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From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis

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Abstract

Although chest physiotherapy is central to the management of cystic fibrosis many report problems with adherence. Research in other long-term conditions suggests that non-adherence may be exacerbated as the child grows older and self-care responsibilities are transferred to the young person. We explored the nature and variation in roles of family members, how responsibility was transferred from the parent/family to the child, and what factors aided or hindered this process.

We conducted in-depth interviews with 32 children with a diagnosis of cystic fibrosis aged 7–17 years, and with 31 parents attending cystic fibrosis clinics in two Scottish regions. Family responsibilities were primarily focused on mothers. The level and nature of involvement varied along a continuum that separated into six parental and five child roles and changed over time. However, this movement was frequently reversed during periods of illness or mistrust. The day to day experience of such a transfer was not straightforward, linear or unproblematic for any of the family members. Three factors were identified as assisting the transfer of responsibility: parents' perceptions of the benefits of transferring responsibility, children's perceptions of the benefits, and the available physical, social and psychological resources to support such a transfer.

The principles and lessons from "concordance" (a therapeutic alliance based on a negotiation between equals and which may lead to agreement on management or agreement to differ) may provide a foundation for newly developing relationships between parents and their children emerging into adulthood. Further research is required to develop more specifically the content and structure of required support, its effectiveness in achieving more concordant relationships, and the resulting impact on adherence, perceived health and well-being from the perspective of the young person and parent.

Keywords: UK; Cystic fibrosis; Adherence; Children; Concordance; Parents; Physiotherapy; Partnership; Scotland

Introduction

Survival for cystic fibrosis (CF) has increased dramatically over the past 20 years. Between 1985 and 1999 mortality fell 61% for those aged 2–5 years, 70% for 6–10 years, and 45% for 11–15 years (Kulich, Rosenfield, Goss, & Wilmott, 2003). Mean survival is currently into the fourth decade and a CF child born now is likely to live into the fifth decade (Webb, Jones, & Dodd, 2001).

Physiotherapists continue to be central to the management of CF in both children and adults through the development and overseeing of chest drainage techniques. Chest physiotherapy includes a number of techniques that may either involve a care-giver or be performed by the patient themselves. These include "active cycle of breathing

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exercises'' (ACB) such as thoracic expansion; exercises (e.g. deep breathing), forced expiratory technique (''huffing'' and breathing control), and autogenic drainage which uses the patient's own airflow to release and move secretions, through controlled, graduated inspiratory and expiratory manoeuvres. The established nature of chest physiotherapy and its centrality to the management of CF has meant that conducting randomised controlled trials is ethically controversial and, in terms of recruitment, highly problematic. Consequently, studies have been of a poor design, with small sample sizes and little long-term follow-up (Cheng, Smyth, Motley, O'Hea, & Ashby, 1999; van der Schans, Prasad, & Main, 2000). However, chest physiotherapy *has* shown short-term effectiveness in mucus clearance (van der Schans et al., 2000) and when trials have been possible in other clinical areas (e.g. to prevent complications in post abdominal surgery) the results have been positive (Olsen, Hahn, Nordgren, Lonroth, & Lundholm, 1997).

Chest physiotherapy is often described as tiring, time-consuming and demanding (Carr, Pryor, Smith, & Partridge, 1996; Foster et al., 2001). A substantial proportion of children and parents miss sessions within each day and frequently miss several days of physiotherapy (Chappell & Williams, 2002). These non-adherence rates also rise as children grow older (Drotar, 2000; Drotar & Ievers, 1994; Gudas, Koocher, & Wypij, 1991; McQuaid, Kopel, Klein, & Fritz, 2003). Given the paucity of good-quality evidence of effectiveness of chest physiotherapy, it is not surprising that the impact on non-adherence on pulmonary function and survival is unknown. However, despite current evidence gaps, chest physiotherapy is so well established and central to the management of CF that it continues to be almost universally prescribed. Consequently, it is important to ensure that the experience of chest physiotherapy itself is as unproblematic to children and families as possible. Furthermore, by improving the experience and potentially reducing non-adherence rates, the likelihood that newer and better quality trials will detect changes in outcomes will be increased.

In recent years discussions about compliance and adherence to treatments have moved away from a narrow focus on patient *behaviour* alone and instead stressed the importance of the relationship between health care provider and patient. Adherence is therefore seen within the wider context of ''concordance'', a therapeutic alliance based on a negotiation between equals and which may lead to agreement or agreement to differ over appropriate treatment and regimens (Royal Pharmaceutical Society of Britain, 1997). This ''alliance'' has generally been considered in terms of the relationship between adult patients and health professionals. However, since adherence in the paediatric population depends largely on the relationship between *parents* and children, the concept and principles of concordance may also apply to this relationship (De Civita & Dobkin, 2004). Responsibility for implementing a home regimen usually lies with the parent at the onset of treatment. However, this then progresses to a period when both parent and child are involved, and then ultimately to a point where the child assumes full responsibility and assumes more adult roles and associated autonomy (Chappell & Williams, 2002). Adherence is therefore a complex issue, which may rest on a combination of the beliefs and behaviours of *both* the child and other family members. Furthermore, these beliefs and behaviours may be influenced by, or on occasions be in tension with, those of the health professional team involved in the young person's care thereby highlighting the importance of a therapeutic alliance. This complexity may become particularly problematic during adolescence as young people experience developing autonomy, social maturity, sexuality and an ongoing attempt to create and maintain a personal identity that may increasingly involve concealing their illness (Lowton, 2004).

Most paediatric care provided by allied health professionals (Hanna, 2002; Litchfield & MacDougall, 2002) and nurses (Hutchfield, 1999) has developed a family-centred philosophy. However, while such a philosophy may be appropriate and helpful in earlier years it may become less applicable as the young person moves towards adulthood and attempts to increase the independence and autonomy necessary for long-term self-care and adulthood generally (Madge & Byron, 2002). This raises questions and tensions for both health professionals and parents in terms of the size and nature of their input and roles as the child or young person takes on more responsibility. However, impending adulthood may not negate the importance of parents' and health professionals' views as these years are often characterised by a deterioration in the clinical condition of people with CF, thereby requiring increasing levels of input and support (Nasr, 2000). However, even input in such a context may continue