

Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature

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Accepted for publication
10 December 2012

Keywords: children, literature review, long-term conditions, parents' experiences

Abstract

Background Living with a child with a long-term condition can result in challenges above usual parenting because of illness-specific demands. A critical evaluation of research exploring parents' experiences of living with a child with a long-term condition is timely because international health policy advocates that patients with long-term conditions become active collaborators in care decisions.

Methods A rapid structured review was undertaken (January 1999–December 2009) in accordance with the United Kingdom Centre for Reviews and Dissemination guidance. Three data bases (MEDLINE, CINAHL, PSYCINFO) were searched and also hand searching of the *Journal of Advanced Nursing and Child: Care, Health and Development*. Primary research studies written in English language describing parents' experiences of living with a child with a long-term condition were included. Thematic analysis underpinned data synthesis. Quality appraisal involved assessing each study against predetermined criteria.

Results Thirty-four studies met the inclusion criteria. The impact of living with a child with a long-term condition related to dealing with immediate concerns following the child's diagnosis and responding to the challenges of integrating the child's needs into family life. Parents' perceived they are not always supported in their quest for information and forming effective relationships with health-care professionals can be stressful. Although having ultimate responsibility for their child's health can be overwhelming, parents developed considerable expertise in managing their child's condition.

Conclusion Parents' accounts suggest they not always supported in their role as manager for their child's long-term condition and their expertise, and contribution to care is not always valued.

Introduction

Living with a child with a long-term condition can result in challenges above usual parenting responsibilities because of illness-specific demands such as maintaining treatment and care regimes, social and financial constraints, and maintaining family relationships.¹ Two distinct areas of research have evolved in relation to exploring the impact of living with a child with a long-term condition.² First, studies that have focussed on identifying the factors that might account for variations in the families' responses to the child's illness. Second, studies describing the experiences and perceptions of living with a child with a long-term condition. Findings from studies investigating the impact on parents and family life in households with a child with a long-term condition are equivocal, with good and poor adjustment reported.³⁻⁶ A range of variables such as stress, family functioning and adaptation have been investigated in an attempt to understand the variations in families' responses to living with a child with a long-term condition.⁵⁻⁷ Fewer family stressors and effective stress-coping strategies are associated with better family functioning and adjustment to living with a child with a long-term condition.⁷ These explanatory studies provide valuable information about the variables that contribute to parents' adaptation and coping, but do not reveal what it is really like for parents living with a child with a long-term condition.⁸⁻¹⁰

Studies exploring parents' perspectives of how their child's illness is integrated within family life, and the contextual factors that influence their responses to illness episodes can assist health professionals to develop care packages and services that more closely meet the child and family's needs. Consequently, there has been an increase in research exploring parents' perspectives and experiences of living with a child with a long-term condition.^{2,8-11} Knowledge about parents' experiences of living with a child with long-term condition has the potential to assist health professionals support parents in their role as care manager for their child's condition meets parents' needs. A critical appraisal

of studies that have explored parents' experiences of living with a child with a long-term condition is timely because international health policy advocates that patients with long-term conditions become active collaborators in care decisions.¹²⁻¹⁴ In the context of children, effective collaboration involves health professionals understanding parents' unique knowledge of their child and valuing their experiences of managing their child's condition.

Aim

This study presents a rapid structured review of research that has explored parents' experiences and perceptions of living with a child with a long-term condition. The specific objective was to describe and summarize parents' accounts of living with a child with a long-term condition.

Review design and methods

A rapid structured review was employed to investigate parents' experiences of living with a child with a long-term condition using systematic methods. Rapid structured reviews are used to summarize and synthesis research findings within the constraints of a given timetable and resources and differ from systematic review in relation to the extensiveness of the literature search and methods used to undertake the analysis.^{15,16} Rapid structured reviews are appropriate to identify future research priorities or, as in the case of the review presented in this study, to contextualize empirical studies prior to undertaking research in a related area. The methods used to conduct the review were informed by guidance for undertaking systematic reviews developed by the United Kingdom Centre for Reviews and Dissemination.¹⁶ Primary research studies were included or excluded based on the following criteria:

Inclusion criteria

1. Studies of parents, guardians, foster parents or carers living with a child with a long-term condition;

2. Studies concerned with parents' experiences or perceptions or beliefs about living with a child with a long-term condition, which could relate to the child's health, education or social care needs;
3. Studies about parents' management and decisions relating to the child's long-term condition;
4. Studies published in the English language.

Exclusion criteria

1. Studies about children with learning disabilities due to the heterogeneity of the cause of the disability;
2. Studies with an exclusive focus on children with terminal conditions because the anxiety and anticipatory grief that parents experience is likely to dominate their narrative;
3. Review articles and individual case studies.

Long-term conditions were defined as health conditions that are permanent and impact on the child's growth and development, necessitating on-going health, social and/or educational support for the child and family.^{17–19}

Search methods

Studies were identified by searching three health and social sciences data bases, MEDLINE, CINAHL and PSYCINFO, which routinely index qualitative studies and include a wide range of subject matter.¹⁶ A 10 year period, January 1999–December 2009, was chosen because studies within this period are more likely to reflect contemporary health policy within developed countries, which has a greater emphasis on parent–professional collaboration in relation to the management of long-term conditions in children. An illustration of the search strategy, using PsycINFO as the example, is presented in Table 1.

Additional techniques were employed to reduce sampling bias and offset the imperfections associated with the indexing of qualitative studies²⁰: hand searching all volumes of the *Journal of Advanced Nursing and Child: Care,*

Table 1 Example of search strategy

PsycINFO data base via OvidSP host system: January 1999–December 2009	
1	(parent* or mother* or father* or famil* or guardian* or carer* or foster*).mp. [mp = title, original title, abstract, name of substance word, subject heading word, unique identifier]
2	((long-term or long term or chronic or disabling or long-standing or long standing) adj (disease or illness or condition*)) [mp = title, original title, abstract, name of substance word, subject heading word, unique identifier]
3	Complex needs
4	Medically fragile
5	2 or 3 or 4
6	(child* or paediatric or pediatric or daughter or son).mp. [mp = title, original title, abstract, name of substance word, subject heading word, unique identifier]
7	1 and 5 and 6
8	(experience* or perception* or view* or thought* or attitude* or perspective*).mp. [mp = title, original title, abstract, name of substance word, subject heading word, unique identifier]
9	((parent* or mother* or father* or famil* or guardian* or carer* or foster*) adj2 (experience* or perception* or view* or thought* or attitude* or perspective*s)).mp. [mp = title, original title, abstract, name of substance word, subject heading word, unique identifier]
10	7 and 9
11	Limit 9 to year "1999–2009"
12	Limit 10 to "childhood or adolescence"
13	Limit 12 to "English language"
14	Limit 13 to "empirical study"

Health and Development from 2004 to 2009; grey literature was identified by searching SINGLE, conference proceedings and via e-mail correspondence with child health researchers; bibliographies of key papers were reviewed to identify additional studies.

Article selection bias was reduced by following the stages recommended within the CRD review guidance.¹⁶ The electronic data base searches yielded a total of 356 records; each title was examined by JS to establish if the study related to the focus of the review. Seventy titles related to the review focus; the abstract of these titles were assessed to establish if the study met the inclusion criteria. Any uncertainties about the inclusion or exclusion

of studies were discussed with FC and HB. Following abstract screening and review of the full papers 19 studies were included. A further six papers were identified from the hand search, six identified from references of included papers and three from personal correspondence, resulting in 34 studies being included in the review (Fig. 1).

Quality appraisal

Quality appraisal involved assessing each study against predetermined criteria using an appropriate tool; Critical Appraisal Skills Programme (CASP) qualitative tool,²¹ and the Health Care Practice Research and Development Unit evaluation tools for quantitative studies²² and mixed methods studies.²³

Data synthesis

Integrative data synthesis based on the principles of thematic analysis underpinned data analysis because the primary objective of the review was to describe and summarize parents'

accounts of living with a child with a long-term condition.²⁴ Data synthesis followed the stages of thematic analysis advocated by Braun and Clark.²⁵ After reading, each paper codes (units of data) were generated from each of the reviewed studies. Units of data related to categories, themes, concepts and metaphors used to describe the study findings. Codes were summarized and recorded on a data extraction form to identify patterns across studies. Similar codes were grouped together into broad categories. New categories were developed or existing categories modified as new insights became apparent until a coherent account emerged. Bias was reduced by on-going refinement of categories and discussions between all three authors. An example of the stages described, using the categories labelled grief and chronic sorrow, is presented in Table 2.

Results

Thirty four studies were included in the review. Characteristics in relation to the geographical location of the studies, study settings and

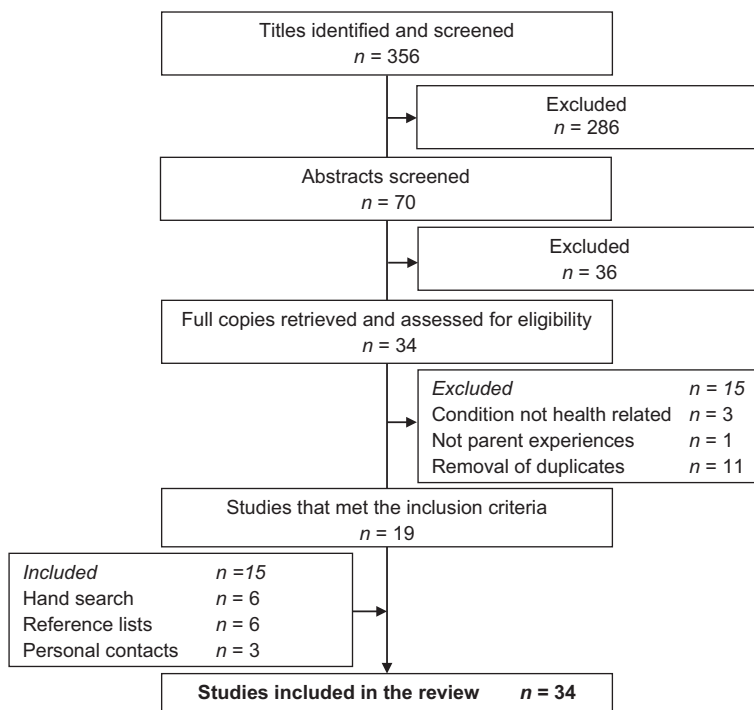


Figure 1 Flow chart of study selection process.

Table 2 Developing categories and themes from coded data

Author	Codes	Categories	Theme
Monsen ³⁰	Initial reactions such as disbelief and confusion were replaced by worrying about the child	Grief	Parent Impact
Maltby <i>et al.</i> ²⁹	Fear and anxiety about the impact of the condition for the child were accompanied by the loss of the image of 'the healthy child'		
George <i>et al.</i> ²⁷	Grief was related to feelings of shock, anger, fear, guilt, denial and were associated with uncertainty of the impact of the condition for the family		
Johnson ²⁸	Mothers lived in the present to meet the child's needs but re-lived the past as grieving continued	Chronic sorrow	
George <i>et al.</i> ²⁷	Chronic grief resulted in on-going sadness which increased as the condition progressed		
Bowes <i>et al.</i> ²⁶	Revisiting the diagnosis suggested parents' grief in relation to the child's diagnosis is on-going		

sample size are presented in Table 3. Analytical methods and key findings are presented in Table 4. Across studies, a range of family members participated including mothers, fathers, foster parents and grandparents. However, in the 11 studies where both parents participated, fathers represented less than a third of the sample (Table 3). Consequently, the review primarily reflects mothers' experiences of living with a child with a long-term condition. Participant details in relation to age, ethnicity, education, income or social class were provided in 16 of the 34 studies; parents' ages ranged from 20 to 60 years, and they were predominately from educated, white middle class backgrounds (Table 3). Children's ages ranged from 1 month to 21 years (Table 3). Diabetes, asthma and juvenile arthritis were the most commonly represented conditions. Fourteen studies did not report the health condition of the children but were included because the child required long-term health interventions such as gastrostomy feeding, intravenous medication, tracheotomy care and home ventilation (Table 3).

Twenty-seven studies were based on qualitative methods, five studies employed mixed methods and two studies employed quantitative methods (Table 5). Interviewing was the most frequent data collection method, and a range of analytical strategies were employed (Table 5).

Summary of the quality appraisal assessment

The research designs and methods chosen were appropriate to gain in-depth insights of parents' perceptions of living with a child with a long-term condition. In some studies, there was a lack of consistency between the underpinning theoretical perspectives adopted and the research methods used to undertake the study. For example, a study underpinned by grounded theory used the framework approach to analyse data rather than the constant comparison method more commonly associated with grounded theory.³¹ Overall the analytical procedures and strategies employed to enhance the studies' credibility were poorly described.

Findings

Despite the variability in the quality of the studies, there were similarities across findings. Three themes emerged from the synthesis of study findings: 'parental impact', 'illness management' and 'social context'. Each theme had associated subcategories; some categories were associated with parents' initial response to the child's diagnosis and others evolved over time (Table 6).

Parental impact

Parents' experienced a range of emotions such as confusion, disbelief, anxiety, turmoil and a

Table 3 Characteristics of the studies

Author(s)	Title	Location	Sample	Long-term health condition
Balling ²²	Hospitalized children with chronic illness: parental care giving needs and valuing parental experience	USA	50 caregivers: parents and foster carers (48 women)	Conditions resulting in home enteral or parenteral nutritional
Bowes ²⁶	Chronic sorrow in parents of children with type 1 diabetes	UK	17 parents (10 mothers)	Children 8–21 years Type 1 diabetes
Gallery ³³	Qualitative study of young people's and parents' beliefs about childhood asthma	UK	25 dyads of young people and main carers (mainly mothers)	Children 9–23 years Asthma
Cashin ³⁴	The lived experience of fathers who have children with asthma: a phenomenological study	Canada	8 fathers	Children 9–6 years Asthma
Dickinson ³⁵	Within the web: family-practitioner relationship in the context of chronic illness	New Zealand	10 families (parents and children, number of mothers/fathers not provided)	Children aged 7–11 years Conditions resulting in child requiring home care interventions
Fawcett ³⁶	Parents responses to health services for children with chronic conditions and their families: a comparison between Hong Kong and Scotland	China/UK	12 health-care practitioners 105 parents (details not provided)	Children 9 months–14 years Conditions requiring on-going care
George ²⁷	Chronic grief: experiences of working parents and children with chronic illness	Australia	11 parents (8 mothers)	Children under 15 years of age, range not included Condition as a result of neurological problems
Gibson ³⁷	Facilitating critical reflection in mothers of chronically ill children	Canada	12 mothers	Children 2–8 years Condition as a result of neurological problems
Goble ³⁸	The impact of a child's chronic illness on fathers	USA	5 fathers	Children 11 months–16 years Conditions requiring on-going care
Green ⁵⁹	'We're tired not sad': benefits and burdens of mothering a child with a disability	USA	110 participants (predominately mothers, numbers not provided)	Children aged 3–6 years Condition as a result of neurological problems
Heaton ³⁹	Families' experiences of caring for technology dependent children at home	UK	75 participant (34 mothers, 12 fathers 13 children, 15 siblings, 1 grandparents)	Average age 5 years, range not reported Conditions resulting in technology dependent child
Hewitt-Taylor ⁴⁰	Children who have complex health needs: parents' experiences of their child's education	UK	14 parents (12 mothers)	Children 4–18 years Conditions requiring on-going care
Hovey ⁴¹	The needs of fathers parenting children with chronic conditions	USA	99 fathers (48 living with child with a chronic condition, 51 fathers of well children)	Children 18 months–18 years Conditions included cancer, cystic fibrosis, juvenile arthritis
Hovey ⁴²	Fathers parenting chronically ill children: concerns and coping strategies	USA	48 fathers	Children's ages not reported Conditions included cancer, cystic fibrosis, juvenile arthritis Children's ages not reported

Table 3. Continued

Author(s)	Title	Location	Sample	Long-term health condition
Johnson ²⁸	Mother's perceptions of parenting children with disabilities	USA	10 mothers	Conditions included cerebral palsy, hydrocephalus, spina bifida Children 3–10 years
Kirk ⁴³	Parent or nurse? The experience of being a parent of a technology dependent child	UK	33 parents (23 mothers)	Child technology dependent Children up to 18 years
Knaf ⁴⁴	Childhood chronic illness: a comparison of mothers' and fathers' experiences	USA	93 parents (50 mothers)	Conditions requiring on-going care Children 7–14 years
Lauver ⁴⁵	Parenting foster children with chronic illness and complex medical needs	USA	13 foster parents (10 women)	Multiple care needs such as gastric tube feeding, central line care, colostomy care, intravenous therapies Children 8 months–20 years
MacDonald ⁴⁶	Parenting children requiring complex care: a journey through time	UK	43 participants: 26 carers (15 mothers, 4 fathers, 4 grandmothers, 3 grandfathers) 13 nurses, 4 social workers 15 mothers	Multiple care needs such as complex feeding and medication regimes, bowel care, catheterization, oxygen therapy Age of children not reported
Maltby ²⁹	The parenting competency framework: learning to be a parent of a child with asthma	USA		Asthma Age of children not reported
Marshall ⁴⁷	Living with type 1 diabetes: perceptions of children and their parents	UK	10 families (child/mother predominantly and child/mother/father)	Type 1 diabetes Children 4–17 years
Miller ⁴⁸	Continuity of care for children with complex chronic health condition: parents perspectives	Canada	66 caregivers (mothers, fathers, grandparents) (45 women) 13 mothers	Conditions requiring on-going care Children 5–13 years
Monsen ⁴⁹	Mothers experiences of living worried when parenting children with spina bifida	USA		Spina bifida Children 12–18 years
Mulvaney ³⁰	Parents' perceptions of caring for a adolescents with type 2 diabetes	USA	101 caregivers (mothers, fathers, grandparents) (89 women) 161 parents (85 mothers)	Type 2 diabetes Young people 12–21 years
Notras ⁵⁰	Parents' perceptions of health-care delivery to chronically ill children during school	Australia		Care needs included gastrostomy feeding, giving medications, blood sampling Children 5–14 years
Nuutila ⁵¹	Children with a long-term illness; parents' experiences of care	Finland	11 parents (10 mothers)	Conditions requiring on-going care Children 1–9 years
Ray ⁵²	Parenting and childhood chronicity: making the invisible work visible	Canada	43 parents (30 mothers)	Requiring at least one care intervention Children 15 months–16 years

Table 3. Continued

Author(s)	Title	Location	Sample	Long-term health condition
Ray ⁵³	The social and political conditions that shape special-needs parenting	Canada	43 parents (30 mothers)	Requiring at least one care intervention
Sallfors ⁵⁴	A parental perspective on living with a and chronically ill child: a qualitative study	Sweden	22 parents (16 mothers)	Children 15 months–16 years
Sanders ⁵⁵	Parents' narratives about their experiences of their child's reconstructive genital surgeries for ambiguous genitalia	UK	10 parents (7 mothers)	Juvenile arthritis Children 7–17 years Ambiguous genitalia Children's ages not reported
Sullivan-Bolyaj ⁵⁶	Fathers' reflections on parenting young children with type 1 diabetes	USA	15 fathers	Type 1 diabetes Children 2–8 years
Swallow ⁵¹	Mothers' evolving relationship with doctors and nurses during the chronic illness trajectory	UK	29 mothers of children	Vesicouretric reflux Children newborns–8 years
Waite-Jones ⁵⁷	Concealed concern: fathers' experiences of having a child with type juvenile idiopathic arthritis	UK	32 participants (8 mothers, 7 fathers, 1 grandmother, 8 children, 8 siblings)	Juvenile arthritis Children up to 18 years
Wennick ⁵⁸	Families lived experiences 1 year after a child was diagnosed with type 1 diabetes	Sweden	32 families (11 mothers, 10 fathers, 11 children)	Type 1 diabetes Children 9–14 years

loss of identity following their child's diagnosis.^{26,28,29,31,34,37,47,55,57} These emotions often dissipated as parents accepted the reality of the situation and focussed on meeting their child's needs.^{26,31} For some parents, a more enduring grief commonly referred to as 'chronic sorrow' evolved.^{26,28,31,34} Chronic sorrow resulted in an inability to retain and assimilate information,³⁴ continually searching for reasons for their child's long-term condition^{26,28,34} and feelings of self-blame.^{26,28,31}

Adaptation and coping was identified as a salient feature of living with a child with a long-term condition. Parent's adjustment appeared to be a dynamic process because of on-going changes in their child's condition and stage of development, balanced with varying family needs.^{40,46,57} Over time most parents adapted and coped with living with a child with a long-term condition.^{29,44,58} Parents gained control of the situation by focussing on their child's achievements,^{28,59} performing caring routines which strengthened parent-child attachment^{52,57} and becoming more flexible in relation to care and treatment regimes.^{33,52,57} However, some parents described being physically and emotionally overburdened which manifested as chronic fatigue,^{39,49,59} frustration^{37,52} and feeling emotionally challenged.^{43,52,56} Parents of children with complex needs found the burden of care particularly challenging because of the physical demands and lack of support when continuous care provision was required to meet their child's daily living activities.^{39,43,49}

Caring roles often dominated parenting roles because of the need to provide on-going care to the child.^{43,56} Care-giving burdens and a lack of effective support systems resulted in parents potentially becoming isolated with few social outlets.³⁹ Mothers' experienced the greatest role change because they were more likely to assume the role of main carer, which impacted on their career aspirations.^{39,59} Fathers' perceived their role as family provider and protector was challenged because of money pressures and claiming financial benefits^{38,41} and a loss of control because of relying

Table 4 Design of the studies

Author	Aim	Recruitment	Theory	Methods	Key findings
Balling ³²	Explore parents' participation in care when a child with a chronic illness is hospitalized	Convenience	Family systems theory	Mixed method survey. Measures: family profile inventory, parent experience scale analysed by descriptive statistics Open questions analysed by content analysis	Higher quality of care provide at home Nurses workloads limited care delivery Child not always incorporated in care Parents want greater involvement in care Professionals' struggle to incorporate parents expertise into ward practices
Bowes ²⁶	Explore parents' experiences of living with a child with type 1 diabetes	Convenience	Grieve and loss Adaptation and change	Qualitative study. Interviews analysed by developing codes and categories	Parents' grief following diagnosis is on-going Acute illness episodes, hospitalization, change in treatments, development changes evoked a resurgence in grief
Callery ³³	Explore the beliefs of young people with asthma and their carers about managing their condition	Purposeful	None	Qualitative study. Interviews analysed using constant comparison method associated with grounded theory	Emotional support was not always available Minimizing the consequences of asthma is a trial and error process Accepting a tolerable levels of symptom control reflected competing demands The impact on asthma on everyday life was variable and unpredictable
Cashin ³⁴	Explore fathers' experiences of caring for a child with asthma	Convenience	None	Qualitative phenomenological study. Interviews analysed using Van Manen's approach to phenomenology	Relief in knowing the diagnosis Need to gain knowledge about the condition and treatment options Living with concerns is constant, being vigilant to illness symptoms is part of everyday life Expertise gained through knowledge
Dickinson ³⁵	Explore parent-professional relationships in families living with a child with chronic illness	Convenience	Family-centred care	Qualitative phenomenological study. Group interviews analysed using Caelili's approach to phenomenology	Families enter a complex web of care with few choices in services and practitioners Tensions occur because of differences between professionals' working practices Moving between practitioners and services is disruptive

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Fawcett ³⁶	Explore parents' experiences of health-care support in children with a chronic illness across two cultures	Convenience	None	Mixed methods descriptive study. Self-developed questionnaire analysed using descriptive statistics. Data analysis for interviews not described	Importance of nutrition was significant in Hong Kong but not UK cultures Expectations health professional would provide support was specific to UK culture Both cultures wanted more information than provided and to participate in care decisions
George ²⁷	Explore parents' experiences of chronic grief in children with chronic illness	Purposeful	Grief and chronic sorrow	Qualitative phenomenological study. Interviews analysed using Van Manen's approach to phenomenology	Range of emotions on receiving the diagnosis and recur at times of uncertainty Chronic grief resulted in sadness which increased as the condition progressed Satisfaction in dealing with professions was variable
Gibson ³⁷	Exploration of empowerment of mothers living with their child with a chronic illness	Convenience	Empowerment	Qualitative study based on feminist inquiry. Data collection included participant observation and in-depth interviews. Data analysis is unclear	Initial frustration and disbelief are replaced with accepting the situation Critical reflection enabled mothers to develop an awareness of their own strengths and resources and own values and goals Mothers developed confidence in their own abilities to care for the child
Goble ³⁸	Explore fathers' experiences of caring for a child with a chronic illness	Convenience	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Financial impacts strained family life Fathers missed previous social activities Relationships with partners were supportive and strong but parents had no time alone Fathers filled the gap in becoming the main care giver to siblings Fathers worried about the child's future

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Green ³⁹	Explore the social experiences of mothering children with disabilities	Convenience	None	Mixed methods survey. Quantitative measure related to stigma and care giving burdens, range of statistical tests applied Analysis not described for qualitative interview data	Mothers' lives are emotionally complex, they developed confidence but care giving was time consuming, expensive and physically exhausting Mothers valued achievements in the child Socio-cultural constraints and stigma associated with disability added to the burden of caring
Heaton ³⁹	Explore families' experiences of caring for a technology dependent child	Purposeful	Social construction of life round multiple temporalities	Qualitative study. Interview data analysed using the framework approach	Family routines were influenced by the type of equipment and duration of treatments Considerable time committed to providing care which was often incompatible with continuing school/work and maintaining a social life
Hewitt-Taylor ⁴⁰	Explore parents' experiences of meeting the education needs of their child with a complex health need	Convenience	None	Qualitative study. Interview data analysed using qualitative content analysis	Pre-school education is limited for children with complex needs Finding the right school is complex, added difficulties related to Statement of Special Needs procedures Effort of learning for the child was challenging and exacerbated by missing school because of acute illness episodes and attending health appointments
Hovey ⁴¹	Compare the needs of fathers of chronically ill children to fathers of well children	Convenience	None	Quantitative survey. Fathers' needs measured using the Hymovich Family Perceptions Inventory Analysis used descriptive statistics	Fathers of chronically ill children have more concerns than fathers of well children in relation to family health matters and the impact of caring routines on their partner than fathers of well children Similarities between the two groups related to fathers coping with family issues and general beliefs about their lives

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Hovey ⁴²	Identify concerns and coping strategies of fathers of chronically ill children	Convenience	Roy's nursing models of adaptation and change	Quantitative survey. Coping and concern identified from Hymovich Family Perceptions Inventory Analysis used descriptive statistic	Fathers' perceived family had extra demands due care-giving burdens, which mainly fell to mothers Fathers were concerned about the child's health Time with their partner was limited A range of coping strategies were used such as gaining information and problem solving in relation to managing their concerns
Johnson ²⁸	Explore parents' experiences of parenting children with physical disabilities	Convenience	None	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Mothers lived in the present to meet the child's needs but relived the past as grieving continued Mothers treated the child as normal while securing services because the child is not normal Mothers dealt simultaneously with the child's and their own issues and feelings
Kirk ⁴³	Explore parents' experiences of caring for their technology dependent child	Theoretical	Social constructs of parenting	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Home is dominated by medical equipment and the frequent presence of health-care workers Parents caring role dominated their parenting role Parents differentiated themselves from health workers because care giving was interwoven into their lives with no respite and emotionally draining
Knaf ⁴⁴	Compare mothers' and fathers' views about living with a child with a chronic illness	Purposeful	None	Mixed method study. Data from family function, mood status measures were analysed using descriptive and inferential statistics. Interview data analysis using grounded theory constant comparison	Parents develop a shared view of the illness, its management and impact on family life, which helped family adjustment For some parents perspectives differed with mothers more likely to emphasize the negative effects of the child's illness on the family compared with fathers

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Lauve ⁴⁵	To understand the experiences of foster parents caring for children with complex needs	Purposeful	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Foster parents were highly committed to meeting the child's needs and learned about these in advance of their commitment Foster parents recognized the need for support but support provision was variable Foster parents experienced a deep sense of loss when their time as a foster parents ended but perceived the experience as life changing Caring processes began at birth and continued throughout infancy and into adulthood
MacDonald ⁴⁶	To describe the care trajectory of children with complex needs	Purposeful	None	Qualitative study based on ethnography. Interviews, participant observations, eco-maps and documentary review were coded, categorized and interrogated to find connections across data	Parents needs changed in relation to the child's stage of development, condition changes, family circumstances and parents age Respite care was important and the need for respite changed over time suggesting regular review with health-care professionals was required to ensure resources matched parents needs
Maltby ²⁹	Describe and explore the daily life of mothers of children with asthma	Sampling strategies are not described	None	Qualitative study based on phenomenology. Interviews analysed using Colaizzi's stages of phenomenology	Mothers' parenting competency and identity was challenged as a result of the child's condition Uncertainties about their own abilities and managing the condition existed Mothers' learned to acknowledge their child's condition and adjusted to meet their child's needs
Marshall ⁴⁷	Explore children and their parents' experiences of living with type 1 diabetes	Purposeful	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Families have to make sense of the condition Transition to becoming independents caused tensions between children and parents, relationships and attachments were challenged Parents' grief was on-going because of perceived losses, disruption, changes to established routines
Miller ⁴⁸	Explore parents' experiences of care across services for children with complex needs	Purposeful	None	Qualitative study. Interview data analysed by the framework approach	Effective communication was integral to achieving continuity of care Compartmentalization of services inhibited continuity of care, parents assumed the role of co-ordinator Consistent care providers were valued by parents because of their knowledge of the child

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Monsen ⁴⁹	Explore mothers' experiences of living with a child with spina bifida	Convenience	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Mothers had on-going worries about the child and family's health and worried about not coping Mothers were anxious the child would not fit in with peers and gain independence Mothers' struggled with the daily complexities of care
Mulvaney ³⁰	Explore parents' experiences of living with adolescents with type 2 diabetes	Convenience	None	Qualitative study. Focus group data were analysed using the framework approach	Role modelling had positive and negative impacts on adolescents self-management of their diabetes Parenting skills impacted on adolescents self-care Maintaining treatment was challenging Environment (clinic, home, school) influenced health behaviours, and the development stages of adolescence amplified consequences of diabetes
Notras ⁵⁰	Explore parents' experience of health-care support for children with chronic illness during school	Convenience	None	Mixed method survey. Questionnaire analysed using descriptive statistics, final themes developed using qualitative content analysis	Continue care regimes was difficult and the child's needs were not always met in school Parents' perceived teachers did not have the skills or training to meet their child's health needs Parents were not supported when they provided health care for their child during school hours
Nuutila ⁵¹	Explore parent-professional relationships with families with a child with chronic illness	Purposeful	None	Qualitative study. Interview data was analysed using qualitative content analysis	Information provision was inconsistent Information was needed across the illness trajectory Professionals lack of appreciation of parents experiences, constant changes in professional challenged parent-professional relationships
Ray ⁵²	To validate a model designed to describe the work relating to parenting a child with chronic illness	Purposeful	None	Qualitative study based on phenomenology. Interviews analysed using thematic analysis	Parents need to master technical care and monitor illness symptoms Parents' compensated for the child's lack of abilities and created opportunities for the child Securing services required parents to 'work' the health, social and education systems Effort was required to support siblings and maintain family relationships

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Ray ⁵³	To describe the social and institutional factors that affect families living with a child with a chronic illness	Purposeful	Giddens' theory of social and structural events that shape actions	Secondary analysis of interview data. ⁵² Interviews were analysed using thematic analysis	Parents' perceived their role of caring for the child was influenced by professional attitudes, information provision, and available services Other influences on families caring for a child with a long-term condition included the feminization of care and societal perceptions of disabilities
Sallfors ⁵⁴	Explore parents' experiences of living with their child with juvenile chronic arthritis	Theoretical	None	Qualitative study based on grounded theory Interview data analysed using grounded theory method of constant comparison	The unpredictability of the child's symptoms resulted in anxiety, parental over protection and watchfulness Emotional challenges related to uncertainties about parenting skills and communication with professionals On-going adjustment as child's condition changed and new demands were balanced with every-day life
Sanders ⁵⁵	Explore parents' experiences of their child's reconstructive surgery for ambiguous genitalia	Purposeful	None	Qualitative narrative study. Data obtained through in-depth interviews and analysed using a narrative framework	Parents' experiences were shaped by the conditions timeline, gender and identity issues Expectations of healthy child were challenged Parents' felt vulnerable Parents had to make a range of complex decision, which were overwhelming
Sullivan-Bolyai ⁵⁶	Explore fathers' experiences of living with a child with type 1 diabetes	Purposeful	None	Qualitative study based on naturalistic inquiry. Interview data was analysed using qualitative content analysis	Fathers' experience grief on hearing the diagnosis but also focused on meeting the child's needs Fathers wanted to learn about the condition and treatments Child's condition was constantly in the background Fathers recognized mother's care responsibilities, but felt they were co-partners in the child's care
Swallow ³¹	Explore the relationship between parents and health professions when a child's has a chronic illness	Theoretical	Illness trajectory model	Qualitative study based on grounded theory. Interview data analysed using framework approach	Mothers needed to develop effective relationships with health-care professionals which was a continual source of stress Building effective relationships was reliant on mutual respect and good communication particularly early in their child's illness

Table 4. Continued

Author	Aim	Recruitment	Theory	Methods	Key findings
Waite-Jones ⁵⁷	Explore fathers' experiences of caring for their child with juvenile idiopathic arthritis	Purposeful	None	Qualitative study based on grounded theory. Interview data analysed using grounded theory method of constant comparison	Fathers described a range of losses in relation to their ability to maintain a normal family environment which was exacerbated by comparisons with fathers of healthy children The amount of care their ill child required resulted in fathers feeling that they did not spend quality time with their ill child
Wennick ⁵⁸	Explore families' experiences of living with a child with type 1 diabetes	Convenience	None	Qualitative study based on phenomenology. Interviews analysed using Van Manen's approach to phenomenology	Families' perceived their lives to be ordinary but different to before the diagnosis Children did not feel their lives were particularly difficult but were frustrated in relation to being healthy but also ill, feeling independent yet supervised, confident yet insecure Parents worried about possible treatment complications

on others to support the family.⁵⁷ In contrast, living with a child with a long-term condition provided opportunities for personal development such as improved communication^{25,59} and organizational skills.^{53,59}

Illness management

A significant feature of living with a child with a long-term condition related to providing medical and nursing interventions. To take control of their child's condition, parents needed: knowledge of the condition and treatments^{33,51}; to learn from illness episodes and to use these experiences to identify and respond to subsequent illness symptoms in their child^{33,53}; and to develop effective relationships with health professionals.^{32,36} Parents wanted information about: the disease and treatments^{32,34}; accessing services and support networks^{27,53}; and strategies that would help them cope.⁵¹ Parents described difficulties in obtaining information and many were dissatisfied with the information provided by health professionals particularly at the time of initial diagnosis.^{27,31,36,53,55} Barriers to effective information provision included: the overuse of medical jargon³¹; insufficient, inaccurate and unclear information^{27,51,55}; information being given quickly with little opportunity for discussion^{27,51}; and inappropriate timing of information.²⁹

For some families, care-giving formed a significant part of parenting their child above usual parenting tasks.^{30,34,39,43,52,54,58} Consequently, parents developed considerable expertise in managing their child's condition and wanted to work collaboratively and share responsibility for their child's care with health professionals.³² They expected care to be negotiated³⁵ and to be involved in care decisions²⁶ but did not necessarily want sole responsibility for such decisions.³² Parents' satisfaction with their relationships with health professionals was variable and they identified communicating with professionals as stressful.^{31,35,52} Relationships built on mutual respect and trust endured over time and provided a consistent support

Table 5 Research approach and methods ($n = 34$)

Research approach	Quantitative survey	Mixed methods	Qualitative approaches				
			Phenomenology	Generic	Grounded theory	Other ¹	
Number of studies	2	5	11	7	5	4	
Data collection	Interview	Self-report questionnaire		Focus group		Observation	
Number of studies	24 (+4 ²)	7		2		1	
Data analysis	Statistical analysis	Phenomenon	Ground. theory	Frame work approach	Content analysis	Thematic analysis	Not stated
Number of studies	7	9	5 (+1 ³)	4	3 (+1 ³)	2 (+2 ³)	4 (+2 ³)

¹Ethnography, feminist perspectives, narrative enquiry, naturalistic enquiry.

²Studies used interviewing along with other data collection methods.

³Studies used more than one method of data analysis.

Table 6 Parents' experiences of living with their child with a long-term condition: immediate concerns and on-going challenges

Theme	Immediate concerns	On-going challenges
Parental impact	Making sense of the condition Grief and loss	Chronic sorrow Adapting and coping Physical and emotional overburden
Illness management	Learning about the condition Monitoring symptoms and responding to changes in the child's condition Interacting with health professionals	Mastering technical aspects of care Collaborating and working in partnership with health professionals Co-ordinating services for the child
Social context	Managing disruption	Maintaining normality Seeking social support systems Maintaining relationships

mechanism once developed.³¹ Relationships were poor when parents felt undervalued for example being labelled as 'non-compliant' if decisions about their child's care did not conform to professionals' perspectives.^{32,35,48,51}

Social context

Family life was disrupted because of the unpredictability of the child's condition such as the frequency of acute hospital admissions^{33,54} and having to accompany the child for therapies and clinic appointments.^{34,39,43,52,54} To manage these disruptions, one parent responded to the needs of the child with a long-term condition, whilst the other met the siblings' needs.^{52,57} Although working as two 'subunits' hindered attempts at maintaining normality,⁵² there were positive aspects to this disruption.⁵⁶ For example, family cohesion strengthened because of having to effectively communicate about sharing care-giving and family tasks on a daily basis.^{36,39,56} Regardless of the child's diagnosis parents strove to create a normal family environment, which was more likely to be achieved if parents had a positive view of living with their child with a long-term condition,^{34,37} shared responsibility for caring routines^{38,39,52} and were proactive in managing their child's condition.³⁴

Family relationships were strained, regardless of the child's condition, and parents' perceived living with a child with a long-term condition placed them at risk of marital breakdowns.^{38,42,52} The main barrier to maintaining family cohesion was the time needed to meet care-giving commitments resulting in parents having limited opportunities to spend time

alone.^{56,59} Different approaches to managing the child's condition also created family tensions.^{44,52} In contrast, some studies reported parents' relationships were strengthened, this being attributed to a mutual commitment to meeting their child's needs and recognition of the care burdens placed on the child's main carer.^{38,52} Establishing social support networks were important aspects of coping with the child's condition.^{45,53} Information about the availability of support groups and specialist networks happened by chance rather than being provided as an integral part of care delivery.⁵³

Discussion

Changes in policy and service delivery within western societies have meant that the care of children with long-term conditions is delivered primarily at home.^{39,60} Consequently, parents of children with a long-term condition have no choice in mastering complex care and treatments because they are an integral part of their child's life.^{32,34,41} The review found that a significant feature of living with a child with a long-term condition, regardless of the diagnosis, related to managing the child's condition. Mastering complex care regimes appeared to develop through experience, resulting in parents developing considerable expertise in the management of their child's condition.^{27,32,34,35,37,40,43,48,51,53,61-63} The process of developing expertise was described as blending knowledge and skill acquisition with experiential knowledge to adapt to changes in the child's condition.^{32,34,43} Through realizing the detailed knowledge of their child and child's condition, parents begin to trust their own judgements when identifying and responding to illness symptoms in their child, and if necessary challenge health professionals' assessments and decisions.³⁷ Professionals rely on parents to provide health-care interventions for their children and to recognize changes in their child's condition. Yet, parents' perceive their expertise and contribution to care is not always valued.^{26,35} The challenge for health professionals

is to integrate parents' expertise with their clinical knowledge to improve a joint understanding of the child's condition and develop effective treatment and care plans.

One of the catalysts for developing the expertise to manage their child's condition was a desire to secure appropriate services to meet their child's needs.^{35,37} Service provision often lacked coordination and was not always responsive to meeting the child's needs.^{27,34,43} The review highlighted a gap in the evidence relating to how services have responded to support parents' role in relation to managing their child's long-term condition. Whilst parents recognized their commitment to their children, with or without a long-term condition, they perceived it was expected they would take on the additional responsibility of meeting their child's health, development and physical needs in addition to everyday parenting.^{32,40-42} The amount of nursing and medical care required was significant for some children, yet there appeared to be a lack of support for parents in relation to their role as caregiver. One explanation for this lack of support could be that the focus of health-care delivery is dominated by prescribing treatments and care plans rather than developing interventions to support parents in their role as care manager of their child's long-term condition.⁶⁴ Poor coordination of services could be the consequence of shifting the responsibility for home care programmes to parents without a reciprocal shift in resources or considering the best way to support parents in their role as the primary caregiver. In addition involving parents, young people and children in future service panning and developing outcome measures to obtain information about the impact of services may ensure services meet the needs of the family in the future.⁶⁵

The shift in responsibility for the day-to-day care decisions from the health professional to the family requires professionals to move from a position of care prescriber to one of collaborator, working in partnership with parents. This mirrors more generally the broad consensus amongst policy and practice communities

that health professionals should enable patients to be involved in decisions about their own health care.^{66,67} This review identified parents' satisfaction with their relationship with health professionals was variable, compounded by poor communication and lack of information, which hindered working in partnership with health professionals.^{27,35,36,52,53,55,66} Developing effective parent–professional relationships has been described as an evolving process that is initially professionally dominated but through time moves to one of collaboration.⁶⁸ The findings review suggests health professional have difficulty operationalizing a model of collaboration; although parent–professional interactions take place, they may or may not be collaborative in nature. Effective collaboration involves enabling parents to express their opinions using active listening and responding to parents' concerns, building rapport with parents, valuing parents' knowledge and experiences with effective information exchange and mutual care planning.^{27,31,32,36,51,63} Although effective communication is a core professional skill and a pre-request for engaging effectively with patients,⁶⁹ professionals may not be equipped to meet the learning, information and support needs of parents.^{64,70} Research exploring ways to support the learning⁷⁰ and information needs of expert parents⁷¹ has potential to assist health professionals develop interventions and strategies to meet parents' needs as the care manager of their child's long-term condition.

Change in one member of the family, such as ill health, impacts on all family members disrupting the equilibrium of the family system.^{7,12} Families are inherently resilient and when faced with adversity and work together to regain stability.^{5,72} Consequently, there is an emergence of research exploring the role of the family in the management of the child's long-term condition.^{73,74} However, as the review findings identified study designs appear to favour the recruitment of mothers (Table 3); fathers, and other family members, remain under-represented when study participants include a range of family members.^{35,37,39,46}

Yet, fathers' involvement in the care and management of their child's long-term condition can impact positively on the child's well-being and family functioning.⁷⁵ In addition, although parents are primary care givers, there is increased recognition of the role of the child, older siblings and extended family in the management of the child's condition. The challenge to researchers is to ensure study designs, recruitment and data collection strategies are not biased towards recruiting mothers.

Review limitations

The review has several limitations. First, as this was a rapid review, all relevant studies may not have been captured. Undertaking a systematic review, where a wider range of data bases would be searched, may have generated additional studies. Second, techniques associated with integrative data synthesis such as meta-ethnography may have resulted in a greater theoretical depth to the analysis.²⁴ The third limitation relates to the heterogeneity of study approaches. Although similarities existed across studies, parents' accounts of disease specific challenges may not have been captured.

Future research directions

Several gaps in the research relating to expert parents managing the care of their child with a long-term condition were identified. First, the reason for the reported lack of collaborative working between parents and health professionals are unclear. Second, there is a paucity of research exploring and evaluating strategies to support expert parents in their role as care manager. Longitudinal research exploring how parents develop the expertise to manage their child's condition could identify ways to best support parents. Third, although there is an increase in studies about fathers' perspectives of living with a child with a long-term condition, as identified in a recently published review of fathers' narratives of their contribution to their child's health care,⁷⁵ participants of studies focusing on long-term condition in children

remain biased towards mothers. In addition, research participants are dominated by those from white, educated, middle class backgrounds. The methods for undertaking research about experiences of living with a child with a long-term condition are dominated by undertaking face-to-face interviews to elicit participants' accounts. Alternative data collecting strategies may appeal to a wider population. For example, greater integration of social media platforms and web-based research activities to collect data alongside more traditional methods such as interviewing may capture the views of participants who may feel intimidated by an individual face-to-face interview, wish to remain anonymous, have time constraints and those who engage in social networking activities as a means of interacting with society.

Conclusion

The review brings together findings from research about parents' experiences of living with a child with a child with a long-term condition, which was dominated by developing the skills to manage their child's condition. However, parents' accounts suggest difficulties in securing the support, in terms of resources and information, to meet their needs as the child's main carer. Through skills acquisition and experience parents' develop considerable expertise in managing their child's long-term condition and want to work in partnership with health professionals. However, parents' perceive their expertise is not always valued, and they are seldom included in decisions about their child's treatment. As the complexity of care delivered in the home environment continues to increase, understanding how parents develop the expertise to manage their child's condition may ensure parents receive the appropriate support to develop their role as the expert parent.

Author contributions

Joanna Smith: Study conception and design, Developing the search strategy, undertaking

data extrapolation and analysis and Developing the paper. Professor Francine Cheater: Study conception and design and Developing the paper. Dr Hilary Bekker: Study conception and design and Developing the paper.

Conflicts of interest

The study was not funded and there are no known conflicts of interest.

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