

RURAL FATHERS' EXPERIENCES OF LOSS IN DAY-TO-DAY LIFE WITH CHRONICALLY ILL CHILDREN

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Key words: fathers, chronically ill children, rural, qualitative research, lived experience

ABSTRACT

The aim of this qualitative study was to gain insight into the experiences of fathers living with their chronically ill children in rural Australia. Data were collected via unstructured interviews with four fathers. Analysis followed the procedural steps for phenomenological data as outlined by Colaizzi (1978). Fathers described their experience of living with their chronically ill child as being filled with progressive losses for themselves and their child, including loss of: 1) pre-conceived expectations of future life; 2) a normal parenting relationship with their child; 3) normal partner relationship; and, 4) control of time and freedom. Findings contribute to knowledge and understanding of the complex nature of fathering a chronically ill child in rural Australia.

INTRODUCTION

Improvements in current medical treatments have extended the lifespan of children who suffer from chronic, progressive and life-threatening illnesses. Many of these children now live for an extended time with complex conditions (Martin and Nisa 1996). Chronic illness is characteristically defined as an illness, long in duration, progressive in nature and relatively incurable (Cohen 1999; Clawson 1996). Variables that impact on the experience of chronic illness are based on functional limitations, symptom prediction, threat to life and the need for external assistance (Stein and Silver 1999).

Ample evidence exists to support the importance of family in the maintenance of the health of its members during periods of childhood chronic illness (Canam 1993). This fact in conjunction with the current trend towards home care means parents are now adopting the role of surrogate health care worker.

The notion of family as being central to the care of its members has provided much impetus for the inclusion of family members, specifically mothers, in the care and research of childhood chronic conditions (Canam 1993). However, for nursing, a best practice model for care delivery also includes the father. Therefore, nurses require a greater understanding of how fathers experience the chronic illness of their children.

LITERATURE REVIEW

The majority of available research regarding fathers has generally relied on mothers' reports of the impact the chronic illness has on the father and her perceptions of his attitude, thereby creating a paucity of first hand accounts from fathers (Violi 2000; Eiser 1993; May 1996). Despite

the stoic and uninvolved portrayal of fathers throughout the literature, increasing evidence indicates that childhood illness has a powerful impact on them (Heaviside 2000; Coe and Neufeld 1999; Cohen 1999; May 1996). Katz and Krulik (1999) believe fathers of children with chronic conditions were profoundly affected by their child's illness and appeared to have more difficulties than mothers in adjusting to the realities of their limitations.

Some literature contends that fathers with chronically ill children enjoy their children less and find parenting less rewarding than fathers of healthy children. Fathers have reported lower self-esteem; feelings of incompetence, failure, guilt and helplessness; and, a sense of low satisfaction and gratification from their ill child (May 1996; Hauenstein 1990). According to May (1996), fathers distance themselves from their ill child as they are embarrassed by the child's appearance and inability to perform the physical, visually pleasing tasks of healthy children. Although the literature presents a plethora of negative emotions and challenges for fathers with chronically ill children, depression is less frequently reported (Hauenstein 1990).

The father's role is commonly described as one of support, especially for the mother of the chronically ill child (Violi 2000; Cohen 1999; Eiser 1993). Nagy and Ungerer (1990) propose that the support fathers provide is crucial in buffering the effects of childhood chronic illness on the mental health of the mother. It is suggested fathers feel a sense of guilt when their partner becomes stressed, believing their support has not been sufficient. Despite spending very limited hours of attendance within the hospital during illness exacerbations, fathers believed they contributed greatly to the childcare practices at home (Hentinen and Kyngas 1998; Hauenstein 1990; Nagy and Ungerer 1990).

The overall body of literature pertaining to rural health is limited. There is an assumption that certain health benefits arise from living in rural areas. These include clean air, fresher food, better housing, less stress and a greater sense of community cohesion. However, rural areas have been shown to have higher incidences of mortality and morbidity than suburban comparisons and suffer from decreased access to health care services (Dixon and Welch 2000). Research in the area of rural health suggests rural areas tend to describe health in the negative, as an absence of disease, therefore their main concern is a cure (Dixon and Welch 2000; Long and Weinert 1992). In light of this, the need for primary care in rural areas is low because of the tendency of rural dwellers to define health as one's ability to perform in the face of adversity (Coster and Gribben, 1999). Men are at particular risk of mental and physical ill health, with greater rates of suicide in small rural areas than those of urban communities (Dixon and Welch 2000). In addition, evidence suggests that although cohesion and support is high in rural areas, it is not necessarily effective. Rather, Stevens (1998) proposes that rural cohesion may actually

operate to limit a man's behaviour and reduce opportunities for support seeking behaviour.

Given the paucity of research about fathers' parenting experiences of their chronically ill children while living in a rural environment, this study contributes to the nursing body of knowledge regarding this complex phenomenon.

THE STUDY

This interpretive qualitative study used in-depth interviews to discover how rural fathers perceived the day-to-day experiences of living with their chronically ill children. Findings related to loss are reported in this paper.

Aim

The aim of this study was to gain insight into the experience of being a rural father with a chronically ill child.

Methodological design

This interpretive research, informed by existential phenomenology for data analysis (Denzin and Lincoln, 1998), explored the day-to-day experiences of rural fathers and their chronically ill children. This approach was chosen to facilitate understanding by acknowledging and valuing the meanings people ascribe to their own existence - their lived experience. It stresses the importance of personal experience in gaining understanding (Walters 1994; Munhall and Oiler-Boyd 1993).

Study participants

Four fathers with one chronically ill child each were recruited using purposive snowball sampling. Inclusion criteria were that fathers: must have been the biological father of the child(ren), have been living with the child(ren) and a partner for a minimum of two years and living in a rural area. Fathers in the study formed a relatively homogeneous sample ranging in age from 36 to 44; all were married and all had other healthy children. All participants lived in a rural area for an extended time and were embedded within the rural culture. The chronically ill children formed a heterogeneous sample. Children ranged in age from two to nine years and their illnesses were vastly different, from those of the respiratory system to those of the central nervous system.

Data collection

Fathers of chronically ill children living in the rural area were relatively few in number, somewhat isolated from mainstream society and therefore difficult to recruit. Contact with the first participant was gained through a father who volunteered for a pilot interview. During the pilot interview it became apparent the participant was reluctant to openly engage in personal discourse, offering only brief descriptions of his experiences and then remaining silent despite careful probing techniques. This

is consistent with the literature that contends unless men have a specific problem to solve they are likely to remain silent and disengaged, finding it difficult to engage in discourse about their personal feelings (Shaw and Beauchamp 2000; Verrinder and Denner 2000). This awareness enabled the researcher conducting the interviews to use this information to develop trigger questions and topic areas to explore should the participants have difficulty talking about their experiences. This recognition highlights the importance of research that explores the perceptions and experiences of men and may help to explain the relative paucity of literature pertaining to men.

Interviews ranged in length from 45-75 minutes and continued until each father believed he had completed his discussion/description of his experience. All interviews began with the statement: *Tell me what it is like for you living with a chronically ill child?* Careful probing questions, such as: *Can you explain that further?* and: *Do you recall how that made you feel?* were employed to engage the participants in continued reflective discussion.

Ethical considerations

The purpose of the study was explained to all fathers who volunteered and written consent was obtained prior to the interview. Ethics approval was obtained from the relevant university committee prior to data collection. Given the nature of rural communities and small available sample, careful steps were taken to protect confidentiality, such as limited demographic information about both the participants and their children.

Data analysis

A member of the research team transcribed all interviews verbatim. Colaizzi's (1978) phenomenologic technique for data analysis was used for thematic development in order to uncover the hidden, ambiguous and mysterious nature of the experience of the fathers interviewed. In-depth contact with the transcripts through phenomenological reflection, allowed the researchers to examine the parts of the whole by extracting significant statements and phrases about the phenomenon. Meanings were formulated from the statements, which were clustered to illuminate the themes or structures that encompassed the experience of rural fathers living with their chronically ill children. Results of each cluster of themes were integrated into an exhaustive description. This paper presents four themes resulting from this analysis process.

Achieving rigour

Written transcripts were compared with the recordings to assure accuracy of data used for analysis. Issues relating to rigour can be complex when research topics are sensitive in nature. Because fathers in this study often struggled to share their feelings and experiences, it was not considered appropriate to return transcripts or findings to them for verification. However, member checking to

enhance rigour (Sandelowski 1986) was achieved by providing three fathers with chronically ill children, who were not part of the research, with a summary of the research findings. These fathers were able to recognise their own experience within the findings provided.

FINDINGS

This paper reports the four themes related directly to the experience of loss encountered by fathers living with their chronically ill children in the rural environment, including: 1) loss of pre-conceived expectations of future life; 2) loss of a normal parenting relationship with their child; 3) loss of normal partner relationship; and, 4) loss of control of time and freedom.

Loss of pre-conceived expectations of the life they had hoped for

Fathers described an intense sense of frustration and sadness when they learnt of their child's condition. They described losses that occurred at different developmental stages because of the inherently progressive nature of chronic illness. The fathers' desire to be a parent, to perform parental roles and to receive the rewards parents of healthy children do, was lost. Their lives became something they had not foreseen for themselves nor expected for their children.

'...Before one has a child we have high expectations of a normal child and then when the child is born... those expectations are dashed.'

Compounding the emotions fathers felt with regard to the hopes and expectations for their child, was the progressive and 'in your face' nature of chronic illness.

'It's all this pumping stuff into her body, you know we are all basically a healthy family and you know just seeing her, you know it's in my face all the time it's in our faces.'

One father described the 'in your face' nature of the illness as coming from the negative connotations of society.

'...I don't know if he gets much embarrassed but we sort of... you don't like people staring at him but he doesn't notice that... but that's probably the hard bit.'

Another father described feeling inadequate in light of the progressive nature of his son's illness. Having preconceived ideas of the expectations on him as father and husband, he was left feeling inadequate in his role as family provider.

'I feel inadequate because I can't help him. I feel inadequate because I'm unable to fully care for my family the way I'd like to as a husband, a father and a... and a man.'

It was evident through their voices that their experiences were filled with loss. The loss of normalcy, the loss of social acceptance of their child and the loss of

adequacy as fathers. In combination, these losses equate to a loss of the lives these fathers had anticipated for themselves and shattered the preconceived expectations they had for their future roles as fathers.

Loss of a normal or typical relationship with the chronically ill child

These fathers tended to compare their children and their developmental milestones with those expected of children without a chronic illness. A prominent component of the experience accentuating the loss was the inability of their child to perform physically in the same way as healthy children. A significant feature of the father-child relationship, especially the father-son relationship, is often sport and physical activity. Fathers within the study expressed their desire to have this relationship with their children and experienced a feeling of inadequacy in not being able to do so.

'...Well it's difficult not being able to do normal things that normal kids do... just probably not being able to get up and run around like a normal kid... that's probably... the hardest thing.'

'I love my sport so I like him to play sport... so as long as I keep him going, you know, playing sport.'

Compounding the emotions of loss involved seeing other fathers fulfilling the roles they had anticipated for themselves.

'...a lot of jealousy. You've seen other mates of mine with their little boys running around at the footy and that sorta thing and we've gotta carry [son] and I can't go and have a kick of footy with him and... and there's other blokes doing it. You get a fair bit jealous I suppose.'

Fathers described having lost or abandoned their preconceived expectations for their chronically ill child. In light of a desire to feel good about their child's developmental achievements fathers appeared to change their expectations for their ill child. The joys of fathering came from small, unexpected achievements parents of healthy children might take for granted. These fathers learned not to expect giant leaps but rather consider small developmental tasks and the ability to learn simple acts as great achievements for their child and something to feel good about for themselves.

'... you just take little things... for instance [son] can't do a hell of a lot of things. But for him just to shut the microwave door. I've taught him how to do that and that's probably like oh, I don't know... when he first done that for me, it was like a normal kid taking his first steps I suppose. I do get a lot of joy out of him, but it's very basic things but you learn not to expect too much I suppose.'

'Every now and then you will get something really special... you have these special moments... moments where you think that this child is so chronically ill, yet they've still got a lot of this love... and that unconditional

love to give and that's good. You tend to take... precious little things more preciously.'

For these fathers, a change in expectation led to increased positive feelings of achievement for fathers and their children. By changing their expectations these fathers placed on their child, they inevitably maximised the potential for desired achievement and created a feeling of satisfaction for themselves as teacher and caregiver, enabling a positive relationship to develop between child and father.

Loss of the pre-child relationship with their partner

Fathers accepted they shared the burden of the illness experience with their partner, but also acknowledged it impacted on their relationship in ways not expected by the normal parenting experience.

'It affects my personal relationship with my wife... in terms of intimacy and in terms of time with each other.'

Although fathers believed they were unable to enjoy the typical aspects of a relationship (as a couple or as parents) because of the shared vigilance required by chronic illness, they described their spousal relationship as crucial to their stability.

'The time I spend with my wife is very limited and for us it's been our relationship that kept us going.'

'She's [wife] a very good support for me... having her as a support in a way helps me cope.'

One father goes on to describe the teamwork required when caring for his chronically ill child, stating the value of the longevity of such teamwork as a means of coping.

'...If it wasn't for the team effort... one of us would have conked out.'

Fathers also recognised a sense of pressure on the spousal relationship to maintain the familial equilibrium in order to cope with the chronicity of the situation.

'How I cope is how she copes and how we both cope living through this together.'

It is evident these fathers lost a sense of individuality within their spousal relationship. Fathers describe becoming one strong team as a couple rather than two separate individuals in order to share the rigours of ongoing daily management of the child. These pressures seemed to limit fathers sharing the usual pleasures and joys of a spousal relationship in a manner akin to their pre-child relationship.

Loss of control of their own time and freedom

All fathers discussed the willingness to sacrifice both intra and extra familial activities to facilitate the emotional and general mainstay of the family and daily running of the household. The experience encompassed fathers describing their 'duty of care' for their child. They discussed sacrificing their personal desires for the

wellbeing of their child, their partner and other children, and felt obligated to their supportive role.

'... I'm not doing what I want to do with my life... I'm not doing what I would like to do, I'm doing what I have to... and I have a sense of obligation and a sense of duty to see this through... but it's a matter of priorities... [son] at this stage... [son is] more important.'

'On a day like today I would like to be outside and do things and but I've gotta have [son] cos [partner] has him for the other six days so you feel as though you've gotta do that but then it is stopping me doing things I would like to do... just normal things I suppose.'

As well as providing support for the individual members of the family singularly, these fathers believed they were obligated to support the family as a whole. This was accomplished by achieving financial stability obtained through employment and the maintenance of the household during an illness crisis. Although they often did not support the ill child directly (while in hospital) they viewed their critical contribution as maintaining and supporting the household.

'... I'd still be up having to go to work and maintain the rest of the family and she [partner] would keep a bedside vigil and I'd pop in... That's where the other stresses come into it, it affects the rest of the house, everybody suffers.'

'When he's in hospital I feel that I need to be focusing and be at his side and focusing on the family needs as well as what my wife needs and what [other son] needs... so there's always little tasks to be done on an ongoing basis.'

The sacrifices these men made as fathers of chronically ill children and their self-appointed obligation to support their family meant they lost a sense of satisfaction and adequacy every time their child was ill or their partner became distressed. One father left paid employment to be with and support his family because of the impact the chronically ill child had on family cohesion. He expressed feelings of satisfaction when he talked about being able to effectively care for his family and buffer the distress inherent in their day-to-day lives. However, his loss of employment equated to a loss of personal satisfaction previously gained through employment, as well as lost identity amongst other men.

'It's difficult as a man because we generally identify ourselves through our work. In conversation one of the first things you say is 'I'm a this', 'I'm a that'. I've long since learnt not to do that but it's still something that rankles in the back of one's mind. Just everything involving men is structured around being at work during the day and I'm not.'

The fathers in this study saw their fundamental role as providing support for the entire family. Fathers were willing to sacrifice employment, leisure time and goal

attainment to ensure their families received needed support. They found being able to provide effective support personally rewarding despite experiencing a sense of inadequacy in times of disequilibrium (within the family) if their efforts were not successful.

DISCUSSION

This study explored the experiences of rural fathers living with their chronically ill children. The experience expressed by these fathers was one of continual adversity, rich in emotion and filled with progressive losses for themselves and their child. Losses included the life fathers had hoped for their child and for themselves and a loss in the ability to share in the usual experiences of fatherhood. Most prominent in their experience was the loss of their child's physical functionalism. Fathers had a 'burning desire' to experience the physical performances of their children in the ways parents of healthy children do. The potential to enjoy the physical achievements of their children in both play and competitive sport was lost to the illness experience. Their child's loss of physical ability created a sense of embarrassment, jealousy and inferiority among fathers in their rural community, a community that values the physical health of its members. This finding supports May (1996), who found many fathers are embarrassed by their chronically ill child's appearance and subsequent inability to perform the typical activities of a healthy child. Cummings (1976) found the esteem fathers lost to the illness experience left them with a sense of inferiority. Fathers within this study described feeling inferior and experienced a myriad of losses, but also described receiving a sense of enjoyment and satisfaction from their children, which contradicts some previous research in this area by May (1996), Hauenstein (1990) and Cummings (1976), who found fathers with chronically ill children enjoy their children less than fathers of healthy children.

Rural areas have a tendency to define or describe health in terms of the amount of value to the community a member contributes with regard to labour division and level of independence, rather than the absence of disease or infirmity (Dixon and Welch 2000; Humphreys 1999 and 1998; Weinert and Burman 1994; Long and Weinert 1992). Incidents when their children had endured the 'ill health' stigma of society generated feelings of inadequacy and sorrow in fathers. The child's stigma manifests the ongoing nature of their illness, bringing the associated losses of the illness and lack of societal acceptance to the forefront of these fathers' minds. Consequently, fathers within the study described the stigma that was directed at their child as having emotional implications for themselves, directly impacting on their self-esteem. This finding is consistent with Rubin (2000) and Katz and Krulik (1999) who found that the stigma commonly attributed to chronically ill children generated feelings of lower self-esteem in fathers when compared to fathers of healthy children.

These fathers perceived their primary role within the chronic illness experience as having to provide beneficial support to the entire family, particularly their partners. Consequently, fathers described a loss of personal freedom that evolved from the provision of such support. Cohen (1999) and McKeever (1981) also found fathers clearly interpret their role as one of familial support, especially for their partner. Katz and Krulik (1999) support this position, adding that fathers also believe any display of personal weakness that interfered with providing support was not acceptable. Fathers described feeling a sense of role conflict during periods of hospitalisation for their children. They felt a need to be at the child's bedside although concurrently perceived their place was maintaining the well being of the family at home. This strongly supports earlier findings of McKeever (1981) who found fathers spent limited hours at the bedside of the ill child. However, they believed they provided needed support through the maintenance of other family members wellbeing and the everyday activities of the household.

Fathers' perceived need to support other family members created a loss of achievement many individuals gain from employment. Available literature provides little insight into the relationship between employment, self-esteem and the illness experience of fathers. However, Sabbeth (1984) suggests fathers accustomed to working actively to achieve, may be particularly 'undone' by their lack of control over a child's illness. Katz and Krulik (1999) found fathers of chronically ill children were reluctant to take employment promotions out of an unwillingness to spend extended periods away from home.

Limitations

Within the limits of a small sample size, the aim of gaining insight into the experiences of rural fathers with chronically ill children was achieved. Additional research with a larger sample would enable a richer and more inclusive description of how rural fathers manage parenting in the face of adversity. This larger sample of fathers would consequently include a larger sample of children. This in turn would shed light on differences of experience related to the specific nature of the chronic illness.

CONCLUSIONS AND RECOMMENDATIONS

Utilising the interpretive paradigm, rural fathers' experience is revealed to be one filled with a myriad of losses for themselves and the life they had hoped for their children. One important finding of this study is the pivotal role fathers of chronically ill children perceive they have in maintaining the emotional and general mainstay of the family and in supporting their spouse as the primary care giver. Their self appointed obligation to support and maintain the stability of the family meant fathers relinquished their normally taken personal time and

freedom fulfilling this supportive role. Most confronting, however, was the loss experienced by these fathers of the normal relationship with their ill child. Further research is needed to build on current findings and illuminate the fathers' experience from different perspectives, such as comparing it with the mothers' experience, exploring it at various stages of the child's development and examining the experience specific to different chronic illnesses. Research in these areas will strengthen the current knowledge that exists on fathers, giving voice to the previous silence about fathers and their chronically ill children.

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