

## Review

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# Detached, distraught or discerning? Fathers of adolescents with chronic illness: a review of the literature

**Abstract:** Parenting a child with chronic disease provides a unique set of challenges for both mothers and fathers throughout all phases of the illness. However, fathers of these children are under-represented in existing research. This review focuses on the fathers of children with chronic disease included in 44 original articles. We address the challenges to the father's role as breadwinner, leader and strength-giver in the family. Three time-periods describe the obstacles fathers tackle when parenting children with chronic disease: a) diagnosis and short-term, characterized by distress, isolation and uncertainty; b) the mastery period, characterized by the struggle to establish routine and by support and spirituality; and c) the long-term, characterized by relationship and personality change, worries and bereavement. Overall, whilst current research has revealed some key themes pertaining to fathers of children with chronic disease, further studies are required to foster the development of support mechanisms for the specific needs of these fathers.

**Keywords:** adolescents; chronic illness; fathers; parent-child relations.

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## Introduction

Parents are the key influences on their child's life. Parenting a child with a chronic disease provides a unique

set of challenges for mother and father alike; both parents need support when their child has a chronic illness. In her traditional role of primary carer, a significant amount of research has investigated mothers of children with chronic illness. Little research, however, has delved specifically into the other side of parenting. Fathers are hence an under-represented population in existing research.

Men are aware that they deal with stressful medical situations differently from women; some men appear detached and spend time at work (1), others are distraught and display somatic symptoms (2). Other fathers are quietly discerning, stay more nights at the hospital, acting as a pillar of strength for child, mother and family (3). The paucity of current literature means that we have little understanding of fathers of children with chronic disease, and hence are unaware of how best to support them.

This knowledge gap provided the basis to the key question of this review; what, exactly, is known about the fathers of adolescents with chronic disease? This article reviews the literature regarding fathers of adolescents with chronic illness. We discuss the role of the father in children with chronic illness and examine his coping and adaptive strategies around diagnosis, in the medium and long-term.

## Methods

The most prevalent chronic illnesses were selected as a representative sample of chronic disease in adolescence. Using PubMed, a search was undertaken using the following MeSH terms: Adolescent, Father, Asthma, Cystic Fibrosis, Diabetes, Juvenile Rheumatoid Arthritis and Neoplastic Disease (Table 1).

The search was performed on 1 June 2010, and returned 152 results. These were assessed for relevance to the review question (Figure 1). Seventy-four of the studies researched another topic (genetic studies, legal cases), 27 were unrelated (causal relationships of childhood disease), and 15 concerned parent illness so were all excluded. One potentially relevant manuscript was also excluded because no English version was available and a further article was excluded because it focused solely on mothers. Additionally, one

**Table 1** Search terms used on PubMed (1 June 2010).

#1 Search “fathers”[MeSH terms] n=4836
#2 Search “adolescent”[MeSH terms] n=1338556
#3 Search (((diabetes[MeSH terms]) OR “arthritis, juvenile rheumatoid”[MeSH terms]) OR “cystic fibrosis”[MeSH terms]) OR “asthma”[MeSH terms] n=376356
#4 Search “neoplasms”[MeSH terms] n=2138738
#5 Search (#4) OR #3 n=2504031
#6 Search ((#2) AND #1) AND #5 n=152

review article was excluded as we sought to analyze only original data.

Consequently, 33 of the 152 articles were selected as appropriate and analyzed. Additionally, the references for these studies were searched for articles pertinent to the review question; 11 further articles were identified bringing the total sample size to 44. The review includes six articles published between 1985 and 1993. A distinct break in literature occurred between 1993 and 1996 where no studies pertinent to our enquiry occurred. The remainder of the sample were published between 1996 and 2010. Geographically, 19 of the papers originated from North America, 17 from the UK and Europe (eight from Scandinavia), five from Asia and three articles from Australasia.

Most manuscripts covered a broad age range, from 6 months up to 20 years. All papers included teenagers in their analysis, however only five papers excluded children under 10 years of age, focusing entirely on adolescents. Eight studies solely investigated fathers; another seven articles investigated fathers and mothers with parents of healthy children as controls; and the remainder researched mothers, patients and siblings, with paternal data described separately. Of the 44 studies, 13 were qualitative research, 27 were quantitative (predominantly questionnaire based), two were a mix of both methods and two were longitudinal studies.

More than one-half of the papers reviewed (23/44) focused only on parents of children with neoplastic disease and eight publications focused on parents of diabetes patients. Seven articles investigated multiple childhood diseases, including neoplastic disease, juvenile rheumatoid arthritis and cystic fibrosis (4), neoplastic disease or sickle cell disease (5), diabetes and asthma (6), diabetes, asthma, cystic fibrosis, spina bifida and phenylketonuria (7), mental and physical disability and diabetes (8), inflammatory bowel disease and diabetes (9) and imperforate anus and juvenile rheumatoid

arthritis (10). The remainder of the sample discussed parents of patients with asthma (11, 12), cystic fibrosis (13, 14) and unspecified chronic disease or life-limiting illness (15, 16). The selection of the articles was done by the first author. The articles reviewed are described in Table 2.

## Results

Fathers are traditionally the figurehead and leader of the family. In recent decades, gradual erosion of traditional roles and more complex family situations have seen the father’s role become more adaptable and involved with parenting. In the majority of families the father remains the major income earner, in addition to playing an active parenting responsibility.

Chronic illness poses significant challenges to the father’s role, actual or perceived. This section examines how the father’s role is again re-defined as a result of the financial, temporal and emotional stresses on the family unit that accompany a child with chronic illness. Importantly, several authors have illustrated a link between paternal distress and poorer outcomes, including a sense of hopelessness or more variable metabolic control, in their chronically ill child (20, 24, 38).

Fathers often highlight a struggle to define their new role within the household after their child’s diagnosis. Fathers interviewed by Nicholas et al. (3) described having their self-perception as the family’s “strength giver” damaged. The men also described their conflicted concept of the father role; their child’s chronic illness threatened their perception of masculinity and protective role. Contrastingly, fathers often took on new domestic and household responsibilities, including meal preparation and caring for the patient’s siblings, when the mother stayed with the child during inpatient care (1, 19).

The “stoic father” stereotype inspires two conflicting views in existing literature. In several studies, men described “being strong” for their spouses (3, 43). Some fathers interviewed by Hayes and Savage (14) described becoming more stressed and upset than their wives. Ware and Raval (16) identified that their interviewees relied on socio-cultural norms of male expression and hence their ability to express emotions was, in some way, deficient. The study emphasized that, despite existing perceptions, fathers do want to talk about their child’s illness.

The role of “breadwinner”, provider and, most often, major income earner also poses a challenge to fathers of chronically ill children. Several articles emphasized the

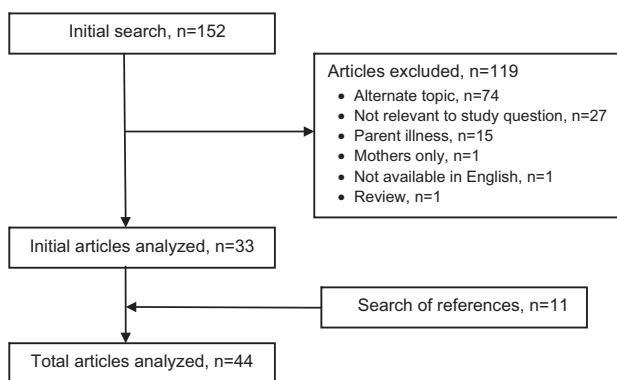
**Figure 1** Article exclusion/inclusion process.

Table 2 Summary of articles reviewed.

Author(s) (reference)	Year	Type	Disease(s)	n (total)	n (fathers)	Children age range (mean), years	Country
Barakat et al. (17)	2006	Mixed	ND	403	107	11–19 (14.7)	USA
Barrera et al. (18)	2009	Qualitative	ND	31	13	0–20.7	Canada
Bennett Murphy et al. (19)	2008	Quantitative	ND	60	20	1.5–18	USA
Blotcky et al. (20)	1985	Quantitative	ND	96	32	8–16 (11.9)	USA
Bowes et al. (21)	2009	Qualitative	D	17	7	9–23	UK
Brody and Simmons (22)	2007	Qualitative	ND	8	8	4–16 (8.2)	USA
Bruce et al. (23)	2005	Quantitative	ND	145	45	11–16 (13.4)	UK
Cashin et al. (11)	2008	Qualitative	A	8	8	7–11	Canada
Chaney et al. (24)	1997	Quantitative	D	99	49	7–16 (11.4)	USA
Cowen et al. (13)	1986	Quantitative	CF	299	Not stated	2–20	Canada
Dockerty et al. (25)	2000	Quantitative	ND	887	197	0–14	New Zealand
Gavin and Wysocki (7)	2006	Quantitative	A, IBD, PKU, SB, D, CF	380	190	2–18 (10.2)	USA
Grootenhuis and Last (26)	1997	Quantitative	ND	163	79	8–18 (13.1)	Netherlands
Hayes and Savage (14)	2008	Qualitative	CF	8	8	1.5–6	Ireland
Hilliard et al. (6)	1985	Quantitative	A, D	128	48	6–12	USA
Hoekstra-Weebers et al. (27)	1998	Quantitative	ND	164	79	0–15	Netherlands
Hovey (4)	2005	Quantitative	ND, JRA, CF	48	48	Not stated	USA
Kazak et al. (28)	1998	Quantitative	ND	864	224	6–20 (13.3)	USA
Lahteenmaki et al. (29)	2008	Quantitative	ND	195	65	9–19 (14)	Finland
Landolt et al. (30)	2002	Quantitative	D	73	36	6.5–14 (10.5)	Switzerland
Lannen et al. (31)	2008	Quantitative	ND	499	191	0–17	Sweden
Leonard et al. (32)	1997	Quantitative	D	58	29	8–14 (11.1)	USA
Lindstrom et al. (9)	2010	Quantitative	D, IBD	413	126	1–18	Sweden
Martinson et al. (2)	1997	Qualitative	ND	176	88	0–17	Hong Kong
McGrath and Huff (1)	2003	Qualitative	ND	19	6	1.5–8	Australia
Mu et al. (33)	2002	Quantitative	ND	80	80	0.6–19 (9.6)	Taiwan
Nicholas et al. (3)	2009	Qualitative	ND	16	16	1–17	Canada
Ojmyr-Joelsson et al. (10)	2009	Quantitative	IA, JRA	152	45	8–13.6 (10.5)	Sweden
Ozono et al. (34)	2007	Quantitative	ND	247	72	12–20	Japan
Palmer et al. (35)	2009	Quantitative	D	515	145	10–14 (12.5)	USA
Patino-Fernandez et al. (36)	2008	Quantitative	ND	201	72	1 month–18 years (8.2)	USA
Peck and Lillibridge (15)	2005	Qualitative	Not specified	4	4	2–9	Australia
Poder et al. (37)	2008	Longitudinal	ND	214	107	9 months–17 years (7.8)	Sweden
Robinson et al. (38)	2007	Quantitative	ND	420	67	8–15 (12.02)	USA
Ryden et al. (39)	1990	Quantitative	D	117	39	8–18	Sweden
Ryden et al. (40)	1993	Quantitative	D	59	19	8–18	Sweden
Schobinger et al. (12)	1992	Qualitative	A	50	27	6–13	Germany
Seiffge-Krenke (41)	2002	Longitudinal	D	504	58	(13.9)	Germany
Sterken (42)	1996	Quantitative	ND	31	31	1–18	USA
Taanila et al. (8)	1999	Mixed	P/ID, D	159	74	12–17	Finland
Ware and Raval (16)	2007	Qualitative	LLI	8	8	Not stated	UK
Wills (43)	2009	Qualitative	ND	17	8	9 months–4 years	Hong Kong
Wolff et al. (5)	2010	Qualitative	ND, SCD	15	15	Not stated	USA
Yeh (44)	2004	Quantitative	ND	342	171	0–20 (7.63)	Taiwan

A, asthma; CF, cystic fibrosis; D, diabetes; IBD, inflammatory bowel disease; IA, imperforated anus; JRA, juvenile rheumatoid arthritis; LLI, life-limiting illnesses; P/ID, physical or intellectual disability; PKU, phenylketonuria; ND, neoplastic disease; SB, spina bifida; SCD, sickle cell disease.

tension between providing financially for the family and physically spending time with the sick child (1, 3, 19). At least one study mentioned fathers who declined promotion as a result of their child's illness (15). Families interviewed by McGrath and Huff (1) described one father's

frustration at the need to return to work a few weeks after their child's cancer diagnosis, rather than care for the child. Contrastingly, fathers in two papers cited employment as an outlet – a chance for time away from the intensity of the child's treatment (1, 15).

Whilst in the majority of cases the mother is the primary health carer (10), a key theme mentioned throughout qualitative studies was the desire for fathers to be seen by the health team as an active carer (5, 16, 22). Fathers were as “in tune” with their children as mothers of children with chronic disease (23, 29). However, two articles noted that medical personnel speak primarily to females ahead of males, which further enhanced the father’s sense of isolation (16, 22). In several interviews, fathers questioned the reinforcement of gender-based stereotypes as unhelpful when it came to the child’s care. Additionally, McGrath and Huff (1) described several situations when the ill child preferred to be accompanied by the father such as staying on the ward overnight for treatment or during weekends as an inpatient.

Notably, Brody and Simmons (22) highlighted the need for awareness of the family situation; that the needs of single fathers are likely different to fathers who are married. Wolff et al. (5) described single fathers’ need for increased gender role flexibility and, in particular, documented the highly variable attitudes from the health system towards single fathers.

## Diagnosis and short term

Diagnosis of a child with chronic illness is a particularly stressful time for both parents (27, 30). For some fathers, diagnosis signifies the end of a long and frustrating path of symptoms and relief at having a clear management plan (11). For others, diagnosis can be an unexpected devastation, a theme repeatedly mentioned by Nicholas et al. (3). Several authors have investigated the post-traumatic stress in parents of children with chronic disease (28, 30, 34, 36, 37). Manifestations of stress, such as dissociation, re-experience, hyper-arousal and avoidance, have been identified as most prevalent closer to diagnosis (37). Indeed, one-half of that study’s parents exhibiting acute stress disorder at 1 week had post-traumatic stress disorder diagnoses made at 4 months. Several studies illustrated that fathers are less distressed than mothers at diagnosis (19, 36), although as time from diagnosis passes, levels of distress decrease in both genders (34).

In addition to psychological distress, some fathers manifest somatic symptoms around the time of diagnosis. A number of qualitative studies included fathers’ descriptions of somatic symptoms (3, 5). Although more prevalent in mothers, Martinson et al. (2) quantified that fathers were more likely to exhibit symptoms of colds closer to diagnosis, while other somatic symptoms (including

nausea, headaches, dizziness, loss of appetite and weight loss) were more prevalent in mothers.

At diagnosis, some fathers prioritized information gathering and learning about the illness (44). Martinson et al. suggested that this is because mothers (in some cultures) rely on the fathers for information. Fathers interviewed by Wills sought concise, accurate and honest information from the physician (43). Conversely, other researchers (5, 14) described some fathers minimizing information-seeking behaviours in order to foster a sense of normalcy.

## Mastery: coming to terms with chronic illness

After the distress of diagnosis, fathers begin to come to terms with disease processes and the treatment regimen the child will have; as a separate entity to long-term outcomes, the ways that fathers adjust to chronically ill children in the medium term is of interest. This period is characterized by the establishment of some routine or daily rhythm, vastly different from the family’s routine prior to diagnosis (11). Through this time, patients and parents learn to cope with the child’s illness and its intricacies; they adapt, develop knowledge, understanding and, to a point, mastery of the chronic illness.

What the fathers (and researchers) view as pragmatism or “task orientation” we have termed mastery. This key theme of coping is approached in several studies (4, 11, 19, 21, 42), and encompasses a degree of both physical mastery (e.g., effective inhaler use in asthma), planning (e.g. knowing when to take insulin), when and where to seek help and, to a degree, amelioration of uncertainty.

A recurring theme is that a father’s key support mechanism is talking with his partner (3). Yeh (44) illustrated that men were significantly more likely to use this as a major coping mechanism than women. Seeking social support was another coping mechanism utilized by significantly more fathers than mothers (27). Additionally, fathers described seeking the support of other family members, particularly their brothers and fathers (43).

In cases of more prevalent or publicized illnesses, such as asthma or cancer, fathers reported receiving high levels of support from both their community and parents of children with the same illness (1, 11, 21). In some settings, particularly rarer diseases (6) or a rural context (20), the nature of the illness left fathers isolated (15); other fathers, whilst at ease talking about either their child, or the chronic disease alone, reported difficulties talking about their child and the illness together in context (14).

For some fathers and families, this is a time of alienation and struggle. Fathers from several qualitative studies (3, 16, 18, 21) discussed feelings of isolation as a result of their child's illness. These findings were contrasted by a study in which the authors quantified that fathers reported significantly fewer feelings of loneliness than mothers (26).

One key form of coping utilized by fathers is the normalization of their sick child. Fathers interviewed by Peck and Lillibridge (15) described the desire to maintain a sense of normalcy; the theme is emphasized throughout a number of articles (4, 15, 32). Indeed, Hilliard et al. (6) illustrated that fathers of children with asthma and diabetes had higher aspirations for their children when compared to aspirations of fathers of healthy children.

Both normalization and mastery may be impeded by uncertainty. Uncertainty correlated with parental anxiety and poor coping (33). Interestingly, the same article also reported high levels of education correlating with increased anxiety in fathers of childhood cancer patients.

Some studies suggested fathers consider themselves as more task oriented than mothers regarding the illness and coping (26, 27). In interviews, fathers often considered themselves more pragmatic than their wives (14).

Several studies identified spirituality as a key component of coping. Wills (43) interviewed eight Hong Kong Chinese fathers of recently diagnosed paediatric patients with acute lymphoblastic leukaemia. The author established the fathers' increased spirituality and faith as a recurring theme. This finding was not unicultural; fathers in Canadian, American and Taiwanese studies also sighted increased faith and spirituality when coming to terms with their child's chronic illness (18, 22, 44).

Notably, burn-out (a combination of emotional exhaustion, physical fatigue, listlessness, tension and cognitive difficulties) may be experienced by parents of chronically ill children. Lindstrom et al. (9) investigated this phenomenon in the parents of children with diabetes and with inflammatory bowel disease, and found that although burn-out was more prevalent in mothers than fathers, fathers of chronically ill children suffered significantly more burn-out than fathers of healthy children. Increased tobacco or alcohol consumption may herald an impending burn-out. Although alcohol, tobacco and illegal substances were utilized by a minority of fathers, they did not identify this as a useful coping mechanism (4).

## Long-term outcomes

In the long-term, fathers, by and large, come to terms with their child's chronic illness (11, 14). Although it is

important to note the specific differences between illnesses, some factors remain central to the long-term outcomes of fathering a child with chronic disease.

Fathers often identified change in their personalities, which they ascribed to their child's illness (22). Fathers interviewed by Brody and Simmons (22) described themselves as becoming more lenient and understanding. Seiffge-Krenke (41) undertook a study in which families (with and without a diabetic adolescent) performed a problem-solving exercise together. This study highlighted a difference in parenting style in fathers of children with diabetes that the authors attributed to childhood illness. Notably, fathers of children with diabetes responded less frequently to their child's requests and requested their input less frequently. However, they were also less likely to interrupt than the fathers of healthy children. The contributions of diabetes-affected fathers were both fewer in number, but also vaguer and less opinionated (41). These findings contrasted strongly with Hilliard et al. (6), who illustrated fathers with higher, often unrealistic, aspirations for their chronically ill children.

In a study of parents of childhood cancer survivors investigating post-traumatic personal growth, 80% of fathers reported one or more positive effect of their child's cancer (17). Such positive effects included the way parents treated other people and how they thought about their life. Another study in which fathers were interviewed mentioned the personal growth that occurred as a result of the child's illness (22). Barakat et al. (17) suggested that post-traumatic growth is associated with a sense of control over the day-to-day aspects of the illness.

A number of articles investigated bereaved parents (3, 18, 25, 31). Dockerty et al. (25) quantified that fathers of deceased children had poorer general health, poorer coping and lower mood ratings than fathers with children undergoing treatment for cancer. Furthermore, Barrera et al. (18) hypothesized that as mothers play a more prominent carer role, they consequently experience a greater feeling of loss and struggle more with re-establishing their self-identity after a child's death.

Irrespective of impeding bereavement, chronic disease casts a long shadow over the lives of fathers with chronically ill children. Fathers in various studies (11, 14, 21) described constant worries, many years into the illness. These involved both concern for the child's immediate health (21), worries about the child's future (14) or fear of the return of malignant disease (22). In some cases, for fathers whose children had survived childhood cancer, this worry manifested in the long-term as somatic symptoms (2). Overall, there was a

strong consensus within the literature that unresolved grief leads to long-term poorer physical and mental health (2, 21, 31, 34).

Long-term illness invariably alters the relationship between parents. Fathers interviewed in a study noted the increased strength and quality of marital relationships, particularly when approaching the illness as a team (11). Other studies highlighted that a child's illness placed enormous amounts of stress on the parents' relationship (10, 39, 40). For interviewees in a couple of studies, the marriage was a source of instability and stress in the long-term. Parents spoke about the elimination of any "special bond" between husband and wife (18) and in some cases resentment of the spouse (3).

In the long-term, fathers also cited relationships with their other children as important. Again, a tension was noted between the fathers' desire to spend time with all their children, whilst acknowledging the increased needs of the unwell child (1, 16). In particular, parents of chronically ill children spoke of the need to maintain strong bonds with the child's siblings (1, 18).

## Discussion

This article reviews the scarce literature concerning the fathers of adolescents with chronic disease. Fathers are a challenging group to assess for several reasons. Indeed, when this review's search strategy is applied using the term "mothers" instead of "fathers", it yields a 26-fold increase in results (4043 articles). This number alone harks to the challenges of recruiting fathers of adolescents.

The lack of research in this domain is also reflected in the age group studied. Even though our objective was to limit our search to fathers of adolescents, we finally enlarged it to include younger children because, if only using studies including participants aged 10 years or older, we would have found only five articles (8, 17, 23, 34, 35).

Less than one-fifth of articles studied only fathers (8/44); the majority of papers instead analyzed data collected for fathers, mothers and often children. Several of the qualitative studies assessed specifically mentioned difficulties in recruiting (11, 14, 16). Other papers instead interviewed "couples", with or without the father present (1, 43). Even in the largest studies analyzed (31, 35), there is a marked disparity between the number of fathers and number of mothers researched. We postulate that the challenges recruiting fathers are 2-fold. Firstly, in the majority of cases, mothers are the primary health carer. Consequently,

fathers are less likely to present with the adolescent to the hospital. This, in turn, decreases opportunities to directly involve fathers in research, instead relying on a second-hand message via the primary carer or child. Secondly, despite some studies describing fathers' desires for the chance to talk, the communication lines remain relatively closed. As mentioned, the father's key support is his partner, and they are less likely than mothers to seek broad and varied forms of support. Indeed, participating in research itself might be viewed by fathers as a form of support; enough to scare most fathers away.

In turn, this leads to a misrepresentation in the existing data; that is, the few fathers who are engaged in their child's healthcare – and consequent research – provide large amounts of information, whereas the silent majority of fathers are under-represented as they do not volunteer information. Hence, we suspect that this review conveys a more optimistic assessment than the reality.

Fathers of children with neoplastic illnesses are relatively well represented in this review. As the majority of the studies analyzed investigate parents of childhood cancer patients, the findings may over-emphasize aspects of diagnosis and immediate treatment, as opposed to the daily approach to chronic illnesses. Hence, although there is significant meaning and unique psychological stressors attached to cancer, the existing literature does not adequately represent the combined burden of adolescent disease.

The theme of mastery, although well established in various articles, was not well quantified by the studies reviewed. Indeed, only two papers (29, 35) used appropriate outcomes to assess either the child's or father's mastery of a chronic disease.

Interestingly, fewer studies than expected discussed the interaction between parents. Literature has previously investigated marital distress and instability and divorce in the parents of chronically ill children (45–48). Although divorce rates are comparable to the general population (45, 46), the studies highlighted an increase in marital distress (47). Investigation of marital distress in parents of chronically ill children specifically from a father's perspective could provide further insight into their coping strategies.

## Limitations

This review has some limitations. First, we limited our searches to one database (PubMed). However, the fact that we subsequently searched the references of the selected articles should minimize this. Second, we limited

our search to the most prevalent chronic illness, which may have reduced the overall sample size. However, we selected the named illnesses that account for the major burden of disease in the adolescent population. Third, we did not include disabilities in our search, which could slightly modify our results. Finally, some of the reviewed articles are based on small samples and their generalization cannot be warranted.

## Future research

As identified throughout this review, fathers of children with chronic illness represent an under-researched population. There is hence broad scope for future research in the area.

A gap exists in father-specific research; studies focusing solely on fathers are essential to further develop knowledge and understanding of this population. In this review the large studies under-represented fathers and more than one-half of those that analyzed fathers alone had fewer than 20 participants.

Moreover, research with adequate and appropriate controls is needed. We reviewed 44 papers, of which seven compared parents or families of healthy controls. Only three directly compared fathers of children with chronic disease to fathers of healthy children. There was also a tendency in the literature to compare multiple illnesses concomitantly, but not healthy controls.

Additionally, of the manuscripts reviewed, only five exclusively researched parents of children aged 10 years and above. Specific research is required on the fathers of adolescents with chronic illness, particularly as this time presents unique parenting challenges. Furthermore, severity and duration of the disease and age at diagnosis should also be included as important research covariates.

## References

- McGrath P, Huff N. Including the fathers' perspective in holistic care. Part 1: findings on the fathers' experience with childhood acute lymphoblastic leukaemia. *Aust J Holist Nurs* 2003;10:4–12.
- Martinson IM, Liu-Chiang CY, Yi-Hua L. Distress symptoms and support systems of Chinese parents of children with cancer. *Cancer Nurs* 1997;20:94–9.
- Nicholas DB, Gearing RE, McNeill T, Fung K, Lucchetta S, et al. Experiences and resistance strategies utilized by fathers of children with cancer. *Soc Work Health Care* 2009;48:260–75.
- Hovey JK. [Fathers parenting chronically ill children: concerns and coping strategies.](#) *Issues Compr Pediatr Nurs* 2005;28:83–95.
- Wolff J, Pak J, Meeske K, Worden JW, Katz E. [Challenges and coping styles of fathers as primary medical caretakers: a multicultural qualitative study.](#) *J Psychosoc Oncol* 2010;28:202–17.
- Hilliard JP, Fritz GK, Lewiston NJ. [Levels of aspiration of parents for their asthmatic, diabetic, and healthy children.](#) *J Clin Psychol* 1985;41:587–97.
- Gavin L, Wysocki T. Associations of paternal involvement in disease management with maternal and family outcomes in families with children with chronic illness. *J Pediatr Psychol* 2006;31:481–9.

It is imperative that future research is well powered. Current data paint a surprisingly positive picture. We propose, however, that existing data may not be truly representative of fathers of children with chronic disease, and that future research will more accurately reveal the challenges these men face. Disengaged, hard-to-reach fathers must be the target of future research.

## Conclusions

This article has reviewed the existing literature regarding the fathers of children with chronic illness. Whilst current research has established some key themes pertaining to these fathers, more studies are needed to quantify specific areas that might help to support and understand fathers at diagnosis, as they come to terms with their child's disease and in the long-term, both generally and focused on specific illnesses. Indeed, further understanding of fathers' distress, detachment or discern would be beneficial both to fathers, their chronically ill children and the entire family unit.

Finally, clinicians dealing with chronically ill children should encourage the participation of fathers in the consultations to make them part of the process.

**Acknowledgments:** Henry Goldstein undertook this work during a final-year medical student elective at the Research Group on Adolescent Health in Lausanne, Switzerland.

### Conflict of interest statement

**Competing interests:** none.

**Funding:** none.

Received November 16, 2011; accepted December 28, 2011; previously published online January 12, 2013

8. Taanila A, Jarvelin MR, Kokkonen J. Cohesion and parents' social relations in families with a child with disability or chronic illness. *Int J Rehabil Res* 1999;22:101–9.
9. Lindstrom C, Aman J, Norberg AL. Increased prevalence of burnout symptoms in parents of chronically ill children. *Acta Paediatr* 2010;99:427–32.
10. Ojmyr-Joelsson M, Nisell M, Frenckner B, Rydelius PA, Christensson K. A gender perspective on the extent to which mothers and fathers each take responsibility for care of a child with high and intermediate imperforate anus. *J Pediatr Nurs* 2009;24:207–15.
11. Cashin GH, Small SP, Solberg SM. The lived experience of fathers who have children with asthma: a phenomenological study. *J Pediatr Nurs* 2008;23:372–85.
12. Schobinger R, Florin I, Zimmer C, Lindemann H, Winter H. Childhood asthma: paternal critical attitude and father-child interaction. *J Psychosom Res* 1992;36:743–50.
13. Cowen L, Mok J, Corey M, MacMillan H, Simmons R, et al. Psychologic adjustment of the family with a member who has cystic fibrosis. *Pediatrics* 1986;77:745–53.
14. Hayes CC, Savage E. Fathers' perspectives on the emotional impact of managing the care of their children with cystic fibrosis. *J Pediatr Nurs* 2008;23:250–6.
15. 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.
16. Ware J, Raval H. A qualitative investigation of fathers' experiences of looking after a child with a life-limiting illness, in process and in retrospect. *Clin Child Psychol Psychiatry* 2007;12:549–65.
17. Barakat LP, Alderfer MA, Kazak AE. Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *J Pediatr Psychol* 2006;31:413–9.
18. Barrera M, O'Connor K, D'Agostino NM, Spencer L, Nicholas D, et al. Early parental adjustment and bereavement after childhood cancer death. *Death Stud* 2009;33:497–520.
19. Bennett Murphy LM, Flowers S, McNamara KA, Young-Saleme T. Fathers of children with cancer: involvement, coping, and adjustment. *J Pediatr Health Care* 2008;22:182–9.
20. Blotcky AD, Raczynski JM, Gurwitsch R, Smith K. Family influences on hopelessness among children early in the cancer experience. *J Pediatr Psychol* 1985;10:479–93.
21. Bowes S, Lowes L, Warner J, Gregory JW. Chronic sorrow in parents of children with type 1 diabetes. *J Adv Nurs* 2009;65:992–1000.
22. Brody AC, Simmons LA. Family resiliency during childhood cancer: the father's perspective. *J Pediatr Oncol Nurs* 2007;24:152–65.
23. Bruce S, Rodgers J, Firth M, Freeston M. Mum knows best? Psychological status in an oncology sample. *Child Care Health Dev* 2005;31:643–8.
24. Chaney JM, Mullins LL, Frank RG, Peterson L, Mace LD, et al. Transactional patterns of child, mother, and father adjustment in insulin-dependent diabetes mellitus: a prospective study. *J Pediatr Psychol* 1997;22:229–44.
25. Dockerty JD, Williams SM, McGee R, Skegg DC. Impact of childhood cancer on the mental health of parents. *Med Pediatr Oncol* 2000;35:475–83.
26. Grootenhuis MA, Last BF. Predictors of parental emotional adjustment to childhood cancer. *Psychooncol* 1997;6:115–28.
27. Hoekstra-Weebers JE, Jaspers JP, Kamps WA, Klip EC. Gender differences in psychological adaptation and coping in parents of pediatric cancer patients. *Psychooncol* 1998;7:26–36.
28. Kazak AE, Stuber ML, Barakat LP, Meeske K, Guthrie D, et al. Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *J Am Acad Child Adolesc Psychiatry* 1998;37:823–31.
29. Lahteenmaki PM, Makiperna A, Helenius H, Salmi TT. Opinions on childhood cancer care and degree of agreement between patient/mother and mother/father pairs. *J Pediatr Hematol Oncol* 2008;30:39–45.
30. Landolt MA, Ribl K, Laimbacher J, Vollrath M, Gnehm HE, et al. Posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. *J Pediatr Psychol* 2002;27:647–52.
31. Lannen PK, Wolfe J, Prigerson HG, Onelov E, Kreicbergs UC. Unresolved grief in a national sample of bereaved parents: impaired mental and physical health 4 to 9 years later. *J Clin Oncol* 2008;26:5870–6.
32. Leonard BJ, Kratz BJ, Skay CL, Rheinberger MM. Comparison of mother-father perceptions of their child's self-management of diabetes. *Issues Compr Pediatr Nurs* 1997;20:69–87.
33. Mu PF, Ma FC, Hwang B, Chao YM. Families of children with cancer: the impact on anxiety experienced by fathers. *Cancer Nurs* 2002;25:66–73.
34. Ozono S, Saeki T, Mantani T, Ogata A, Okamura H, et al. Factors related to posttraumatic stress in adolescent survivors of childhood cancer and their parents. *Support Care Cancer* 2007;15:309–17.
35. Palmer DL, Berg CA, Butler J, Fortenberry K, Murray M, et al. Mothers', fathers', and children's perceptions of parental diabetes responsibility in adolescence: examining the roles of age, pubertal status, and efficacy. *J Pediatr Psychol* 2009;34:195–204.
36. Patino-Fernandez AM, Pai AL, Alderfer M, Hwang WT, Reilly A, et al. Acute stress in parents of children newly diagnosed with cancer. *Pediatr Blood Cancer* 2008;50:289–92.
37. Poder U, Ljungman G, von EL. Posttraumatic stress disorder among parents of children on cancer treatment: a longitudinal study. *Psychooncol* 2008;17:430–7.
38. Robinson KE, Gerhardt CA, Vannatta K, Noll RB. Parent and family factors associated with child adjustment to pediatric cancer. *J Pediatr Psychol* 2007;32:400–10.
39. Ryden O, Nevander L, Johnsson P, Westbom L, Sjoblad S. Diabetic children and their parents: personality correlates of metabolic control. *Acta Paediatr Scand* 1990;79:1204–12.
40. Ryden O, Johnsson P, Nevander L, Sjoblad S, Westbom L. Cooperation between parents in caring for diabetic children: relations to metabolic control and parents' field-dependence-independence. *Diabetes Res Clin Pract* 1993;20:223–9.
41. Seiffge-Krenke I. "Come on, say something, dad"! communication and coping in fathers of diabetic adolescents. *J Pediatr Psychol* 2002;27:439–50.
42. Sterken DJ. Uncertainty and coping in fathers of children with cancer. *J Pediatr Oncol Nurs* 1996;13:81–8.
43. Wills BS. Coping with a child with acute lymphocytic leukemia: the experiences of Chinese fathers in Hong Kong. *Cancer Nurs* 2009;32:E8–E14.
44. Yeh CH. Gender differences in the use of coping strategies among Taiwanese parents whose children have cancer. *Cancer Nurs* 2004;27:100–7.



45. Cappelli M, McGarth PJ, Daniels T, Manion I, Schillinger J. Marital quality of parents of children with spina bifida: a case-comparison study. *J Dev Behav Pediatr* 1994;15: 320–6.
46. Sabbeth BF, Leventhal JM. Marital adjustment to chronic childhood illness: a critique of the literature. *Pediatrics* 1984;73:762–8.
47. Taanila A, Kokkonen J, Jarvelin MR. The long-term effects of children's early-onset disability on marital relationships. *Dev Med Child Neurol* 1996;38:567–77.
48. Seltzer MM, Krauss MW, Hong J, Orsmond GI. Continuity or discontinuity of family involvement following residential transitions of adults who have mental retardation. *Ment Retard* 2001;39:181–94.