathers [[11](#_ENREF_11)]. However, while this review reported that some parents were unhappy with the care received, it did not explore possible reasons for difficulties in the parent-practitioner relationship or how the difficulties could usefully be addressed.

Our review aimed to synthesise published qualitative studies that focussed on problems within the parent-practitioner relationship in order to understand these problems, including how they arise and how they may be resolved. Qualitative meta-syntheses encompass a collection of methods for reviewing published qualitative research studies to provide an interpretive integration of these studies’ findings [[12](#_ENREF_12)]. For this review, we selected the particular qualitative meta-synthesis technique of meta-study [[13](#_ENREF_13)] because it involves analysis of the methods and theory, as well as findings, of qualitative research [[13](#_ENREF_13)]. Meta-study therefore lends itself to exploring how authors’ assumptions and methods have influenced the research, including its scope, framing and findings.

**METHODS**

**Literature search**

The following electronic databases were searched for relevant published literature: PsycINFO, Medline, Scopus, Web of Knowledge and CINAHL Plus, as these were the most relevant for our topic. We performed the literature searches between January and June 2015, having first conducted several scoping searches to refine the final search strategy. As the scoping searches indicated that the number of relevant studies was small, we did not apply year limits so searches dated from the inception of the databases. We identified papers which included terms in the article title, abstract or keywords from each of the following categories: (i) parent, (ii) doctor, (iii) cancer, together with one of the following categories: (iv) words describing the process (e.g. relationship, communication), (v) words describing parental psychological state (e.g. emotions, cognitions), (vi) words describing negotiation of power (e.g. authority). Specific search terms are presented in Table 1. We did not use filters for qualitative research, as these have not been validated[[14](#_ENREF_14)].

One author (SD) conducted the searching, screening and subsequent full-text review of studies, while regularly discussing her work with the other two authors. Records retrieved from each of the databases were combined and duplicates were removed. Screening of titles and abstracts focussed on identifying articles that reported on qualitative studies of the parents’ perspectives on the parent-healthcare professional relationship or communication in childhood cancer. We retrieved full texts of screened articles and retained those meeting the following inclusion criteria: were written in English; reported empirical qualitative data generated by methods such as interviews or focus groups; explored the relationship between parents of children treated for cancer and their child’s health care professional; and focussed on parents’ reports of problems in the relationship between themselves and their child’s health care professional. We identified further papers that met the inclusion criteria by searching the bibliographies of included papers, and by using Scopus and Web of Knowledge to conduct citation searching of the included papers and to search for additional papers by the key authors of the included papers. As all authors consulted periodically during screening and full text reviewing we cannot report levels of agreement on inclusion and exclusion. However, a second author checked the full texts of all included papers and a sample of excluded papers against the inclusion criteria. Figure 1 illustrates the process and results of the literature search, screening, and the review of titles, abstracts and full texts.

**Analysis procedure**

Using the meta-study approach [[13](#_ENREF_13)], SD led the data extraction, analysis and synthesis of the primary research studies, meeting regularly with BY and PS to review and discuss the process and the developing synthesis. The analysis and synthesis was inductive, and focussed on three elements: meta-data analysis (the findings), meta-method analysis (rigor of research methods, as well as influence of methodological characteristics) and meta-theory analysis (key theoretical influences). Data relevant to each of the three elements, which were not confined to the methods and results sections of papers but could appear in the introduction and discussion too, were extracted into notes and these are summarised in Table 2. Our summary of data analysis methods was influenced by how clearly the authors of the papers had described their analyses and therefore involved interpretation on our part where details were unclear. We categorised the methods of analysis according to whether these appeared to be descriptive, indicated by thematic coding, or interpretive. In making these categorisations we looked for evidence of a contextualised analysis (e.g. that the authors had attended to participants’ use of language, and to what was absent or given little emphasis in their accounts as well as what they emphasised). Whether analysis was deductive or inductive was also noted to identify whether researchers used pre-existing concepts or pre-defined codes to categorise data, or allowed these to develop from the analysis of parents’ accounts. Reflecting the diverse ways in which quality is understood in qualitative research, and the lack of consensus about quality criteria and how these should be applied to the review of qualitative research [[15](#_ENREF_15)], we did not exclude papers on the basis of poor quality [[16](#_ENREF_16)]. Nevertheless, we did appraise the methodology of the studies and this appraisal informed our synthesis. Finally, the three elements of the analysis were synthesised through discussion within the team. This synthesis went beyond just summarising the content and findings of the studies, to interpreting how authors’ use of theory and methodology influenced the reported findings [[13](#_ENREF_13)].

Reflecting the principles of meta-study, it is important to outline our disciplinary backgrounds as authors of this review and how our assumptions may have influenced this review. As psychologists, we are clearly influenced by psychological theory. Additionally, two of the authors have worked clinically with patients and their families, helping to address mental health difficulties. As such we assume that intrapersonal as well as interpersonal factors are important in understanding how people experience services and their interactions with health professionals. Whilst being aware of these assumptions, in conducting the literature search and review, we aimed to explore theoretical approaches from a range of disciplines.

**RESULTS**

The final data set for review comprised 10 papers. Of these, four papers reported data that were drawn from four separate study samples, two papers reported data drawn from a single study sample [[17](#_ENREF_17),[18](#_ENREF_18)], and four papers reported data in various combinations and subsets that were drawn from two study samples [[10](#_ENREF_10),[19-21](#_ENREF_19)]. Therefore this review reports on 10 papers from seven studies. Key features of the ten papers included in the review are summarised in Table 2.

**Meta-data analysis**

Most authors explained parents’ accounts of problems in the parent-practitioner relationship in terms of interpersonal conflict or problems with health care practitioners. They understood the difficulties that parents reported as stemming from conflict of roles [[22](#_ENREF_22)], differences in perspectives [[17](#_ENREF_17)], or power and authority issues [[10](#_ENREF_10),[20](#_ENREF_20),[21](#_ENREF_21)]. The problems parents faced in dealing with health care practitioners were seen as adding an additional layer of suffering for parents who were already in an extremely stressful situation [[18](#_ENREF_18)], conceptualised as ‘surplus suffering’ by [Clarke and Fletcher [21]](#_ENREF_21). One paper diverged from this pattern, conceptualising problems in the parent-practitioner relationship intrapersonally, as an expression of the distress and fear that parents experienced linked to their child’s condition[[23](#_ENREF_23)].

Authors of the papers that conceptualised problems in the parent-practitioner relationship interpersonally focussed on parents’ reports of: difficulties with communication and information [[10](#_ENREF_10),[17](#_ENREF_17),[19](#_ENREF_19),[22](#_ENREF_22),[24](#_ENREF_24)]; how staff lacked empathy with their child [[22](#_ENREF_22)] and were unable to accommodate to parents’ efficacy and authority [[10](#_ENREF_10),[17](#_ENREF_17),[19-22](#_ENREF_19)]; clinical errors and incompetence of staff [[17-22](#_ENREF_17),[25](#_ENREF_25)]; and staff unkindness or lack of caring [[17](#_ENREF_17),[19-22](#_ENREF_19)]. Over time, such problems were seen to reduce some parents’ trust in the medical team, driving them to act as advocates in their child’s care [[19](#_ENREF_19),[21](#_ENREF_21),[24](#_ENREF_24)]. The authors of one paper pointed to how, for some parents, responding to conflict with health care providers by engaging in open confrontation had enabled parents to become more effective advocates for their child [[18](#_ENREF_18)].

As noted above, the authors of one paper gave a very different picture of the parent-practitioner relationship [[23](#_ENREF_23)]. These authors understood some parents’ accounts of difficulties in the relationship as arising from how they responded to the threat of their child’s illness. Most parents in this study were reported to have faith in their child’s doctor, and the authors linked this to parents’ need to maintain hope. Maintaining hope was understood as an interpersonal process in which parents and doctors both had a role. Having faith in the doctor allowed parents to hope by investing in the short term goals while setting aside longer term fears about the child’s survival. Only a small minority of parents in this study reported difficulties in their relationship with doctors. These parents’ doubt in their child’s doctor was linked to a difficulty in sustaining hope, arising from their feeling unable to delegate responsibility for their child’s longer term survival and well-being to the doctor [[23](#_ENREF_23)].

Few studies examined changes in the parent-practitioner relationship over time. One reported that parents were more likely to feel that their information needs were unmet during the later stages of treatment [[24](#_ENREF_24)]. Some papers linked lack of information to parents’ loss of trust in health care practitioners [[24](#_ENREF_24)] and their perceived need to advocate for their child [[18](#_ENREF_18),[19](#_ENREF_19)]. In contrast, one paper [[23](#_ENREF_23)] described how some parents developed faith in the doctors over time and moved towards trusting them. Nevertheless, for most parents in this study, trust in their child’s doctor was immediate [[23](#_ENREF_23)] and relatively constant over time.

**Meta-method analysis**

Reviewed studies had drawn on qualitative methods of data collection and analysis only, except for two which had also drawn on quantitative approaches [[22](#_ENREF_22),[25](#_ENREF_25)]. Qualitative methods were appropriate as the studies aimed to explore parents’ own experiences. This is a departure from most previous studies which have used quantitative methods to explore influences on parents’ coping (see [Grootenhuis and Last [26]](#_ENREF_26) for a review). Yet exploration of the methodological characteristics of the included studies indicated how methods may have influenced research findings.

As noted above, all but one paper [[23](#_ENREF_23)] focussed on how the difficulties parents experienced in their relationships with practitioners stemmed from the health care practitioners’ behaviour. The findings of these papers were presented in ways that tended to emphasise that it was common for parents to experience such difficulties. However, sampling procedures may have been influential here. Most samples in these papers were recruited from self-help or support groups for parents of children with cancer [[10](#_ENREF_10),[17-21](#_ENREF_17),[25](#_ENREF_25)]. It is possible that the sampled parents were drawn to such groups because of difficult experiences with health care practitioners or medical systems. Authors of these papers did not report attempts to sample for diversity, for example by seeking out variant cases such as parents whose relationships with health care practitioners had been more positive. One study which recruited participants through self-help groups reported that 56 percent of parents had found it necessary to intervene in their child’s medical care [[25](#_ENREF_25)]. This study reported a response rate of 49 per cent but the authors did not discuss how the sampling limitations may have influenced the findings.

Studies which did not rely on parent support groups but recruited participants via treatment centres reported different results. Only a few parents in one such study reported difficulties in their relationships with health care practitioners [[23](#_ENREF_23)]. In another study which also recruited from treatment centres, 40 per cent of parents indicated no problems with health care practitioners [[22](#_ENREF_22)]. In that study, parents having a higher level of education, children being older at diagnosis and the occurrence of relapse were all reported to be associated with increased parental reporting of problems in their relationships with health care practitioners [[22](#_ENREF_22)].

Studies had involved one-to-one or focus group interviews except for one self-report questionnaire study [[25](#_ENREF_25)]. In some studies, experiences explored in the interviews had happened years previously, raising the possibility that parents’ memories had altered over time. Only one study collected data at specific points in children’s treatment, enabling parents to discuss their most recent experiences, as well as allowing the researchers to make comparisons over time [[23](#_ENREF_23)]. Furthermore, the data had not been corroborated by observation or recording of interactions with health care practitioners except in one study which audio-recorded parents’ consultations with doctors [[23](#_ENREF_23)].

Difficulties were also evident in the data analysis of some studies. Presentation of some findings indicated differences between the stated methodological intentions and their enactment. For instance, within one set of papers reporting data from two study samples or subsets of them, a range of methods were listed, including semi-phenomenological qualitative analysis [[20](#_ENREF_20)], qualitative content analysis [[19](#_ENREF_19)], thematic analysis [[21](#_ENREF_21)] and narrative method [[10](#_ENREF_10)]. However, the presentation of the findings in all four papers seemed more consistent with thematic analysis - identifying recurrent themes and organising data into thematic categories. Indeed, the methods used in most papers appeared to be descriptive. It is questionable whether such methods allow nuances in parents’ accounts to be conveyed, whereas being more interpretive - attending to how parents talk about their experiences - might identify processes that underpin their experiences.

While most studies seemed inductive, two were clearly not [[17](#_ENREF_17),[18](#_ENREF_18)]. In one of these, data were coded and categorised using a pre-developed framework of strategies for dealing with conflict [[18](#_ENREF_18)]. Similarly, the other [[17](#_ENREF_17)] used a pre-existing conceptual framework to categorise sources of conflict. The researchers’ assumptions which had led them to select these frameworks were therefore not exposed to challenge by the data.

Indeed, none of the researchers made their assumptions explicit. There were some clues to these assumptions in the stated aims of research, such as in papers which set out to explore parents’ experiences of *conflict* with health care practitioners [[17](#_ENREF_17),[18](#_ENREF_18)]. The absence of clarity around researchers’ assumptions does not allow for consideration of how those assumptions may have influenced the data collection and analysis process.

Two authors were parents of survivors of childhood cancer and authored over half of the papers in this review [[10](#_ENREF_10),[19-22](#_ENREF_19),[25](#_ENREF_25)]. While their experiences as parents are likely to provide in-depth personal insight into the issues discussed, these authors did not report having reflected on the extent to which their experiences had shaped their research questions and interpretation of findings. One commented that her own experience of having a child with cancer had prompted the study to help her to understand her family’s own experience [[21](#_ENREF_21)]. However, she did not consider how her experience might have shaped the study findings. One interviewer who was the parent of a survivor of childhood cancer described having shared her own experiences with interviewees. The interviewer was passionate about enabling parents’ stories to be told [[10](#_ENREF_10)], but the possibility that this may have influenced parents’ responses was not acknowledged.

Similarly, none of the remaining papers considered the influence of the researcher’s role and how this might have shaped the data collected. A nurse had acted as focus group moderator and interviewer [[24](#_ENREF_24)] in one study and, while it was unclear whether or not he was a member of the participants’ healthcare team, the potential influence of his professional role on the data was not discussed. From the perspective of parents, sharing their views of health care professionals with someone employed in such a role might have been uncomfortable and this may have influenced their responses.

**Meta-Theory**

Most studies pointed to a lack of clarity of roles between parents and practitioners as a factor underlying the problems experienced by parents. Some authors presented problematic interactions with health care practitioners as symptoms of this lack of mutually negotiated roles [[10](#_ENREF_10),[21](#_ENREF_21),[25](#_ENREF_25)]. Difficulties in communication between parents and health care practitioners were understood as resulting from power and authority issues; for instance, parents being responsible for their child yet lacking in authority over the child’s health care [[19](#_ENREF_19)], parents knowing their child best but doctors knowing medicine best [[10](#_ENREF_10)], or parents becoming involved in medical care as a means of maintaining their parental role [[25](#_ENREF_25)]. Findings suggested a need to address communication, responsibility and authority among health care professionals and parents [[10](#_ENREF_10)]. Recommendations for practitioners based on these proposals included clarification of mutual roles and responsibilities [[20](#_ENREF_20)], improved information provision [[24](#_ENREF_24)], acknowledgement of the knowledge, resources and perspectives of parents [[10](#_ENREF_10),[19](#_ENREF_19)], allowing parents a more active role in the child’s care [[25](#_ENREF_25)], and improved rights for parents [[19](#_ENREF_19)].

Authors were mainly from nursing and sociology backgrounds and drew upon theories from these domains, in particular a discourse of doctor-patient relationships shaped by power, dominance and oppression that has been prominent for many decades [[27](#_ENREF_27)]. A corresponding focus on inequality in power, authority and knowledge appeared to have shaped much of the research, and was visible in the conclusions about the need to empower parents. Some authors argued that conflict with practitioners led to parents benefitting by becoming more effective advocates for their children [[18](#_ENREF_18)]. However, one study [[24](#_ENREF_24)] concluded that parents felt burdened by the need to inform different health care practitioners about aspects of their child’s care, were reluctant to take this role and wanted health care practitioners to be the experts [[24](#_ENREF_24)].

Few authors had psychology backgrounds and this was reflected in the limited consideration of psychological models that offer different understandings of the parent-practitioner relationship. Unsurprisingly, the influence of parents’ psychological state was not considered, with the exception of one study [[23](#_ENREF_23)] which discussed the role that parents give to doctors in trying to sustain hope. In this study [[23](#_ENREF_23)] the authors applied attachment theory to understand the internal world of parents when their child has cancer. According to attachment theory, when an individual is under threat, attachment behaviours are activated and safety figures are sought. Authors drew also on the psychoanalytic concept of projective identification to understand why a few parents were unable to fully trust their child’s oncologist whereas most did so automatically. Authors considered that some parents may project their hopes and fears onto health care practitioners [[23](#_ENREF_23)].

**DISCUSSION**

This review aimed to illuminate the problems that arise in parents’ relationships with their child’s health care practitioners during treatment for childhood cancer, in order to inform ways to understand and resolve these problems. Due to the descriptive nature of most studies we still know little about the processes underlying the problems that can arise in the parent-practitioner relationship. Instead the approach to synthesis undertaken in this review exposed the potential influence of researchers’ prior assumptions on their methods and therefore their findings.

The predominant finding that problems in the parent-practitioner relationship are due to power imbalances appears to reflect theoretical positions that focus on dominance and conflict. Moreover, it is likely that sampling procedures which relied on self-help or support groups for parents resulted in a lack of diversity within samples, and participants who were perhaps more likely to endorse researchers’ underlying assumptions. Analysis was generally descriptive in nature and offered little contribution to theory development beyond advocating for empowerment of parents within the medical system.

With the exception of one paper [[23](#_ENREF_23)] there was little consideration of psychological factors. That is, most studies regarded conflict with health care practitioners as a source of additional distress for parents rather than as a consequence of the distress and fear parents experienced around their child’s condition. Moreover, by taking a descriptive approach to the difficulties that parents report, such as problems with communication and information, most studies arguably re-emphasised the symptoms of parents’ difficulties rather than helping to understand the processes that may underlie them. Most of the current literature therefore does not consider how the prominence that parents attached to interpersonal problems with health care practitioners might provide clues to parents’ emotional needs. For instance, the emphasis parents placed on communication and information-giving in some studies [[10](#_ENREF_10),[17](#_ENREF_17),[19](#_ENREF_19),[22](#_ENREF_22),[24](#_ENREF_24)] could reflect their emotional needs. Indeed, the dominant suggestion in the reviewed papers that parents experienced conflict due to loss of power and control [[17](#_ENREF_17),[20](#_ENREF_20)] overlooks the possibility that feelings of loss of power and control are intrinsic to the experience of having a child with cancer. However, just as most papers can be seen as limited by regarding parents’ difficulties as arising solely from failings of care, the authors of the contrasting study [[23](#_ENREF_23)] can be criticised for not acknowledging the possibility that some of the parents in their study might have experienced medical mistakes, poor practice or other problems in care.

Perhaps future research can find a way forward from these diverging positions. We think it will be helpful for researchers to recognise that relationships and communication are multidimensional. That is, what is observed by researchers can be very different to how the individuals involved experience the relationships and communication to which they are party [[28](#_ENREF_28),[29](#_ENREF_29)]. Reflecting this multidimensionality, future inductive research needs to investigate relationships and communication as both observed and experienced. This will involve collection of both consultation and interview data; such data will also allow access to both external and intrapersonal factors. Analyses of these data will have to go beyond simply identifying divergences between what is observed and experienced. It will also have to go beyond simply identifying problems as either failings of care or symptoms of parents’ needs, and use such divergences as a resource to develop theory about processes from which we can infer what might improve care [[30](#_ENREF_30)]. In showing the ways that researchers’ unstated assumptions influenced the studies’ findings, our synthesis also points to the need for researchers to be more explicit about their assumptions, to be permeable to their data, and to ask questions and seek data that challenge their interpretations. Writings on this span several decades, as does the broader agenda of improving the quality of qualitative research [[31-36](#_ENREF_31)]. Reflecting on our own experience in preparing this review and as authors of one of the included papers, the questions we asked of the data might have benefited from the inclusion of team members from other disciplines, particularly practitioners and disciplines that focus on power and control. Future research to resolve the divergences between what is observed and experienced, or between conceptualising problems as either failings of care or symptoms of parents’ needs may benefit from the involvement of such researchers who can offer multi-disciplinary perspectives. It will also demand creativity on the part of researchers to develop theory that transcends those divergences.

Given the limitations of research in this area, there is relatively little that this review can offer practitioners. To avoid the same pitfalls as research, practitioners will want to reflect on how their assumptions inform their interpretations about problems in relationships with parents. Whilst recognising that the problems voiced by parents can alert practitioners to failings of practice that need to be eradicated, as psychologists we would draw attention to how problems can signal a need for parents to *feel* better cared for.

**Limitations and strengths of the review**

While the literature search strategy was designed to be systematic, subjectivity is unavoidable with regard to decisions around search terms and the inclusion and exclusion of papers. We did, however, address this by having a second author review a sample of included and excluded papers against the inclusion criteria. Two authors of this review authored one of the reviewed papers [[23](#_ENREF_23)]. To help counteract any undue influence on analysis, the authors took a systematic approach to reviewing the papers and were mindful of the need to take a critical approach to all the papers.

Drawing on meta-study has strengthened this review by focussing our attention not just on the findings of the studies but also on how those findings were arrived at, and we have traced the ways that researchers’ assumptions and choice of methods have shaped the knowledge they produced. We doubt these insights would have been apparent had we not taken an interpretive meta-study approach. This went beyond aggregating the findings of the reviewed studies to scrutinise their theory and methods, and explore how these linked to the studies’ findings. Because authors of the reviewed papers did not explain their assumptions, scrutinising theory was a challenge but, once we resolved to interpret this from the information that authors did provide (about their backgrounds, their agendas in conducting the studies and the questions they prioritised), the process became clearer. In identifying researchers’ assumptions we had to draw on information that was distributed throughout the papers, not just in the methods sections. Disagreements about these interpretations were few and quickly resolved through discussion. However, this could reflect our shared assumptions as psychologists and we acknowledge that reaching agreement may be more testing in teams comprising a mix of disciplinary backgrounds.

While we have concluded that the work we have reviewed is not a strong basis from which to offer recommendations for practice, our use of a meta-study approach has helped to identify how future work can build upon this review to produce knowledge that will provide a stronger basis for improving healthcare relationships in practice.

**CONCLUSIONS**

Our review of the existing literature has important lessons for future research. Such research should address the methodological limitations of previous papers. A multidisciplinary approach could encourage consideration of different theories and models. Consideration of psychological factors could help to develop a more complete understanding of the problems that can arise within the parent-practitioner relationship and offer new ways of resolving these problems. However, it is crucial that such work also remains alert to external sources of difficulty for parents, such as the poor professional practice of health care practitioners or problematic care systems. That is, the design and analysis of future research needs to allow for integrative exploration of both external and intrapersonal factors.

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**Table 1**

**Search terms**

|  |  |
| --- | --- |
| 1 | cancer AND parent\* AND (doctor\* OR p\*diatrician\* OR oncologist\* OR physician\* OR practitioner\* OR h\*matologist\*) |
| 2 | 1 AND anger OR fear OR confus\* OR comfort OR faith OR hope |
| 3 | 1 AND authority OR empower\* OR power OR decision-making |
| 4 | 1 AND communic\* OR relationship OR trust OR attach\* |
| 5 | 1 AND problem OR difficulty |
| 6 | 2 OR 3 OR 4 OR 5 |

**Table 2**

**Features of the 10 studies synthesised**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Source paper  (*n*=10) | Country setting | Participants | Sample origins | Data collection | Data analysis | Main findings | Background and theoretical orientation of the authors |
| Chesler, M. A., & Barbarin, O. A. (1984). | USA | 75 (42 mothers, 33 fathers,) | Treatment centres | Interviews | Thematic coding.  Inductive.  Descriptive. | Problems parents reported in their relationship with health care practitioners were grouped into seven areas: conflict resolution, interpersonal contact, empathy with the child, acceptance of parental efficacy, transmission of information, communication, staff competence. | Academic sociologist and psychologist.  Parent of survivor of childhood cancer.  Theory of coping. |
| Clarke, J. N. (2004). | Canada | 90 (76 mothers, 14 fathers) | Data from two separate studies.  Parent support group contacts.  Treatment centres. | Telephone interviews. Focus groups. | Thematic coding.  Inductive.  Descriptive. | Parents experienced conflict between their own power, authority and knowledge and that of the health care practitioners and needed to be advocates for their children. | Academic sociologist.  Parent of survivor of childhood cancer.  Sociological theories of power. |
| Clarke, J. N. (2006). | Canada | 49 mothers | Parent support group contacts | Focus groups | Thematic coding (qualitative content analysis).  Inductive.  Descriptive. | Advocacy was a “moral imperative” for mothers, sometimes felt necessary because of perceived errors of health care practitioners, understaffing, lack of coordination and communication within the medical care system and advice from other parents. | Academic sociologist.  Parent of survivor of childhood cancer.  Sociological theories of power. |
| Clarke, J. N., & Fletcher, P. (2003). | Canada | 29 (no. of mothers and fathers not stated) | Parent support groups | Telephone interviews | Thematic coding.  Inductive.  Descriptive. | Parents’ concerns regarding communication issues included getting the diagnosis, conflicts and contradictions, amount of information, good communication and feeling listened to. Parents can lack knowledge, authority and power yet are responsible for their child. | Academics in sociology and kinesiology (study of human movement).  Parent of survivor of childhood cancer.  Sociological theories of power. |
| Clarke, J. N., & Fletcher, P. (2004). | Canada | 29 (25 mothers, 4 fathers) | Parent support group contacts.  Treatment centre. | Telephone interviews | Thematic coding.  Inductive.  Descriptive. | Relationship between parents and practitioners is fragile due to lack of shared meanings and power differences in a situation in which mutual roles and responsibilities are not clearly specified. Conflicts of power and knowledge are central to parents’ difficulties | Academics in sociology and kinesiology (study of human movement).  Parent of survivor of childhood cancer.  Sociological theories of power. |
| Lozowski, S., Chesler, M. A., & Chesney, B. K. (1993). | USA | 116 (102 mothers, 14 fathers) | Self-help groups for parents of children with cancer | Self-report questionnaires | Thematic coding.  Inductive.  Quantitative element: chi-square analyses of differences between groups.  Descriptive. | 56% of parents intervened in their child’s treatment to prevent or correct a medical mistake. Parents who intervened were less satisfied with their relationships with health care practitioners. | Policy analyst and academic sociologists.  Parent of survivor of childhood cancer. |
| Moore, J. B., & Beckwitt, A. E. (2003). | USA | 17 (14 mothers, 3 fathers) | Group meetings for parents of children with cancer | Interviews | Deductive.  Descriptive. | Parents use strategies identified by [Rubin, et al. [37]](#_ENREF_37) to deal with interpersonal conflict with health care providers. Strategies were: problem-solving, yielding, withdrawing, inaction or contending. When parents used contending they transformed into more effective advocates. | Academics in nursing and research.  Theories of conflict. |
| Moore, J. B., & Kordick, M. F. (2006). | USA | 27 participants (14 mothers, 4 fathers, 9 children) | Group meetings for parents and children | Interviews | Deductive.  Descriptive. | Health care professionals and health care system factors can greatly influence the experience of parents and children with cancer by preventing, reducing or causing conflict.  Conflicts experienced by participants were classified according to Moore’s [[38](#_ENREF_38)] categories of sources of conflict: data, interest, structural, relationship and value conflicts. | Academics in nursing and research.  Theories of conflict. |
| Ringner, A., Jansson, L., & Graneheim, U. H. (2011). | Sweden | 14 (10 mothers, 4 fathers) | Paediatric oncology ward at a treatment centre | Interviews  Focus groups | Thematic coding (qualitative content analysis).  Inductive.  Descriptive. | Identified two conditions for parents with regard to gathering and using information. Having information needs met resulted in ‘feeling acknowledged as a person of significance’. Not having information needs met resulted in ‘feeling like an unwelcome guest’. Parents were less satisfied with access to information at later stages. | Academics and clinician in nursing. |
| Salmon, P., Hill, J., Ward, J., Gravenhorst, K., Eden, T., & Young, B. (2012). | UK | 51 (31 mothers, 22 fathers) | Treatment centres | Interviews  Audio recording of parent and doctor consultations | Within and across case analysis. Development of broad analytic categories.  Inductive.  Interpretive. | Parents gave doctors a role in sustaining hope by relinquishing concern with the longer term to doctors while focusing on the short term themselves. Some parents could not fully trust the doctors and were unable to hope. | Academics and clinicians from psychology, psychiatry and paediatric oncology.  Psychoanalytic theory.  Attachment theory. |

**Statement regarding ethics and any potential conflicts of interest**

Ethical approval was not required for this work as it was a review paper only. No potential conflicts of interest exist.

1. Pennine Care NHS Foundation Trust, UK. [↑](#footnote-ref-1)
2. Department of Psychological Sciences, University of Liverpool, Liverpool, U.K [↑](#footnote-ref-2)