doi: 10.1111/j.1369-7625.2011.00674.x

Fathers' contributions to the management of their child's long-term medical condition: a narrative review of the literature

Veronica Swallow PhD MMedSci BSc(Hons) RGN RSCN,* Ann Macfadyen MSc BA(Hons) BN,† Sheila J. Santacroce PhD MSN BSN‡ and Heather Lambert MBChB PhD FRCP FRCPCH§

*Senior Lecturer, School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK and Honorary Researcher, Newcastle University, Newcastle upon Tyne, UK, †Honorary Researcher, School of Nursing, Midwifery and Social Work, University of Manchester and Principal, School of Health, Community and Education Studies, Northumbria University, Newcastle upon Tyne, UK, ‡Professor, School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA and §Consultant Paediatric Nephrologist, Department of Paediatric Nephrology, Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle upon Tyne and Newcastle University, Newcastle upon Tyne, UK

Correspondence
Veronica Swallow PhD, MMedSci, BSc (Hons), RGN, RSCN
Senior Lecturer
School of Nursing
Midwifery and Social Work
University of Manchester
Room 4.315, University Place
Manchester M13 9PL
UK
E-mail: veronica.swallow@manchester.ac.uk

Accepted for publication
14 February 2011

Keywords: children, chronic, fathers, long-term, management, mothers

Abstract

Context Fathers' contributions to the management of long-term childhood medical conditions are under-represented in the literature; therefore, the full extent of their involvement is poorly understood by practitioners and researchers, so strategies for promoting their involvement have not yet been fully considered.

Objective To review studies of fathers' actual contributions in a wide range of conditions, the potential to optimize their contribution through additional interventions by health professionals and a direction for future research.

Design Narrative review of the literature.

Methods CINAHL, Medline, PsychInfo and ERIC databases were searched electronically between the years 1995–2008. The terms adherence, adjustment, child, chronic, compliance, concordance, condition, coping, disease, father, illness, information, long-term, management/intervention, mother, role, self-care and treatment were searched for separately and in combination. English language papers reporting primary research were selected and supplemented by hand-searching reference lists. Thirty-five papers (arising from 29 studies) met criteria and were selected for narrative review.

Results Five themes were identified: (i) the impact of long-term conditions on fathers' ability to promote their child's well-being, (ii) factors influencing fathers' involvement in health care, (iii) personal growth/beneficial effects for fathers, (iv) the impact of father's involvement on family functioning and (v) strategies that increase fathers' participation in their child's health care and in research investigating fathers' participation.

Conclusions The review suggests that fathers' involvement in children's health care can positively impact on fathers', mothers' and children's well-being and family functioning. A range of strategies are identified to inform the promotion of fathers' contributions and future research investigating their input.

Introduction

Society depends on families to care for children with long-term conditions[1]; this often means family members acquiring new skills and taking on additional responsibilities such as condition monitoring, delivering medical/supportive care therapies, conferring with health professionals, adapting family life to demands of the condition, adjusting family budgets to contend with additional expenses, coming to terms with the condition and it's effects on family life, supporting the healthy development of all children in the family,[1–8] learning to share aspects of management with professionals[9] and supporting children's progress towards shared management as they grow and develop.[10] In addition, there are 'invisible' tasks such as promoting and maintaining friendships, searching for appropriate services, changing priorities, staying physically and mentally healthy to continue caring, and seeking and accepting help[1:427]; the success with which they cope depends on a combination of personal, financial, psychosocial, socioecological and clinical factors.[2,3,6,7,11–13]

The literature related to parents' management has primarily focused on mothers[14–16] although the need to consider fathers and the challenges this can present are increasingly recognized.[2,12,17–25] For instance, the representativeness of fathers who participated in family health research was examined in 661 families.[26] Those with working-class and ethnic-minority backgrounds, poor education, later-born children, more ambivalent marriages, partners with more traditional child-rearing beliefs, suboptimal parenting environments and with children who were unwell, unplanned and/or had difficult temperaments were all under-represented. The researchers hypothesized that fathers with more time constraints were less available to participate in research and families of non-participating fathers tended to be larger, with the index-child later born. This suggests that non-participating fathers perceived too many competing family commitments to participate in research, while fathers holding more traditional gender-typed views of their parenting role may be less inclined to appreciate the potential value of their own research contributions.[26]

Since the 1970s, the amount of time men spend on childcare is reported to have increased dramatically,[27,28] consequently there is growing awareness of the importance of fathers' involvement and of their positive influence on children's development. Initiatives to increase flexibility of work arrangements have emerged[29,30] with parental child-care leave now being available to either parent[31] and many employers recognizing the positive effects of family-friendly policies on staff recruitment and retention.[32,33] These developments have the potential to increase fathers' involvement in child care.[19,34,35] Changing aspirations of fathers wishing to be more involved in child care,[36,37] the fact fathers' contributions can differ from mothers'[4,17,32,38,39] and the benefits of fathers' increased involvement for the child, women, business, society and men themselves have all been highlighted.[40] Over this time, researchers' interest in families' involvement in long-term condition management has been significant yet evidence of fathers' specific contributions is still insufficient compared with the abundant literature relating to mothers', parents' and families' contribution.

For these reasons, the review was undertaken to determine the current knowledge in this area and identify a future direction for research. In this review, the terms: 'child' refers to infants, children, young people and adolescents 0–18 years; 'father' refers to biological, step or adoptive-fathers of any age; 'chronic' and 'long-term' are used interchangeably when referring to long-standing conditions; 'condition', 'disease' and 'illness' are used as synonymous, and 'management' is used to describe self-management, shared-management and family management. The definition used for 'chronic condition' is the following: (i) it occurs in children aged 0–18 years; (ii) diagnosis is based on scientific knowledge and can be established using reproducible and valid methods; (iii) it is not (yet) curable; and (iv) if it has been present for longer than 3 months, if it will, very probably, last longer than 3 months or if it has occurred three times or more during the past year and will

probably recur again.[41] Comorbidity (the co-occurrence of two or more conditions[42] such as a physical condition and learning difficulties) is recognized in this review as an additional factor that can exert varying care-giving demands on parents according to the combined nature and severity of the conditions(s), with uncertainty about the future of the condition(s) sometimes creating an immobilizing effect on coping processes.[13,15,43]

Our aim was to identify, summarize and critically review the evidence relating to fathers' management contributions. A narrative review involving a thematic analysis of factors influencing fathers' involvement was considered appropriate to meet our aims (given the broad range of literature we were examining and, from our initial scoping of the literature, the likelihood of finding few intervention studies), thus allowing flexibility when reviewing qualitative and quantitative studies and enabling findings and interpretations to be 'preserved in their original form'[44:12] without any attempt to transform them for analytical purposes.[44]

Methods

The review was based on primary research published in English language, peer-reviewed journals between 1995 and 2008. CINAHL, Medline, PsychInfo and Eric databases were searched electronically using the terms: chronic disease, long-term condition, long-term illness, chronic illness and adjustment (all in conjunction with children); chronic illness and coping, coping, mother and illness, mother and disease, management/intervention and child, compliance, adherence and treatment, concordance, provision of information, information and treatment, role and illness self-care (all in conjunction with father). This resulted in over 2000 possible papers (Fig. 1).

The search was refined by screening keywords/abstracts for those that addressed the following key categories: impact of a condition on the family; coping of family members; roles within the family; concordance with/adherence to treatment; strategies used to help parental coping/adjustment to life with a child (0–18 years) who has a long-term condition. After screening, the resulting 70 papers were further scrutinized; text and reference lists were hand searched for additional papers that explored the key categories in relation to fathers. In line with published guidance,[44] the review was shaped by five questions that developed as the evidence was examined (Table 1).

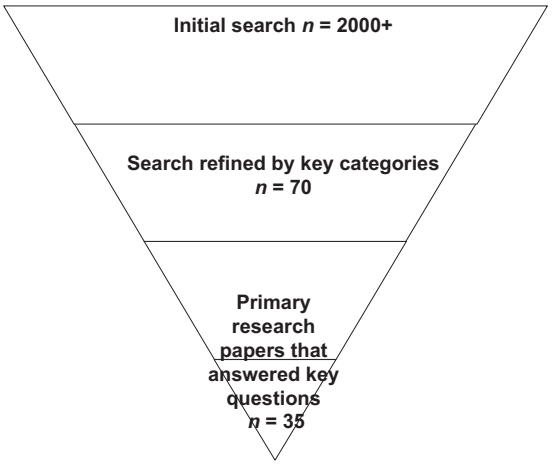

Figure 1 Illustration of review process.

The next step was to identify which papers were (i) primary research articles and also (ii) addressed the review questions. The resulting 35 papers (arising from 29 studies) that met our criteria were selected for in-depth review and analysis. Using the questions outlined in Table 1 as an initial structure, one author identified key issues. All authors then undertook individual, detailed reviews each focussing on particular questions before finally discussing results until a consensus was achieved.

Table 1 Review questions

How do long-term conditions affect fathers' ability to promote their children's well being?
What factors can influence fathers' involvement in management?
Does involvement in management positively influence fa thers' personal growth?
What is the impact on family functioning of fathers' contri bution to management?
How can fathers' contribution to management and to re search about management be supported and advanced?

Results

The papers reviewed (Table 2) arose from 29 studies involving qualitative (n = 12), quantitative (15) and mixed methods (2). Papers[25,45,69] arose from a single study; papers[17,47,48] arose from a single study; and papers[49,50,65] arose from a single study. The research reported therein was conducted in Australia (2), Canada (6), China (1), Israel (1), Taiwan (1), UK (3), USA (14), UK and USA (1); study populations included fathers only (11) or fathers and mothers (18) of children diagnosed with a wide range of conditions. The following five themes were identified and offer new understanding of the antecedents and consequences of fathers' contributions to chronic disease management.

The impact of long-term conditions on fathers' ability to promote their child's well-being

For some fathers, stresses associated with diagnosis and treatments were compounded by their expectation that they themselves should be 'strong and silent'. The interaction of these stresses with gender 'challenged men's ability to cope'.[22:370] Over half the fathers in a quantitative study examining psychosocial stressors experienced significantly elevated stress levels and distress compared to standardized norms.[52] In addition to potentially delayed stress responses, another result of the 'strong and silent' coping style was that many men failed to express feelings of sadness or vulnerability and consequently did not receive the support they needed.[22,53,59]

A summary of mothers' and fathers' scores on the Family Crisis Oriented Personal Evaluation Scale (F-COPES) and Coping Health Inventory for Parents (CHIP) revealed that in intact families (meaning both parents were present), mothers were more active than fathers in acquiring support from relatives, friends, neighbours and extended family (acquiring social support, subscale) (Wilcoxon z (34) = −2.84, P = 0.004) and demonstrated a significantly greater tendency to use coping patterns related to family integration and cooperation (family subscale) (Wilcoxon z (34,12) = −2.12, P = 0.03).[54]

Professionals sometimes provided information to fathers using different media to those that they used with mothers,[21,22,53–57] and in several studies fathers reported a need for more information and support from professionals to help them promote their child's well-being,[52,53,56] while some fathers said that mothers were the main recipients of information meaning fathers obtained 'second-hand' information[53] and fathers were not always involved in discussions with professionals.[58] In a study measuring parenting stress, distress and need for psychological services, 56% of fathers wanted more information on medical insurance, 48% on disease management and 42% on relationships.[52] Fathers also identified specific situations when they could support their child, such as when difficult decisions arose, an element of risk existed regarding treatment[35] or children wanted to be held particularly at difficult times[4,35,59] and paternal involvement was associated with more favourable adherence and quality of life amongst adolescents.[45] Some fathers took actions to ensure their child could safely participate in physical activities with other children by supporting or coaching sports[1,60] (Table 3).

Factors influencing fathers' involvement in health care

Three qualitative studies reported that changes in the way society views fathers' roles can positively influence fathers' involvement,[22,35,53] while in a quantitative study conducted in Israel and comparing fathers of well children (control) with fathers of ill children: '…low but significant correlations were demonstrated between social support and father's involvement in the care of the child (r = 0.18, P < 0.05) in the control group, whereas in the research group, involvement in the care of the child correlated positively with stressful life events (r = 0.18, P < 0.05).'[17:304]

In one Canadian study, 21/22 fathers were in full-time employment when their daughters received the diagnosis of chronic disease,[35] and

Table 2 Summary of results

Citation number	Author (Year) Country Condition(s)	Objective(s)	Design	Method
64	Barakat *et al.* (2006) USA Cancer	Describe post-traumatic growth in adolescent survivors of cancer and their parents	Quantitative: randomised clinical trial	Perceptions of changes in self scale; assessment of life threat and treatment intensity questionnaire; impact of events scale; intensity of treatment ratings. 146 mothers, 107 fathers
54	Brazil & Krueger (2002) Canada Asthma	Examine adaptation patterns among children with moderate/severe persistent asthma and their parents	Quantitative: non-experimental descriptive design	Family adjustment adoption model – Faces III, F-COPE, CHIP, medical and social variables 49 mothers, 35 fathers
24	Chaney *et al.* (1997) USA Diabetes	Examine transactional patterns of child/mother/father adjustment over 1 year	Quantitative longitudinal study	Parents: psychological adjustment 27 mothers, 21 fathers assessed with Symptom checklist 90 (Revised) on two occasions one year apart (self-completion). Children: interviews with administered questionnaire
22	Chesler & Parry (2001) USA Cancer	Analyse fathers' experiences of childhood cancer through gender lens	Qualitative	In-depth individual interviews (n = 52), seven group workshops with fathers (n = 115). Deductive then inductive analysis
59	Clark and Miles (1999) USA Congenital heart disease (CHD)	Explore fathers' experiences of CHD	Qualitative: part of larger longitudinal study	Interviews with eight fathers at diagnosis of infant's CHD and 12 months post-diagnosis. Content analysis.
68	Dashiff (2003) USA Diabetes	Describe perceptions of division of diabetes self/dependent-care responsibility between adolescents/parents and relationship to metabolic control	Quantitative: descriptive correlational study	31 adolescents and their parents (dyads) completed Diabetes Family Responsibility Questionnaire
61	Douglas *et al.* (1998) UK Post-renal transplantation	Assess whether renal transplantation affects child's later behaviour/eating and whether outcome is related to parental stress/coping	Mixed methods (qualitative and cross-sectional study)	Semi-structured interviews and self-completion of General Health Questionnaire, Parenting Stress Index, Child Behaviour Check List Coping Health Inventory, Family Crisis Orientated Personal Evaluation Scale, four couples
25	Gavin and Wysocki (2006) USA Asthma, Cystic Fibrosis, Diabetes, Phenylketonuria, inflammatory bowel disease, spina bifida	Explore association between father involvement and other aspect of family functioning	Quantitative: cross-sectional design	Used Dads Active Disease Support scale (DADS), a measure of the amount and helpfulness of paternal involvement in disease management to explore association between father involvement and other aspects of family functioning.

Table 2 (Continued)

Citation number	Author (Year) Country Condition(s)	Objective(s)	Design	Method
63	Goble (2004) USA Cerebral Palsy, osteogenesis imperfecta, autism	Examine fathers' experiences	Qualitative: phenomenological approach	Unstructured, open-ended, informal interviews with five fathers. Content analysis
4	Hatton *et al.* (1995) Canada Diabetes	Understand parents' experiences of caring for infant/toddler with diabetes	Qualitative: phenomenological approach	14 in-depth joint interviews with couples. Inductive phenomenological analysis
65	Hovey (2003) USA Cancer, Cystic Fibrosis, Juvenile Rheumatoid Arthritis (JRA)	Compare parenting needs of 48 fathers of children with chronic conditions to the parenting needs of 51 fathers of well children.	Quantitative: descriptive comparison design	99 fathers completed Hymovich Family Perception Inventory (HFPI)
50	Hovey (2005) As above	Identify concerns/coping strategies of fathers and their perceptions of their wives' concerns/coping strategies		As above
49	Hovey (2006) As above	Compare concerns/coping strategies of fathers with household incomes $<$ \$50 000 pa, with fathers/with incomes of \$50 000		48 fathers completed HFPI
47	Katz (2002) Israel Cancer, heart and kidney disorders, asthma, JRA, diabetes	Examine differences in impact between non-life-threatening (NLT) and life-threatening (LT) illness	Quantitative	Standardized measures: sociodemographic and illness-related questionnaire; short version of Social Readjustment Scale; Self-esteem Scale; Social Support Questionnaire; Marital Adjustment Test; Fathers' involvement in care of child questionnaire. Eighty fathers and 80 mothers of children with LT (40) or NLT (40) illness
17	Katz & Krulik (1999)	Compare 80 fathers of ill children and 80 fathers of healthy children on the variables: stressful life events/self-esteem/social support/marital satisfaction/involvement in care		As above

Table 2 (Continued)

Citation number	Author (Year) Country Condition(s)	Objective(s)	Design	Method
48	Katz (2002)	Investigate differential impact of chronic illness on 80 fathers and 80 mothers and psychosocial variables contributing to adaptation; predict parents' adaptation		As above
20	Knafl & Zoeller (2000) USA Diabetes, asthma, JRA	Explore how mothers and fathers of children with chronic illness view their experience and its impact on personal life	Mixed methods	Individual, in-depth qualitative interviews analysed using constant comparison and matrix display. Feetham Family Functioning Survey, profile of mood states 43 couples and seven women
55	McGrath & Chesler (2004) Australia Acute lymphoblastic leukaemia (ALL)	Describe fathers' coping with child's difficult treatments	Qualitative: phenomenological approach.	Semi-structured interviews with 13 mothers and six fathers of children completing induction therapy for ALL.
35	McNeill (2004) Canada JRA	Understand how fathers experience parenting role	Qualitative: grounded theory approach	Semi-structured interviews with 22 fathers. Analysed using constant comparative method
62	Mu Pei-fan (2005) China Epilepsy	Examine fathers' stress	Quantitative: survey design	210 fathers, self-completion of a general family information form and Chinese language versions of: Coping Health Inventory for Parents; Parental Perception of Uncertainty Scale; Beck Depression Inventory Analysed using descriptive statistics
53	Neil-Urban & Jones (2002) USA Cancer	Describe fathers' experiences	Qualitative	Two focus groups each involving five fathers. Analysed using thematic analysis
56	Peck & Lillibridge (2005) Australia Chronic respiratory And nervous system diseases	Gain insight into fathers' experience	Qualitative: interpretive phenomenological approach	In-depth interviews with four fathers
57	Pelchat, *et al.* (2003) Canada Down's syndrome	Identify differences and similarities in the experiences of parents of children with Down's syndrome	Qualitative: exploratory interpretative approach	Focus groups: one with five mothers and female researchers, one with four fathers and male researcher. Content analysis
1	Ray (2002) USA Chronic illness and disability	Validate a model describing work involved in raising child with chronic condition	Qualitative: philosophic hermeneutics approach	30 mothers and 13 fathers interviewed/given model (parenting and childhood chronicity) to discuss. Thematic analysis

Table 2 (Continued)

Citation number	Author (Year) Country Condition(s)	Objective(s)	Design	Method
51	Rodrigues & Patterson(2007) Canada Wide range of conditions	Examine impact of the severity of chronic condition on family functioning compared with families of healthy children	Quantitative	262 families of children with chronic conditions for whom both mother and father participated. Parents completed Family Assessment Measure (FAM) and the Functional Status Questionnaire. One sample t tests used to compare mothers' and fathers' FAM scores with reported norms
66	Soliday *et al.* (2000) Canada Kidney disease	Examine levels of parenting stress, child behaviour problems and family environment	Quantitative	39 fathers and 70 mothers (parents of 41 children with kidney disease and 34 healthy children) completed family environment scale, Child Behaviour Checklist (CBCL) and Parenting Stress Index
21	Sterken (1996) USA Cancer	Describe uncertainty and consequential coping patterns in fathers	Quantitative: descriptive correlational	31 fathers completed Parent Perception of Uncertainty Scale, Jalowiec Coping Scale and Demographic data sheet
60	Sullivan-Bolyai *et al.* (2006) USA Diabetes	Describe fathers' experiences parenting and managing care	Qualitative: fundamental descriptive design	In-depth open-ended interviews, 15 fathers of children age <10 years. Content analysis
58	Swallow (2008) UK Renal conditions	Explore parents' views of their identities as they learn to manage their child's chronic kidney disease.	Qualitative Grounded Theory	Six mothers and two fathers of six children with a recently diagnosed chronic kidney disease participated in a total of 21 semi-structured interviews during the 18 months after referral
46	Watson (1997) UK & US Renal replacement therapy (RRT)	Examine long-term demands and outcomes in families with children commencing RRT	Quantitative	Parents of 24 children Response: Fathers: UK 66%, USA 38%. Perceived stress and hospital Anxiety and Depression Scales, Information Needs, Impact Illness Questionnaires
52	Wiener *et al.* (2001) USA HIV/AIDS	Examine psychosocial stressors experienced by fathers	Quantitative	31 fathers completed Parenting Stress Index (PSI)
67	Worrall-Davies *et al.* (2002) UK Diabetes	Measure expressed emotion (EE) in parents of young children with diabetes, examine relationship between this, glycaemic control (HBA1) over 24 months	Quantitative	47 children, mothers and fathers studied over 24 months. HBA! Measured at 0, 12 and 24 months. At 12 months parental EE measured using Camberwell Family Interview. Mothers completed Child Behaviour Checklist 12 months
69	Wysocki and Gavin (2004) As Gavin & Wysocki (2006)	Assess validity/reliability of Dads Active Disease Support scale	Quantitative: cross-sectional design	190 couples completed DADS scale, family assessment device, impact on family scale, Didactic adjustment scale. Mothers completed parenting stress index/brief symptom inventory.

Table 2 (Continued)

Citation number	Author (Year) Country Condition(s)	Objective(s)	Design	Method
45	Wysocki & Gavin (2006) As Gavin & Wysocki (2006)	Assess Paternal Involvement in Disease Management, Associations with Adherence, Quality of Life and Health Status.	Quantitative: cross-sectional design	DADS scale data and measures of treatment adherence, quality of life, health status, and health care utilization obtained from 190 couples
38	Yeh (2002) Taiwan Cancer	Compare gender differences of parental distress	Quantitative	A subset of data obtained from 164 matched sets of parents Chinese version of Parenting Stress Index

Table 3 Summary of Theme 'The impact of long-term conditions on fathers' ability to promote their child's well-being' (Review question 1)

Citations	Topics
22,59	Fathers thought they should be 'strong and silent', this 'challenged ability to cope'; many denied feelings of vulnerability so did not receive support
22	Paternal suppression of emotions may be counter-productive or perceived by others as lack of concern
52	Fathers experienced elevated levels of parenting stress and psychological distress compared to standardized norms
54	In intact families, mothers exhibited greater efforts than fathers in coping patterns and acquiring social support
21,22,53–57	Information was sometimes provided to fathers and mothers through different mediums
52,53,56,58	Fathers often obtained information 'second hand' and needed more support from health professionals
53	Fathers required more information on medical insurance, disease management and more support in their relationships
4,35,59,60	Fathers could support their child when difficult decisions were needed, risk existed regarding treatment, or at difficult times; paternal involvement was associated with better adherence and quality of life among adolescents
1,45	Fathers offered support/coaching so their child could safely participate in sports with other children

some of these fathers viewed diagnoses as a catalyst for meaningful involvement in health care; three made significant changes to work arrangements to enable them to assume primary management responsibilities. Fathers reporting increased involvement in their child's health care also described improved relationships with their child and consequently were better able to handle invasive procedures involving their child.[4]

Data obtained from a combination of the Social Support Questionnaire, CHIP, Sociodemographic and Illness-related Questionnaire and Perception of Impact of Child's Chronic Illness on the Parent Questionnaire were analysed as follows: parents together, fathers/mothers separately and parents of children with life-threatening (LT) and non-life-threatening (NLT) conditions were compared using ANOVA, MANOVA and double-multivariate analysis; fathers and mothers reported significant differences in the use of professionals as a coping behaviour with mothers being more likely to access this support, although when examining the impact on parents of life-threatening and NLT conditions no significant differences were noted between the groups in relation to social support and impact of illness.[47] This was the only study we found that compared fathers of LT and NLT but in other studies reported, fathers made significant lifestyle changes to become more involved with their child's management[4] and some re-evaluated priorities because of their child's illness, choosing a different job or taking up new recreational activities.[53]

In contrast, parents in one study reported improvements in self-esteem and social support through work-for-pay, thus relying on work to facilitate involvement with their child's management, although fathers assumed less responsibility than mothers for mobilizing family-coping resources and were less involved in health care communications.[61] Hovey[49] also found more lower-income than higher-income fathers were concerned about obtaining insufficient health care information;[49] accordingly, fathers from both groups valued opportunities to spend time with other fathers in their situation and appreciated nurses' efforts to include them in management.[53]

In both qualitative and quantitative studies, fathers were often frank about their interactions with professionals.[56–58,62] Researchers hypothesized that the quality of parent–professional relationships may influence fathers' interactions with professionals[58] potentially influencing the way fathers define their child's condition.[20] This influence sometimes manifested as fathers' seeking information from other parents rather than professionals, believing that negative knowledge from professionals could generate greater family stress.[56] In a pilot study of the Chinese version of the CHIP, communication with professionals was identified as a primary predictor of how fathers manage condition-related stress,[62] while in a longitudinal qualitative study of UK families learning to manage their child's condition, fathers and mothers believed themselves to be positioned as 'students' by professionals over the course of shared management.[58] Furthermore, to alleviate the dearth of 'father-friendly' health-care environments and in recognition of the fact that fathers sometimes relate better with other men, hiring male professionals whenever possible was recommended by researchers.[53]

Factors impeding fathers' involvement included the need to maintain control while at the same time feeling loss of control,[50,59] and where employers prohibited men from taking family medical leave this resulted in some taking unauthorized absences only to be faced later with job losses/changes.[22] Conversely, it is common for Taiwanese fathers to return to work soon after diagnosis so avoiding the early stressors associated with management.[38] Gendered assumptions and the social organization of employment adversely affected fathers' careers more than mothers', consequently social pressures to continue working were barriers to fathers' direct involvement in management. When salaries were insufficient to cover medical expenses, fathers' roles as family provider/protector were challenged, causing distress to many[53] (Table 4).

Personal growth/beneficial effects for fathers

Aspects of some fathers' lives (personal relationships, emotional and spiritual awareness and lifestyle priorities) changed for the better after diagnosis.[22,35,48,53,55,60,63] Sixty-two per cent of fathers in a randomized trial believed their life changed for the better, and 48% treated others better because of experiences with cancer and paternal growth was significantly associated with perceived treatment intensity.[64] Fathers who participated in open-ended, qualitative interviews reported enhanced self-confidence, new life-directions, greater appreciation of life and improved sense of personal strength[60] with more than 80% endorsing one marker of personal growth.[64] Factors promoting personal growth included the following: mental health, access to counselling, support from fathers with similar experiences,[22,35] a well-paid job with flexible hours,[35,60] complementariness with spousal coping[35,55] and reciprocal shift in spousal work and family roles.[22] Personal growth seems to be stimulated or impeded by fathers' initial responses to a child's diagnosis, most having little prior expectation of the possibility of a serious medical condition for their child.[55,60] McNeill[35] and Ray[1] found that over time fathers developed strategies to protect and advocate for their child in the health-care setting, these include attempting to prevent unnecessary procedures, ensuring painful procedures were performed while the child was anaesthetized for another reason, controlling who could/could not care for their child, ensuring

Table 4 Summary of Theme 'Factors influencing fathers' involvement in health care' (Review question 2)

Citations	Main topics
Factors promoting fathers' involvement	
17,22,35,53	Changes in the way society views fathers' roles have been found to positively influence fathers' involvement
17	Economic security reduces need for fathers to work longer hours to pay medical expenses
35	Some fathers viewed diagnosis as a catalyst for meaningful involvement in management; flexible leave enabled changes to work arrangements to assume management responsibilities
4	Fathers with increased involvement in their child's health-care, also described improved relationships with their child, being better able to handle invasive clinical procedures
61	Some parents relied on social support at work to increase self-esteem and social support
53	Fathers value spending time with other fathers in their situation and appreciate nurses' efforts to include them in management
47	No significant differences reported between parents of children with life-threatening and non-life-threatening condition related to social support and perceptions of the impact of illness
53,58	Professionals involving fathers and mothers in discussions about their positions as 'students' in the management process and appointing male professionals to communicate with fathers whenever possible
49,56,57,62	Communication with professionals is a primary predictor of how fathers manage stress
Factors impeding fathers' involvement	
49,50,59	Fathers' involvement includes the need to try maintaining control while feeling loss of control
22	Employers who do not permit family medical leave so some took unauthorised absences, only to be faced later with job losses/changes
38	Taiwanese fathers return to work soon after diagnosis so avoiding stressors associated with management
53	Social pressures to continue working and employment structures that provide insufficient funds to pay medical expenses were barriers to fathers' involvement
53	Gendered assumptions and the social organization of employment adversely affect fathers' careers more than mothers'
49	Lower-income fathers expressed greater concerns about not obtaining health-care information than higher-income fathers

difficult conversations happened in the child's absence[53] and supporting their child during procedures.[4] Fathers were more likely to adopt these strategize as they became expert at observing professionals' technical and interactional expertize.[1] When fathers changed their expectations for their child, there was an increase in personal feelings of satisfaction.[56] Consequently, 'joys' of fathering a child with a chronic illness arose from small, unexpected achievements that parents of healthy children may take for granted;[56] these included seeing small developmental tasks as great feats for their child and something to relish for themselves.

Not all fathers, however, described personal growth and of those who did, some also discussed on-going uncertainty and emotional distress.[35,52,53,60,63] Low socioeconomic status, mental ill-health, inflexible gender identity and lack of spousal support impeded personal growth,[35] and in several studies[22,35,53,55,60,63] fathers described the child's diagnosis and treatment as traumas that evoked terror, disbelief, numbness, uncertainty and a sense of powerlessness. Fathers initially coped with diagnoses by 'walling-off' emotions and focusing on protector/provider roles, at some point later accepting the situation and seeking other means of coping to regain control (Table 5).[55]

The impact of father's involvement on family functioning

Differences were noted between parenting concerns of fathers of ill and well children[65]; in the minority of cases where parents held discrepant views, it was mothers who emphasized negative aspects of management,[20] yet if families are functioning effectively, it appears both fathers and mothers can potentially undertake management tasks,[61] and child well-being is significantly affected by maternal and paternal

Table 5 Summary of theme 'Personal growth/beneficial effects for fathers' (Review question 3)

Citations	Main topics
Factors promoting personal growth	
4,22,35,48,53,55,60,63	Fathers reported aspects of their lives that changed for the better after diagnosis (personal relationships, emotional/spiritual awareness and lifestyle priorities, enhanced self-confidence, appreciation of life, sense of personal strength and new life directions)
64	Growth significantly associated with perceived treatment intensity
1,22,35,55,60	Mental health, access to counselling, support from fathers with similar experiences, a well-paying job with flexible hours, complementariness with spousal coping, and reciprocal shift in spousal work and family roles helped personal growth.
55	Fathers' initial responses to the child's diagnosis, most having little prior expectation of the possibility of a serious condition for their child
56	When fathers changed their expectations for their child, there was an increase in personal feelings of satisfaction so 'joys' of fathering a child with a chronic illness arose from small, achievements parents of healthy children may take for granted
Factors inhibiting personal growth	
55	Initially coped with the diagnosis by 'walling-off' emotions and focusing on ingrained social roles of protector and provider, however, later, they accepted the situation and looked for other means of coping to regain control
22,35,52,53,55,63	Diagnosis and treatment sometimes evoked terror, disbelief, numbness, uncertainty and a sense of powerlessness.
22,35,53,63	Low socioeconomic status, mental health impairment, inflexible gender identity, lack of spousal support, ongoing uncertainty and emotional distress impeded personal growth

adjustment to chronic illness.[17,51,66] Fathers who felt more able to handle invasive procedures believed they developed special relationships with their child as a result.[4]

Children adjusted better if there were higher levels of family cohesion and lower levels of family conflict,[66] while increases in fathers' (but not mothers') distress over time contributed significantly to poorer subsequent child adjustment after controlling for age, gender, socioeconomic status and disease parameters.[24] Decline in fathers' adjustment was a significant predictor of better mothers' adjustment at follow up,[51] while mothers who are unsupported by fathers were less able to support their child.[66,67] Data obtained using the Dads Active Disease Scale (DADS)[45] showed that treatment adherence, expressed as the percentage of possible points earned, decreased with increasing age of the child for those with DADS 'helpfulness-amount' scores in the low and moderate tertiles, but no such decrease was evident for those with DADS scores in the high tertile. Post hoc comparisons showed that, for those over 14 years of age, adherence scores in the high DADS helpfulness-amount tertile were significantly higher than those in either the low or moderate tertiles.

To maintain family integrity and promote child/family adjustment, fathers used strategies such as maintaining a positive outlook,[62] making the child feel special,[35] valuing individuals by developing closer relationships,[4,35] promoting family activities,[35,53] maintaining routines[35,56,62] and day-to-day involvement in their child's care,[1,60] although Dashiff[68] found fathers' involvement levels were lower than those of mothers. Wysocki and Gavin[69] found positive relationships between maternal perceptions of father involvement, marital satisfaction and family adjustment,[25] suggesting that father involvement may beneficially affect family's experience of illness demands (Table 6).

Strategies that increase fathers' participation in their child's health care and in research investigating fathers' participation

Individual-, family- and organizational-level strategies to promote fathers' participation in their child's health care were reported. The

Table 6 Summary of theme 'The impact of father's involvement on family functioning' (Review question 4)

Citations	Main topics
61,65	Differences were noted between parenting concerns of fathers of ill and well children and if families are functioning effectively, it appears fathers can undertake tasks involved in managing the child's condition
20,68	Mothers emphasised negative aspects of management, while fathers' were less involved than mothers in diabetes care
17,51,66	Child well-being is significantly affected by maternal and paternal adjustment to child chronic illness
4	Fathers who felt more able to handle invasive procedures believed they developed special relationships with their child as a result.
66	Children adjusted better if there were higher levels of family cohesion and lower levels of family conflict
24	Increases in fathers' distress over time contributed to poorer subsequent child's adjustment, after controlling for age, gender, socioeconomic status and disease parameters.
51,66,67	Decline in fathers' adjustment was a predictor of better mothers' adjustment at follow-up, while mothers unsupported by fathers were less able to support their child
1,4,35,53,56,60,62	To maintain family integrity and promote child/family adjustment, fathers used strategies such as maintaining a positive outlook, making the child feel special, valuing individuals by developing closer relationships, promoting family activities, maintaining routines, and day-to-day involvement in their child's care.
25,69	Positive relationships existed between maternal perceptions of father involvement, marital satisfaction and family adjustment; father involvement may beneficially affect family's experience of illness demands although some fathers underestimated how extensive/helpful their involvement was perceived by others.

positive impact of an intergenerational connection was evident, for instance, when one man described how coaching from his own father on strategies to handle tense situations related to his child's condition increased his feelings of protectiveness towards the family; however, this also emphasized his need to 'be strong' for his family even if not feeling strong.[35] In a longitudinal mixed-methods study, there were correlations between fathers' levels of distress and children's subsequent adjustment; thus, Time 1 Child Adjustment Schedule (CAS) scores were significantly associated with Time 2 CAS scores ($t = 4.05$, $P < 0.001$), while fathers' Time 2 Global Symptom Index (GSI) scores '($t = 2.44$, $P < 0.02$) contributed significant unique variance to Time 2 CAS scores. Thus, increases in fathers' level of distress from Time 1 were associated with elevated levels of subsequent children's distress.'[24:237]

Reporting on a qualitative study of fathers' parenting experiences, McNeil[35] recommended that organizational strategies to support fathers can enhance their involvement in health care; these include increased efforts to make support and information accessible to fathers, designing services that take account of unique challenges fathers face and that professionals can promote fathers' involvement through encouraging them to be present during care-giving, valuing their input, providing opportunities for father-to-father support, giving adequate notice of forthcoming meetings and ensuring communications are directly addressed to both parents.[53] Other suggestions included providing quiet places where fathers can reflect,[35] hiring male health professionals to support fathers,[53] 'booster' sessions on information provided at the illness outset,[60] assuring staff continuity to promote consistency with agreed-upon management plans, ensuring hospital policies support both parents to stay if they wish,[35] providing practical facilities such as chairs big enough for fathers, developing sensitivity to paternal adjustment processes, arranging behavioural interventions that help fathers develop functional means of coping, co-ordinating support groups specifically for fathers[22] and providing guidance for professionals on fathers' support needs.[35,52,53,60,65] As parents'

clinical duties and obligations can lead to them assuming the additional identity of a 'student' involving fathers and mothers in on-going discussions about their positions in management may promote their active and informed participation.[58]

Changes in the way a society views fathers' roles could also make it easier for them to become involved in the child's medical care,[22,35,53] and in cultures where fathers have clearly defined roles in child development or where institutional policies make this financially possible, there seem to be more opportunities for fathers to be involved.[17] While a need to access fathers' views through research is highlighted in the literature, some inherent challenges have also been identified.[22,46,56] These include the need to promote greater paternal participation in descriptive and interventional research to increase our understanding of the barriers to their health-care participation and to the range of incentives (informational, financial, social and psychological) that might encourage participation (Table 7).

Discussion

The evidence reviewed from research conduced in seven counties over a 13-year period using qualitative, quantitative and mixed methods, and involving a wide range of conditions extends the previously limited knowledge about fathers' management contributions.[58,70,71] This review indicates that levels of paternal involvement are likely to be underestimated in the literature because of difficulty obtaining views from a group that is often less 'visible' to health professionals, therefore harder to reach for research purposes.[70] Understanding and overcoming male barriers to participation in research may help overcome men's difficulties with respect to their overall engagement in long-term condition management and help us understand whether or not lack of paternal research involvement indicates lack of involvement in their child's medical care.[22,58]

The need to consider fathers when planning provision of management support at institutional and policy level is also highlighted.

Table 7 Summary of theme 'Strategies that increase fathers' participation in their child's health care and in research investigating fathers' participation' (Review question 5)

Citations	Main topics
35	The positive impact of an intergenerational connection was evident, for instance, when one man described how coaching he received from his own father on strategies to handle a tense situation related to his child's condition appeared to increase his feelings of protectiveness towards the family
35	Making support and information accessible to fathers and designing services and environments that take account of unique challenges fathers face can enhance their involvement in health care.
24	Correlations between fathers' levels of distress and children's subsequent adjustment
35,53	Involving fathers in care-giving; telling them their input is vital, providing opportunities for father-to-father support, giving fathers adequate notice of forthcoming meetings, ensuring health care communications are directed to both parents; providing quiet places in hospitals where fathers can reflect, hiring male health professionals to support fathers, booster (teaching) sessions to refresh basic information/techniques and staff continuity to promote consistency with agreed-upon management plans.
35	Ensuring hospital policies support both parents to stay if they wish
22,35,52,53,60,65	Providing chairs big enough for fathers, being sensitive to the unique nature of paternal adjustment processes, arranging cognitive behavioural interventions for fathers to develop functional means of coping, co-ordinating groups for fathers in tertiary/community settings and providing guidance for professionals on fathers' support needs
58	Involving fathers as well as mothers in ongoing discussions about their positions in management may help promote their active and informed participation
17	Where fathers have defined roles in child development or institutional policies make this financially possible, fathers have more opportunities for involvement.
22,46,56	Understanding barriers to fathers' participation in research and the range of incentives (informational, financial, social and psychological) that might encourage their participation is essential

Promoting fathers' involvement was not previously viewed as a priority in workplace, health-care or child-care legislation or provision. However, policies are now increasingly promoting flexible working arrangements for fathers as well as mothers (for example, the UK Department of Work and Pensions,[31] the Fatherhood Institute[32] and US public and private initiatives[30,72]). Cross-cultural comparisons of the literature identified interesting differences in fathers' roles; evidence from four studies (USA, Canada and Israel) indicates that changes in the way society views fathers' roles can positively influence fathers' involvement[22,35,53] with one notable example[17] that the authors attributed to the fact that Israeli society encourages fathers' participation in child-rearing, with all employees being entitled to sick leave when their child is ill. The economic security this engenders combined with freely available health insurance (or a national health service such as that provided in the UK[46,58,61,67]) reduced the need for fathers' to work longer hours to pay medical expenses.[17,48] In the only Taiwanese study identified in our review,[38] mothers took leave to care for their sick child, thus mothers needed to confront the stressors more directly than fathers who commonly returned to work, thereby escaping from the stressors, even for short periods. As flexible parental leave opportunities become more widely available and as more fathers become primary caregivers, this may reflect fathers' conscious or unconscious adoption of societal norms when carrying out their parental roles.[17,22,35,38,53,56,62] There is evidence from this review that fathers' efforts to promote their child's well-being may be hampered by their own suppression of emotion to appear 'strong' and may result in them receiving 'second-hand' information. The review also demonstrates that employment can be a positive catalyst for coping with stresses of a child's condition, and fathers who experience inflexible employment practices (such as those in Taiwan) may have more difficulty being fully involved in management, while acceptance of the child's condition, helping to protect their child and changed expectations for their child's development can promote the beneficial effects for fathers. The differing international perspectives and cultural differences considered in this review highlight the need for local factors to be taken into consideration while still acknowledging the potential benefits of research designs that attempt to make international comparisons.[7,46]

Health-care information is sometimes provided to fathers and mothers through different mediums;[21,22,53–57] this may affect fathers' roles in promoting their child's well-being. When fathers are supported, this can result in improved family functioning and treatment adherence. Specific advice about what fathers need could reduce stress associated with uncertainty, which might, in turn, enhance fathers' coping. Fathers' interest in understanding their child's condition is more likely to be addressed effectively, therefore, if they are included in communications with professionals and if support is made available to them through multiple means.[1,70] Communication with professionals is reported to be a primary predictor of how fathers manage stress.[56–58,62] In intact families, mothers exhibited greater efforts than fathers in coping patterns including strategies to acquire social support and support from professionals.[54]

The serious and startling nature of diagnosis and the profound powerlessness fathers experience seem to promote their personal growth, so it may be that instead of being an outcome of the process, personal growth may be an indicator of active coping. Thus, it would appear that a key factor in family adjustment to chronic illness is healthy father adjustment, and a combination of individual-, family- and organizational-level strategies to potentially strengthen fathers' participation in management and related research is presented. Nevertheless, further study is needed that involves fathers from under-represented and often 'hard to reach' groups such as those previously identified.[26]

Paternal involvement in management appeared to retard the typical deterioration in treatment adherence that often begins in early adolescence.[45] A deteriorating developmental trajectory around disease management may persist through early adulthood;[73] therefore,

levels of paternal involvement in management during late childhood and early adolescence might be expected to exert long-lasting effects on subsequent treatment adherence during later adolescence and early adulthood. It appears, therefore, that promoting fathers' involvement early in the trajectory and in particular with adolescents may have a positive impact on adherence to treatment regimens.

A range of research methodologies were used to investigate fathers' contributions (Table 2). However, many studies were condition specific. While it is possible the findings may have generic application, generalizability and transferability of the findings are limited by this and other factors including the wide range of research sites in seven different countries, the use of convenience and unmatched samples, and the wide range of instruments used to assess fathers' involvement. Although a number of validated measures and qualitative methods were used, only a small number of studies either utilized these measure with fathers specifically or analysed fathers' and mothers' data separately to produce 'father-specific' results. A full understanding of fathers' actual contributions and support needs will only be obtained if support systems and research studies are accessible to and appropriate for fathers.

This narrative review highlights some key areas where fathers' contributions can be optimized and findings have implications for intervening with fathers during the early phase of the long-term condition trajectory. Creative strategies to support fathers' roles are needed, such as key health professionals being available to meet with fathers during evening/weekend hours and use of the Internet for information sharing or group discussion with other fathers, possibly led by a man.[53,55] Based on what the literature says about gender roles and fathers' beliefs about being strong for their families,[22,53] health professionals could consider meeting with fathers in the company of the mother and alone, thereby enabling fathers to express concerns they may have and to ask difficult questions that they may censor in the mother's presence to protect her. Professionals could offer anticipatory guidance to mothers about how fathers tend to respond to diagnoses to normalize the situation and explain what may in some instances appear to be fathers' lack of concern and/or selfishness. Professionals could also educate mothers about potential benefits to the family of fathers' management involvement and coach mothers in specific ways to promote fathers' involvement.

The dearth of published longitudinal studies involving fathers has meant we were unable to speculate on the ways in which fathers' roles change over time as the child makes the transition from infancy, through adolescence and into adulthood. However, recent work is beginning to address this issue. For example in Glidden and Natcher's study,[74] couples parenting children with developmental disability (DD) completed measures of depression and subjective well-being and an inventory that assesses parental reaction to children transitioning into adulthood. For fathers, but not for mothers, the use of distancing (cognitive effort to detach from and minimize significance of the situation) was predictive of lower levels of social well-being related to the child with DD. Meanwhile, Swallow *et al.*[70] uncovered key differences between mothers' and fathers' accounts of their care-giving contributions; these were subsequently explored through individual and joint interviews with parents, and the results are being reported elsewhere.[75]

In conclusion, the review suggests fathers' management involvement can positively impact on their own and their children's well-being and family functioning. A range of strategies are identified to inform professionals and researchers who may wish to promote and support fathers' management contributions and research participation. However, there appears to be a shortage of rigorous studies involving fathers, in particular fathers from the full range of social, ethnic and educational backgrounds. Given the potential benefits for children of paternal involvement in condition management, researchers and practitioners need to make co-ordinated efforts to develop services that optimize fathers' contributions, and the future direction of research needs to involve collaborative longitudinal

studies involving qualitative and quantitative methods using novel designs that make research participation interesting and accessible to all fathers.

Acknowledgements

Grateful thanks to the parents who participated and Mr Roger Olley, Director of Fatherhood, Children North East, Newcastle upon Tyne who was adviser to the project.

Sources of funding

British Renal Society (Grant 06-017) and the Children's Kidney Unit Fund, Newcastle upon Tyne, UK.

Conflicts of interest

No conflicts of interest.

References

1 Ray LD. Parenting and childhood chronicity: making visible the invisible work. *Journal of Pediatric Nursing*, 2002; **17:** 424–438.
2 Robinson KE, Gerhardt CA, Vannatta K, Noll RB. Parent and family factors associated with child adjustment to pediatric cancer. *Journal of Pediatric Psychology*, 2007; **32:** 400–410.
3 Knafl K, Breitmayer B, Gallo A, Zoeller L. Family response to childhood chronic illness: description of management styles. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, 1996; **11:** 315–326.
4 Hatton D, Canan C, Thorne S, Hughes A. Parents' perceptions of caring for an infant or toddler with diabetes. *Journal of Advanced Nursing*, 1995; **22:** 569–577.
5 Canam C. Common adaptive tasks facing parents of children with chronic conditions. *Journal of Advanced Nursing*, 1993; **18:** 46–53.
6 Wallander JL, Varni JW, Babani L, Banis HT, Wilcox KT. Family resources as resistance factors for psychological maladjustment in chronically Ill and handicapped children. *Journal of Pediatric Psychology*, 1989; **14:** 157–173.
7 Swallow V, Lambert H, Clarke C, Campbell S, Jacoby A. Childhood chronic-kidney-disease: a longitudinal-qualitative study of families learning to share management early in the trajectory. *Patient Education and Counseling*, 2008; **73:** 354–362.
8 Schilling LS, Grey M, Knafl KA. The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis [Review] [84 refs]. *Journal of Advanced Nursing*, 2002; **37:** 87–99.
9 Swallow V, Clarke C, Campbell S, Lambert H. Nurses as family learning brokers: shared management in childhood chronic kidney disease. *Journal of Nursing and Healthcare of Chronic Illness*, 2009; **1:** 49–59.
10 Kieckhefer G, Trahms CM. Supporting development of children with chronic conditions: from compliance towards shared management. *Pediatric Nursing*, 2000; **26:** 354–363.
11 Jokinen P. The family life-path theory: a tool for nurses working in partnership with families. *J Child Health Care*, 2004; **8:** 124–133.
12 Eiser C, Havermans T. Mothers and fathers coping with chronic childhood-disease. *Psychology & Health*, 1992; **7:** 249–257.
13 Santacroce SJ. Parental uncertainty and posttraumatic stress in serious childhood illness. *Journal of Nursing Scholarship*, 2003; **35:** 45–51.
14 Sleigh G. Mothers' voice: a qualitative study on feeding children with cerebral palsy. *Child: Care, Health and Development*, 2005; **31:** 373–383, doi:10.1111/j.1365-2214.2005.00521.x
15 Swallow VM, Jacoby A. Mothers' coping in chronic childhood illness: the effect of presymptomatic diagnosis of vesicoureteric reflux. *Journal of Advanced Nursing*, 2001; **33:** 69–78.
16 Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. Constant vigilance: mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing: Nursing Care of Children and Families.*, 2003; **18:** 21–29.
17 Katz S, Krulik T. Fathers of children with chronic illness: do they differ from fathers of healthy children? *Journal of Family Nursing*, 1999; **5:** 292–315.
18 Phares V, Lopez E, Fields S, Kamboukos D, Duhig AM. Are fathers involved in pediatric psychology research and treatment? *Journal of Pediatric Psychology*, 2005; **30:** 631–643.
19 Tiedje L, Darling-Fisher C. Promoting father friendly healthcare. *The American Journal of Maternal Child Nursing*, 2003; **28:** 350–359.
20 Knafl K, Zoeller L. Childhood chronic illness: a comparison of mothers' and fathers' experiences. *Journal of Family Nursing*, 2000; **6:** 287–302.
21 Sterken DJ. Uncertainty and coping in fathers of children with cancer. *Journal of Pediatric Oncology Nursing*, 1996; **13:** 81–88.
22 Chesler MA, Parry C. Gender roles and/or styles in crisis: an integrative analysis of the experiences of fathers of children with cancer. *Qualitative Health Research*, 2001; **11:** 363–384.

23 Arockiasamy V, Holsti L, Albersheim S. Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics*, 2008; **121:** 215–222.

24 Chaney J, Mullins L, Frank RG *et al*. Transactional patterns of child, mother, and father adjustment in insulin-dependent diabetes mellitus: a prospective study. *Journal of Pediatric Psychology*, 1997; **22:** 229–244.

25 Gavin L, Wysocki T. Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illnesses. *Journal of Pediatric Psychology*, 2006; **31:** 481–489.

26 Costigan C, Cox M. Fathers' participation in family research: is there a self-selection bias? *Journal of family psychology*, 2001; **15:** 706–720.

27 O'Brien M. *Shared Caring: Bringing Fathers into the Frame*. London: Equal Opportunities Commission, 2005.

28 Yeung W. Fathers: an overlooked resource for children's school success. In: Conley D, Albright K (eds) *After the Bell: Solutions Outside the School*. London: Routledge, 2004: 145–169.

29 Lower-Basch E. *Opportunity at Work: Improving Job Quality*. Washington, DC: Ter for Law and Social Policy, 2007.

30 Beers W. When the community cares. *Health Progress*, 2000; **81:** 43–45.

31 DWP. *Flexible Working*. London: Department of Work and Pensions, 2007.

32 Fatherhood-Institute. *The Difference a Dad Makes*. Abergevenny: The Fatherhood Institute, 2007.

33 Corporate-Voices. *Flexible Work Strategies: Attitudes and Experiences*. Washington, DC: Corporate Voices for Working Families, 2008.

34 Pelchat D, Lefebvre H, Levert M-J. Gender differences and similarities in the experience of parenting a child with a health problem: current state of knowledge. *J Child Health Care*, 2007; **11:** 112–131.

35 McNeill T. Fathers' experience of parenting a child with juvenile rheumatoid arthritis. *Qualitative Health Research*, 2004; **14:** 526–545.

36 Reeves E, Timmons S, Dampier S. Parents' experiences of negotiating care for their technology dependent child. *Journal of Child Health Care*, 2006; **10:** 228–239.

37 EHRC. *Working Better: Fathers, Family and Work Contemporary Perspectives*. London: Equality and Human Rights Commission, 2009.

38 Yeh C. Gender differences of paternal distress in children with cancer. *Journal of Advanced Nursing*, 2002; **38:** 598–606.

39 Burgess A. Fathers and public services. In: Stanley K (ed.) *Daddy Dearest: Active Fatherhood and Public Policy*. London: Institute of Public Policy Research, 2005: 57–74.

40 Dex S, Ward K. *Parental Care and Employment in Early Childhood*. Working paper Series No. 57London: Equal Opportunities Commission, 2007.

41 Mokkink L, van der Lee J, Grootenhuis M, Offringa M, Heymans H. Defining chronic diseases and health conditions in childhood (0–18 years of age): national consensus in the Netherlands. *European Journal of Pediatrics*, 2008; **167:** 1441–1447.

42 Vessey J. Psychological comorbidity in children with chronic conditions. *Pediatric Nursing*, 1999; **25:** 211–214.

43 Mishel MH. Uncertainty and coping in fathers of children with cancer. *Journal of Pediatric Oncology Nursing*, 1996; **13:** 89–90.

44 Mays N, Pope C, Popay J. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research Policy*, 2005; **10:** 6–20.

45 Wysocki T, Gavin L. Paternal involvement in the management of pediatric chronic diseases: associations with adherence, quality of life and health status. *Journal of Pediatric Psychology*, 2006; **31:** 501–511.

46 Watson A. Stress and burden of care in families with children commencing renal replacement therapy. *Advances in Peritoneal Dialysis*, 1997; **13:** 300–304.

47 Katz S. When the child's illness is life threatening: impact on the parents. *Pediatric Nursing*, 2002; **28:** 453–463.

48 Katz S. Gender differences in adapting to a child's chronic illness: a causal model. *Journal Of Pediatric Nursing*, 2002; **17:** 257–269.

49 Hovey JK. Differences in parenting needs of fathers of children with chronic conditions related to family income. *Journal of Child Health Care*, 2006; **10:** 43–54.

50 Hovey JK. Fathers parenting chronically ill children: concerns and coping strategies. *Issues in Comprehensive Pediatric Nursing*, 2005; **28:** 83–95.

51 Rodrigues N, Patterson J. Impact of severity of a child's chronic condition on the functioning of two-parent families. *Journal of Pediatric Psychology*, 2007; **32:** 417–426.

52 Weiner L, Vasquez M, Battles H. Brief report: fathering a child living with HIV/AIDS: psychosocial adjustment and parebting stress. *Journal of Pediatric Psychology*, 2001; **26:** 253–258.

53 Neil-Urban S, Jones J. Father-to-father support: fathers of children with cancer share their experience. *Journal of Pediatric Oncology Nursing*, 2002; **19:** 97–103.

54 Brazil K, Krueger P. Patterns of family adaptation to childhood asthma. *Journal Of Pediatric Nursing*, 2002; **17:** 167–173.

55 McGrath P, Chesler M. Fathers' perspectives on the treatment for pediatric hematology: extending the

findings. *Issues in Comprehensive Pediatric Nursing*, 2004; **27:** 39–61.
56 Peck B, Lillibridge J. Normalization behaviours of rural fathers living with chronically-ill children: an Australian experience. *J Child Health Care*, 2005; **9:** 31–45.
57 Pelchat D, Lefebvre H, Perreault M. Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care*, 2003; **7:** 231–247.
58 Swallow V. An exploration of mothers' and fathers' views of their identities in chronic-kidney-disease management: parents as students? *Journal of Clinical Nursing*, 2008; **17:** 3177–3186.
59 Clark S, Miles M. Conflicting responses: the experiences of fathers of infants diagnosed with severe congenital heart disease. *Journal for Specialists in Paediatric Nursing*, 1999; **4:** 7–14.
60 Sullivan-Bolyai S, Rosenberg R, Bayard M. Fathers' reflections on parenting young children with type 1 diabetes. *MCN, American Journal of Maternal Child Nursing January/February*, 2006; **31:** 24–31.
61 Douglas JE, Hulson B, Trompeter RS. Psycho-social outcome of parents and young children after renal transplantation. *Child Care Health and Development*, 1998; **24:** 73–83.
62 Pei-Fan Mu. Paternal reactions to a child with epilepsy: uncertainty, coping strategies, and depression. *Journal of Advanced Nursing*, 2005; **49:** 367–376.
63 Goble L. The impact of a child's chronic illness on fathers. *Issues in Comprehensive Pediatric Nursing*, 2004; **27:** 153–162.
64 Barakat L, Alderfer M, Kazak AE. Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology*, 2006; **31:** 413–419.
65 Hovey JK. The needs of fathers parenting children with chronic conditions. *Journal of Pediatric Oncology Nursing*, 2003; **20:** 245–251.
66 Soliday E, Kool E, Lande MB. Family environment, child behavior, and medical indicators in children with kidney disease. *Child Psychiatry & Human Development*, 2001; **31:** 279–295.
67 Worrall-Davies A, Owens D, Holland P, Haigh D. The effect of parental expressed emotion on glycaemic control in children with Type 1 diabetes: parental expressed emotion and glycaemic control in children. *Journal of Psychosomatic Research*, 2002; **52:** 107–113.
68 Dashiff CJ. Self- and dependent-care responsibility of adolescents with IDDM and their parents. *Journal of Family Nursing*, 2003; **9:** 166–183.
69 Wysocki T, Gavin L. Psychometric properties of a new measure of fathers' involvement in the management of pediatric chronic diseases. *Journal of Pediatric Psychology*, 2004; **29:** 231–240.
70 Swallow V, Macfadyen A, Lambert H, Santacroce S, Olley R. Fathers and mothers of children with long term kidney conditions: a qualitative study of their contributions to their child's healthcare (Nephrology and clinical genetics joint session). *Archives of Disease in Childhood*, 2009; **94:** A34–A37.
71 Aldridge M. How do families adjust to having a child with chronic kidney failure? A systematic review *Nephrology Nursing Journal*, 2008; **35:** 157–162.
72 Lower J. Creating a culture of civility in the workplace: use these 7 challenges to clean up a toxic work environment. *American Nurse Today*, 2007; **2:** 49.
73 Bryden K, Peveler R, Stein A, Neil A, Mayou R, Dunger D. Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care*, 2001; **24:** 156–1540.
74 Glidden LM, Natcher AL. Coping strategy use, personality, and adjustment of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research*, 2009; **53:** 998–1013.
75 Swallow V, Lambert H, Santacroce S, Macfadyen A. Fathers and mothers developing skills in managing children's long-term medical condition: how do their qualitative accounts compare? *Child: Care Health & Development*, in press. DOI: 10.1111/j.1365-2214.2011.01219.x, 6 March 2011.