

## What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?

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## **What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?**

### Abstract

The majority of those diagnosed with cystic fibrosis (CF) now live to adulthood. In response to increased survival age, transition services have been developed to ensure smooth transfer from paediatric to adult specialist healthcare, although the majority of treatment and care continues to be delivered in the home. However, little is known about how young adults and staff conceptualise the nature of the parental role after young people have left paediatric care. The aim of this study is to explore the nature of parental support that is perceived to be available at this time. As part of a larger study of transitional care, semi-structured interviews were conducted with 50 young people with CF aged 13–24 years (32 with experience of transition and/or adult CF services) and 23 specialist healthcare professionals (14 working in adult care) across two CF centres in Southeast England. Interviews took place in young people's homes or within CF services, using a topic guide and were recorded, transcribed and analysed thematically. Four domains of perceived parental support were identified by the young people interviewed, with varying degrees of continuity into adult care: (1) Providing non-clinical practical and emotional support; (2) Acting as 'troubleshooters' in times of health-related crisis; (3) Working in partnership with offspring in ongoing disease management in the home and clinic; (4) Acting as 'protectors' of their children. Young people and service staff expressed tensions in managing parental involvement in post-paediatric consultations and the degree to which parents should be aware of their offspring's deteriorating health and social concerns. Parental anxiety and over-involvement was perceived by many young people and staff as unsupportive. We suggest that although health and social care providers are mindful of the tensions that arise for those leaving paediatric services, the place of parental support in adult care is currently contentious for these 'new' ageing populations.

Key words: adolescence, cystic fibrosis, family support, transition.

## Introduction

Cystic fibrosis (CF) remains the most common life-threatening autosomal recessive disease among people of European heritage. A multi-system condition, those affected predominantly experience repeated chest infection and inflammation, reducing lung capacity over time (Konstan & Berger 1997). However, significant advances in understanding the condition and refinement of medical interventions have enabled average survival age and quality of life to improve significantly over the past three decades, such that median life expectancy is currently around 40 years (Dodge et al. 2007).

The bulk of daily treatment such as medication and chest physiotherapy is home-based, with children being cared for predominantly by their parents. Although improvements in care have enabled longer and better quality of life, the shift into older age has brought new disorder-related conditions into the experiences of those affected by CF. These include CF-related diabetes (Mohan et al. 2008), liver disease (Sokol et al. 1999) and osteoporosis (Conway et al. 2000). Most young people require multiple complex treatments and care for deteriorating health and the advent of CF-related conditions; for patient comfort and to reduce hospital admissions, these continue to be administered in the home by family members wherever possible, requiring knowledge, skill, time and energy (McGuffie et al. 2008). The effects of CF and the contexts in which young people are placed, have led to varying self-perceptions of their health from 'normal' to 'distressing', with distinct styles, ways of coping and related strategies developed to manage their condition (Lowton & Gabe 2003) that include reliance both on formal CF services and support of family members throughout the lifespan.

In paediatric CF care, children attend regular outpatient appointments to monitor the condition; CF centres are staffed by a multidisciplinary team including specialist nurses, consultants, physiotherapists and dieticians (Kerem et al. 2005); as with all childhood conditions, parents have long been considered an integral part of these consultations (Conway 1998). In response to the increasing life expectancy of young people with long-term conditions, transition and adult specialist services have developed. Young people typically prepare for transfer to adult services from early teenage years and most will complete transition by age 18 (Rosen et al. 2003). In CF care, it is usual for many professionals to work across paediatric and adult settings, preparing young people to take responsibility for their treatment and aiming to increase independence in their move to adult care (Conway 1998, Rosen et al. 2003).

As with other young people with long-term conditions or disabilities, parents continue to play a pivotal role in the care and support of their offspring, although the nature of their role in caring for children as they age is complex and dependent on the nature and severity of the condition and available treatment. For example, while adolescents with type 1 diabetes report their parents as being both sources of conflict and support (Weinger et al. 2001) in their health-related care, parental 'status' of adults with intellectual disability is influenced by parents' values and behaviours, resources available and ongoing relationships with professional caregivers (Llewellyn et al. 2004).

In the context of CF, young people acknowledge that family members provide tangible support, with teenagers' perceived lack of support being related to psychosocial maladjustment (Graetz et al. 2000). Although a family-centred approach to caring for children in health services is recommended (Coyne 1997), there is little evidence of the nature of parental involvement in care

at, or after, transition to adult services for young people with traditional diseases of childhood. Although North American parents continue to provide support to young adults with CF, performing tasks such as collecting prescriptions and arranging and attending clinic appointments (McGuffie et al. 2008), and parents in the UK similarly report acting as ‘lay carers’ for their adult offspring in a role, which overlaps that of trained nurses, parents’ degree of felt inclusion in adult services is reported to depend heavily on the nature of their relationship with their offspring (Lowton 2002). However, how young people and staff perceive parental care and support at transition and how this might change over time is unclear.

## **Aim**

This study examines how young people and staff perceive the nature of parental care and support for those with CF who have left paediatric services. The findings reported here are part of a larger study concerning experiences of transition care among young people with CF and health professionals at two CF centres in southeast London.

## **Methods**

### *Participants and context*

The relevant NHS Local Research Ethics Committees granted study approval. Letters requesting participation were sent to 125 young people who were registered at either of two CF clinics in South-East London. Letters were addressed to young people and sent by the clinics to comply with the UK Data Protection Act 1998. A leaflet containing detailed information about the study was included with the request. Interested young people were asked to return a reply slip in a prepaid envelope to the researchers, who then contacted them to arrange an interview. Informed

consent was obtained from all young people, with consent additionally obtained from the parents of those under 18 years.

As we were interested in hearing from a wide range of young people who were anticipating, using or had recent experience of transition services, our only inclusion criteria were age 13–24 years and fluency in English. To ensure we captured the full range of age, gender and disease severity across the two centres, we aimed to obtain a sample size of 48 young people. In practice, 50 were interviewed to ensure we achieved a maximum variation sample. Prior to sending letters, one CF nurse specialist at each centre reviewed the clinic lists to advise the researcher of participants' health state and to ensure that each young person could be contacted. Only five young people, all near to death, or having experienced a recent bereavement, were excluded.

Fifty-five (44%) young people consented to participate; five replied too late to be included in the sample. Of the 50 interviewed, a wide range of disease severity was represented, from one respondent awaiting heart–lung transplant to those considering themselves to have 'mild' CF. Young people themselves chose the interview location; venues were their own home (n = 29), in a private space at the CF clinic or inpatient ward (n = 18), or over the telephone (n = 3). Parents were present during 17 interviews; those interviewed with a parent present or in an adjoining room generally attended paediatric services.

Eighteen participants (8 male) were using paediatric care; five (3 male) were attending transition clinics, and 27 (12 male) were using adult CF services. The 32 young people who had experienced transition or adult care are the focus of this paper; Table 1 shows the characteristics of these young people.

### Table One about here

Twenty-three health professionals were also interviewed. Staff were purposively sampled to include a range of team members from adult and paediatric services; there were no refusals to participation. After being given information about the study and obtaining informed consent, staff were interviewed in a private workspace at a time convenient to them. Fourteen staff who worked in transition or adult services are the focus here; Table 2 shows their professional background and gender. All interviews took place between February and August 2006.

### Table Two about here

Semi-structured interviews were conducted by the first author using a topic guide derived from relevant literature and from the second authors' previous research with young people with CF and their families. Clinic staff were also consulted about the general content of the interviews. To enable respondents to speak freely about their experiences and expectations, the interviewer had no clinical contact with any of the respondents and introduced herself as a researcher employed by the local University. All participants were assured of confidentiality in both their clinical context and in reports arising from the research and that their data would remain anonymous. Issues covered with young people included their experience of growing up with CF; perceived sources of support; and perceptions of CF care they received, focusing on expectations and/or experience of transition to adult services. Interviews with staff focused on professional expectations and experiences of providing transition services. Interviews lasted between 15 to 60 minutes (mean 31 minutes for young people in transition or adult care, and 18 minutes for staff).

## *Analysis*

All interviews were audiotape recorded and transcribed verbatim. A thematic approach to analysis was taken (Braun & Clarke 2006). Transcripts were anonymised, checked against the original tapes and coded using the ATLAS-ti programme (ATLAS.ti GmbH, Berlin, Germany) for qualitative data. Initial codes were created and agreed for the first interview, which was coded independently by both researchers. Categories were generated inductively through identifying patterns of experiences recounted by respondents, which were grouped through codes into themes and further developed by the authors during and after the course of the fieldwork.

Two broad themes emerged from interviews with young people; these related to their experiences of CF services and relationships with professionals, and care and support provided by family (predominantly parents). The second theme is reported in this paper. Themes emerging from staff interviews were: communication between staff and patients; the perceived role of the family (again predominantly parents) in young people's care; provision of CF services by the multidisciplinary team; and provision of end-of-life care. Staff's perceived role of young people's parents is reported here.

## **Findings**

Four categories emerged of young people's perceived parental support during and after transition to adult services, the nature of support changing by varying degrees into adulthood: Parents providing financial, practical and emotional support; Parents 'troubleshooting' through attempting to resolve health problems or crises; Parents working in partnership with their child in disease management; and parents being 'protectors' of their child from CF-related distress.



Staff's perceptions of parental support in the first two categories appeared uncontentious; tensions arose in considering the latter two domains of support.

### *Parent as provider*

Although the majority of young people aged 16 and over had studied at a further or higher education level, several reported difficulties in completing studies without interruptions for ill-health and finding or maintaining employment. The majority also reported some form of practical and/or financial support from their parents; only three young people living independently stated they did not receive this. All participants who had been to university reported returning home during holidays, where the 'provider' role continued; others reported choosing work or college commitments that enabled them to continue to live at or near the family home. Rhiannon, a 21-year-old student, described the benefits of such support:

Since I've been home, I've been really well, because my lung function is better than it has been for years. [Later] I think it's just because I'm home, so mum cooks properly, it's not me using tins at three in the morning when I get in! So I get veg [vegetables] and I just get looked after a lot more when I come back.

Although many young people reported close relationships with friends, siblings and grandparents from which they drew support, parents were perceived to provide continuous support into young adulthood, reported generally as 'being there' for young people both at home and when admitted to hospital. Thus, the parent's 'provider' role appeared uncontentious, changing relatively little during and after young people's transition to adult services.

### *Parent as troubleshooter*

In a similar way to the ‘provider’ role, the ‘troubleshooting’ role of parents continued from childhood into young adulthood and was largely uncontentious. ‘Troubleshooting’ was reported as fulfilling a specific health need at a definite point and differed from provision of other types of support in that it involved a relatively fast response to rectify a problem or crisis.

‘Troubleshooting’ had three elements: liaising with primary and specialist services; arranging admission for acute episodes of illness or medical emergencies; and dealing with perceived inappropriate inpatient care.

Liaising with health services included communicating with primary and secondary care services, for example to ensure prescriptions were written correctly. Arranging admissions for acute episodes of illness was exemplified by reports of parents contacting healthcare staff to ensure fast admission:

If I start coughing up blood again, she immediately knows what to do. She knows to make sure I start to slow down, grab a bucket, get in the car, shoot to the nearest hospital; let her deal with it (Martin, 16 years)

The third ‘troubleshooting’ element was parents intervening when episodes of acute care were regarded by young people as inappropriate. These interventions drew on the knowledge and experience of CF treatment gained by families over many years. Sally, a 23-year-old student, described such an episode:

I ended up getting flu because I missed my flu jab. So I went to the local GP [at university] and I just said: "I can't breathe and I've got CF". So he sent me to the local hospital. But they didn't know what to do with someone with CF! I was having less medication in hospital there than I would have been just in my flat at university. So my mum came up and basically I discharged myself and we came all the way down here [home] and got a room in the hospital here the next day.

Only one young person reported rejecting their parent's troubleshooting attempts; Danielle, 18, recounted her distress when several of her friends died within a short period when she was 15. Despite these deaths continuing to affect her, she unfortunately reported still not seeking any help from her parents or CF services:

[Author]: Did you talk to anyone when that happened?

Danielle: I went a bit haywire. I went a bit mad. I didn't talk to anyone about it. My mum was trying to get me to talk to people, because I went, I was quiet for a couple of days and then I just lost it, really, really badly. My room got wrecked, I punched the window in.

The three elements of troubleshooting appeared to change little according to the young person's age or transition status. Staff perceptions of this role were not contentious, as the vast majority of young people appeared willing for parents to act on their behalf in these circumstances to gain the best possible care. By contrast, the 'parent-as-partner' role appeared to change in nature as young people matured, raising tensions among young people and staff.

### *Parent-as-partner*

Young people perceived their parents to work in partnership with them in two domains: the ongoing delivery of routine home-based treatment and care; and attending post-paediatric

outpatient visits. The 'parent-as-partner' in home-based treatment began with parents instilling a regime that encouraged medication-taking from a young age and prompting when medicines were due to be taken. For most young people, parental support in medication administration enabled them to take more responsibility for their treatment as they matured, being described as changing from a managerial to an assistive role, with parents demonstrating, then checking techniques:

When I was younger obviously my mum did them (set up nebulisers), and then obviously she just, I started to do it and then when I first started doing it, she, my mum, just used to make sure that I didn't overdose myself or anything. (Nell, 16 years)

The majority of young people reported a satisfactory, smooth, gradual transition of home-based treatment administration for both themselves and their parents. Only one young person reported that his mother's willingness to be involved in his treatment made it difficult for him to take over the role completely at that point, although perhaps demonstrating the gradual nature of the transition of a home-based partnership:

My mum does the morning one [intravenous antibiotic]. Then I do the lunchtime and the 'before bed' one, because I can never get up very early, and she normally gets up [early]...so she says she doesn't mind doing it. I always say, "You just need to wake me up." But she says, "No, I don't want to." (Martin, 16)

Outside the home, perceptions of the parental role in attending transition or adult outpatient appointments were influenced by two factors: young people's willingness for active involvement in their clinic appointments; and their desire for a confidential consultation. Many young people

reported embracing opportunities to take the lead in adult clinic consultations, negotiating with their parents to facilitate this:

Since I went over to the adults' [clinic] it's been me more involved and she's just sat back and she'll take me if I want her to and she'll sit there and she won't say anything unless I ask her. (Davina, 17)

However, it was in the hospital setting that tension existed in young people's and staff's accounts of 'partnership'. In addition to taking the lead in consultations, many were clear that they wanted to talk confidentiality about personal matters and did not want parents present during these consultations:

My mum used to come with me to the clinic when I first transferred. I mean she'd come with me now if she could get time off work, if I'd *let her*, but sometimes I'd rather she wasn't there because there are obviously personal things you want to talk to the doctor about, like when I got my first boyfriend and stuff, I didn't want her to be there. (Sally, 23)

The desire to take control of their adult clinic consultations was sometimes so great that despite acknowledging their parents' duty to care for their children, some young people reported not having told their parents when appointment dates were:

I didn't tell my mum I was transferring. I didn't tell her, because my mum's a bit obsessive about the clinic and she feels she has to know everything, you know, even though I'm 17... I mean I know it's the duty of the parent, I know that's their job...But that's the good thing about the adult clinic, is the parents don't have to be there, just the child or the patient's wishes. That's the good thing about being in the adult [service]. (Oliver, 17)

Whilst Oliver acknowledged his mother's duty of care, he expressed his own need to have private consultations, illustrating the tensions inherent in young people's autonomy as adults, and the need to provide continuous supportive care. This tension was also evident in the desire for control of the consultation, and ensuring that CF staff received accurate information about their health, which was acknowledged to sometimes require parents to be present:

She always thought I wouldn't tell the truth about how I was feeling; that I'd lie and make myself sound better than I actually was. So she'd be there [in the clinic consultation] going, "Actually, this happened the other day." (Sally, 23)

Staff confirmed the need for a continuing partnership between the adult service, young person and their parents, drawing on the dedication of parents to maintaining their child's health. However, all staff saw young adults as the decision maker in their adult service care, especially in deciding whether parents should attend appointments:

I think that when they move to the adult side we very much leave it up to the young person. Some of them leave their parents in the waiting room, others very firmly bring them in. (Specialist physician, Centre 1)

Parents' own transition from being a central member in paediatric consultations to being excluded appeared far more sudden than the transition in partnership working recounted in home-based care. Indeed, before their teenager's interview, many parents mentioned difficulties in no longer being able to obtain information from adult services about their child's health. This was especially difficult for parents who had had long-term

relationships with staff members working across paediatric and adult services and who had previously had open discussions with parents. While staff expressed empathy with this situation, there was an understanding that parents of children in adult services no longer had the right to receive information about them and reported encouraging parents to reduce their involvement in their child's care:

I make it very clear to the parents, when they come up, that I am quite happy to discuss anything with them that the patients *want* me to discuss with them, but that they are now adults and it's up to them if I speak to them. I mean I will ask my patients, "Do you mind if I discuss your treatment options with your parents?" And nine times out of ten, they have no problem with it. But I make it very, very clear to the parents that I can't talk to them the way that I could do or [others] used to when they were children and it's really part of learning to let go for them.. (CF Nurse Specialist, Centre 2)

Thus, although parents' gradual encouragement of young people to increase responsibility for medicines management in the home environment was reported as a relatively smooth and unproblematic transition, parents' involvement in adult consultations was reported to lead to tension among some young people, their parents and staff.

#### *Parent as protector*

The final category of perceived support was parents' emotional protection of young people, most usually from thoughts of an early death, which were reported to arise in early teenage years. Additionally, staff expressed tensions in handling the sensitive issues surrounding the life-limiting nature of CF and the place of parents in formally addressing these. However, parental 'protection' appeared to change in nature as young people aged, generally lessening as children's desire to protect their parents grew.

The main way in which young people perceived their parents to protect them was in withholding information during childhood about the terminal nature of CF; indeed one parent of a 15-year-old participant specifically requested prior to their interview that life expectancy not be discussed with their child. Similarly Martin, aged 16, described how his mother had initially not wanted to tell him about the death of a friend:

You know, I know a person [with CF], my mum knew him. And my mum never wanted to tell me [he had died] until I had turned 15.

Several older respondents reported that information concerning the potential severity of their condition was withheld in their younger years and they did not now perceive this as having been beneficial:

When I was about 14, 15, kind of age it would have been quite nice to talk to someone then, because I wasn't quite ready to start saying to my sister [with CF] "Oh by the way, when are we going to die?" My dad knew someone who'd died on her 13<sup>th</sup> birthday or something, something quite horrible. So I was convinced that I was going to die on my 13<sup>th</sup> birthday. So when I was 14, I was really happy because I wasn't going to die any more. (Rhiannon, 21)

Staff also acknowledged the difficulties that parents faced in dealing with their child's limited life expectancy and the tensions that arose from discussions of end-of-life care, where it seemed that young people were perhaps more able than their parents to have these discussions with staff:



We had to have a discussion whether to go on to mechanical ventilation would be the right thing for [one young person] and what would happen if she didn't, and what would happen if things didn't get better and her heart stopped. And she was able to have that discussion. And I asked her did she want me to let her mother know, if she wasn't going to tell her, that we had had that discussion? She asked me to tell her [mother]. And her mother was initially comfortable that we had had that discussion. Then over the space of about two or three hours, became very agitated and very upset that we'd had it... it was a huge stress for the mother, whereas her daughter, although finding it very difficult, was actually able to have [the conversation] and was – in the end, I think, glad she had had it. (Chest Physician, Centre 1)

The protective role that parents were reported to play in both protecting their child and perhaps themselves from thoughts of an early death appeared to reverse as children aged, with many young people stating that they had started to protect their parents from knowing the extent of their deteriorating health that they found out about through conversations with clinic staff:

Mum always used to sit in on consultations until, until I could get rid of her about three years ago. That made it really hard to talk about anything, because Mum obviously gets upset if you mention stuff like dying. So you have to be really careful. (Sally, 23)

Thus it appears that while parents may protect young children from knowing the extent of their condition, many young people appreciate discussion of possible life expectancy and end-of-life care at appropriate points in their contact with health services. Tensions appear to arise between young people, parents and staff when these discussions become necessary in adult services, as in limiting parents' access to clinic consultations, young people may begin to protect their parents from knowledge of their deteriorating health.

## **Discussion**

This study begins to conceptualise ways in which parents are perceived, and to an extent managed, by their offspring and staff to support young people with CF in adult care. These young adults are pivotal in deciding for how long parents continue to act as partners in adult consultations, and to what extent they are protected from potentially distressing news of their child's health. Relationships between parents and children are likely to be a contributory factor (DeLambo et al. 2004) in these decisions, although most CF research has focused on young children's experiences of family support, rather than the extent and nature of family care and support in adult services.

Our study demonstrates that young people continue to perceive parents as supportive in a variety of health-related capacities both during and after transition to adult services. The perception of parents as providers of financial, physical and emotional support is not contentious and parallels both the 'physical' and 'emotional' support given by family and professionals in the contexts of domestic and hospice care (James 1992), and parents' 'tangible' and 'emotional' support of adolescents with CF (Graetz et al. 2000). Continued parental provision into young adulthood is common for most young people, both with and without a life-threatening or a long-term condition. However, parental support given, for example, to young people moving out of the family home appears to take more financial, practical and emotional effort both in young people with CF (Lowton 2005) as well as other chronic conditions (Twigg & Atkin 1994).

Parental 'troubleshooting' appears most likely to occur in situations that prevent young people from acting independently on signs of deteriorating physical health, or because they lack experience of speedily and effectively navigating the adult healthcare system. Although

respondents did not report problems with parental troubleshooting for physical health problems, we were unable to assess the nature and extent of its effectiveness in times of emotional crisis; this needs further investigation, particularly, in the context of young people affected by deaths of others with CF.

The 'parent-as-partner' role supports the 'lay carer' role described by parents themselves (Lowton 2002), the 'shared care' role of parents and young people in home administration of treatment (Badlan 2006) and is similar to the continuing role of many parents in 'prompting' older offspring with CF to take their medication, even when they are no longer co-resident (McGuffie et al. 2008). Parents' continued assistance in home treatment for adolescents has been reported in many other chronic conditions; for example mothers acting as 'alert assistants' in the management of their sons' diabetes or asthma (Williams 2000, 2005) However, in the current study, partnership appeared to gradually and smoothly evolve as the young person matured only in the context of home-based care, with this transition appearing to be an implicit process taking several years. This was likely to be influenced by a range of factors including the young person's relationship with their parents, their maturity and their 'readiness' to take more control of their own care (Cappelli et al. 1989). This is akin to the role transition described in chest physiotherapy for young people with CF (Williams et al. 2007); with parental involvement shifting from 'complete direction' to 'non-involvement' and the child's role from 'overwhelming recipient' to an 'independent administrator', as the child matured.

However, tensions were apparent in the partnership role in the hospital setting. Although staff acknowledged that the parents should be partners in their offspring's adult care, here, they deferred to the young person as the central decision-maker, both in treatment planning and in

making a decision about parental inclusion. Here, the significance of the organisational and legal setting in influencing the partnership of parent, young person and staff (Gabe et al. 2004) was evident. Although staff expressed empathy towards parents' plight, the notion that they no longer had a right to information about their child's health was embedded in professional practice, which views the adult aged 18 and over as autonomous in their care (Dimond 2005). The clinician's perceived duty towards the adult patient, sometimes to the exclusion of parents, has previously been described and problematised in relation to other chronic conditions, particularly mental health problems (Twigg & Atkin 1994) and anorexia nervosa, where parents report feeling excluded from knowing about their child's care and progress despite providing day-to-day care and support in the family home (Tierney 2005).

The 'protector' role of the parent, particularly in relation to preventing or avoiding discussions of dying, has previously been suggested for parents of children and teenagers with cancer (Young et al. 2003). However, this role appears to reverse in CF as the child becomes adult; young people protecting parents from potentially distressing knowledge about their deteriorating health, for example through barring parents from clinic consultations. Because of the life-limiting and unpredictable nature of CF, it is likely that change in the parent-child protective role seen here may differ from parents caring for young adults with less life-threatening long-term conditions; for example, Williams (2000) found no evidence of sons 'protecting' their mother from knowledge of their asthma or diabetes. Although 'protection' in CF may in some ways be akin to offspring maintaining the dignity of older parents by focusing on past memories rather than talking about the present (Piercy 1998) or a limited future, the phenomenon of parent and young person protecting each other from the 'truth' about CF may be unique to this condition and requires further investigation.

The place, nature and value of ‘partnership’ and ‘protection’ appear the most contentious issues of parental support roles during transition to adult care. That the ‘protective’ behaviour of parents, staff and young adults with CF might not always be in the best interests of the young person if it prevents open discussion about issues of concern, reflects findings from a cohort of bereaved parents of young people with the condition (Lowton 2005), who expressed frustration in caring for their dying child despite a lack of knowledge about recent health events. Furthermore, that some staff report difficulties in knowing whether or how to include parents in end-of-life care discussions for this ageing population suggests that ongoing development of adult services where such discussions are more easily achieved between staff, young adults and their parents, who are likely to continue to provide significant care throughout their child’s life, is an area that requires much more understanding.

### *Limitations*

Because of the focus of the interviews, all parental roles reported here are health-related and thus in-depth analysis of the extent and type of other support provided in adulthood was not possible. Although our response rate was good, it is possible that young people with unsupportive or no parents were not represented in our sample. Furthermore, the roles reported are those perceived by young people and staff; parents may have different interpretations of their position in adult care services; however, informal talks with some of the parents of young people that occurred during fieldwork lends support to the validity of our findings. Interviews with both young adults and their parents would test our findings, and a longitudinal perspective including parents of older offspring would enable examination of how roles are shaped and changed as young people age. Additionally, the quality and amount of interview data gathered may have been influenced

by the different contexts in which the interviews were conducted (i.e. hospital, home or telephone). Although home interviews were slightly longer than those conducted in hospital, all interviews took place at the location of the young person's choice, with participants appearing to be as relaxed in the hospital setting as at home, perhaps because of their familiarity with staff and the environment.

## **Conclusions**

In accordance with the UK's National Service Framework for Children, Young People and Maternity Services (NSF: Department of Health 2004), staff need to work in partnership with the family if services are to be effective while maintaining confidentiality for young people (Ford et al. 2004). Indeed, the NSF requires staff to balance young people's need for privacy and confidentiality with their parents' need for sufficient information to enable them to provide support (Department of Health 2006). As the population of young adults with CF ages and grows, it is now essential to define and measure family support for those in adult services to ensure optimum care outcomes are achieved.

Although we report a relatively young sample, it is evident that as survival age increases further, the nature and demands of family care and support for this new adult population will require fuller understanding. How tensions arising from young people's needs in formal services are addressed by staff, patients and parents and how, in the best interests of their child, parents might be more formally involved in adult care requires further consideration. We suggest that healthcare staff and managers should be supported in their search for appropriate practical ways of continuing to include parents in young people's care in adult services, while ensuring that privacy and confidentiality are maintained. This may be through helping young people develop

the confidence and skills required to take on the role of decision-maker in adult care while not cutting off support from, or communication with their parents.

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