

**Collins, S. & Reynolds, F. (2008). How do adults with cystic fibrosis cope following a diagnosis of diabetes? *Journal of Advanced Nursing* 64 (5), 478-487.**

## **ABSTRACT**

**Aim.** This paper examines the experience of adults with CF in adapting to the diagnosis of diabetes, a second chronic illness.

**Background.** Diabetes is a common complication of cystic fibrosis; the onset signifies the development of a second chronic illness. No published studies have focused exclusively on how adults with cystic fibrosis have experienced living with diabetes. Both cystic fibrosis and diabetes are complex conditions which require daily treatment schedules as part of their management, it is however unclear how people already living with cystic fibrosis respond to the diagnosis of diabetes.

**Method.** A qualitative method was chosen in order to obtain an 'insider' experience of adjusting to a second chronic illness. Semi-structured interviews were conducted with 22 adults with cystic fibrosis related diabetes in 2004. Verbatim transcripts of the interviews were analysed using Interpretative Phenomenological Analysis.

**Findings.** Four recurring themes were inferred: emotional response to diagnosis of diabetes; looking for an understanding; learning to live with diabetes, and limiting the impact of diagnosis.

**Conclusion.** A lack of awareness of diabetes amongst adults with cystic fibrosis was observed. Having cystic fibrosis appeared helpful in limiting the impact of the diagnosis of diabetes. Juggling conflicting dietary demands of cystic fibrosis and diabetes coupled with the lack of practical professional advice available was seen as one of the biggest challenges in adapting to diabetes. Healthcare professions need to increase awareness of diabetes amongst adults with cystic fibrosis and provide adequate support and structured evidence-based education throughout the course of the illness.

|

## **7 KEY WORDS**

Cystic fibrosis, diabetes, qualitative approach, interviews, experience, coping,  
second chronic illness



## **SUMMARY STATEMENT**

### **What is already known about this topic**

- Diabetes is a common complication of cystic fibrosis affecting 10-15% of adults.
- No published qualitative studies have focussed exclusively on how adults with cystic fibrosis experience living with diabetes.
- Both cystic fibrosis and diabetes are complex diseases that require demanding daily treatment schedules as part of their management; these affect all aspects of normal daily life.

### **What this paper adds**

- There was a lack of awareness of diabetes amongst adults with cystic fibrosis, both as an illness and as a secondary complication.
- Despite being 'expert patients' in the management of cystic fibrosis, participants were not equipped with the knowledge and confidence for managing diabetes.
- Healthcare professionals should educate people with cystic fibrosis about its secondary complications, show understanding of the emotional responses to diagnosis, offer ongoing support and education to help affected people maintain a normal life as possible, and provide tailored dietary / self-management advice, as standard diabetes advice is not adequate for people with cystic fibrosis.

## **How do adults with cystic fibrosis adjust following a diagnosis of diabetes?**

### **INTRODUCTION**

Cystic fibrosis (CF) is the most common life-threatening inherited disease in the Caucasian population; currently affecting over 8000 people in the UK, with an incidence of 1 in 2500 live births (CF Trust 2008). It is a progressive multisystem disease affecting vital organs of the body, especially the lungs and digestive system. Usually diagnosed soon after birth, its symptoms occur throughout life. Following improvements in medical treatments, the median age of survival is 36.9 years, with further increases likely (CF Foundation 2006, Dodge et al. 2007).

Longer survival among people affected by CF has resulted in an increased risk of secondary complications, such as diabetes. Cystic fibrosis-related diabetes (CFRD) occurs in around 10-15% of adults affected by CF, typically around 18-21 years (Lanng et al. 1995). By age 30, 50% of patients develop CFRD (Lanng et al. 2001). CF typically worsens prior to the diagnosis of CFRD, and the development of this secondary complication threatens survival. Koch et al. (2001) reported the median survival in adults with CFRD was 24 years compared to 34 years in non-diabetic CF adults. Insulin is the choice of treatment in the management of CFRD, although oral hypoglycaemic agents (OHA) may also be used (CF Trust 2004).

The diagnosis and onset of diabetes in people with CF signifies the development of a second chronic illness. Clearly, it brings its own burden of monitoring blood glucose levels and self-medication, in addition to the rigorous daily treatments associated with the management of CF. The lead author's experience of working with people affected by CF and CFRD brought recognition that this second diagnosis can be very challenging for patients, and that health professionals have little evidence to guide effective support and information-giving.

## **BACKGROUND**

A small number of studies have explored, through qualitative methods, how adults or adolescents with CF experience their lives (Admi 1996, Christian & D'Auria, 1997, Tracy 1997, Lowton & Gabe 2003, Gjendal et al. 2003, Berge et al. 2007). No published studies on adults with CF have focused exclusively on their experience of living with the secondary complication of diabetes, although the study of Lowton & Gabe (2003) included some people with CFRD.

In some of these studies, participants with CF have described experiencing unpleasant feelings of difference from their peers. Such differences are created not only by daily restrictive treatment regimes (Williams et al. 2007), but by the ways in which CF brings about extra attention and conflict within the family (Berge et al. 2007). However, several studies emphasise 'ordinariness' rather than difference, documenting the struggles of people with CF and their families to live life as *normally* as possible (Admi 1996, Christian & D'Auria 1997, Tracy 1997, Lowton & Gabe 2003, Gjendal et al. 2003).

Commonly described 'normalising' strategies include resisting stigma, avoiding pity, and establishing an identity that is not centred on illness. In addition, normality can be established by perceiving treatment regimes as routine, carefully choosing confidantes who can be trusted with disclosure about CF, playing down differences from healthy peers, hiding visible symptoms such as coughing, and pursuing age appropriate career plans (Admi 1996, Tracy 1997, Christian & D'Auria 1997, Gjendal et al. 2003, Lowton & Gabe 2003, Lowton 2004).

Clearly, a life dominated by arduous daily treatments may not seem normal to outsiders. "To understand the CF patient one has to accept this strange concept of normality." (Gjengedal et al. 2003:158). Such strategies may be better understood not as denial but as attempts to challenge the potential 'master status' of illness (Charmaz 1991) and to assert a positive identity as a person rather than an 'ill patient' (Admi 1996). Yet exacerbations of symptoms can threaten the perception of normality, as does experiencing the death of others with CF (Lowton & Gabe 2003, Gjengedal et al. 2003, Badlan 2006). Despite such setbacks, many participants have described not being unduly preoccupied with the prospect of early death, instead retaining positive plans for the future (Admi 1996). Robinson (1993) suggests healthcare professionals focus too much on serving the illness which can undermine the efforts of people with CF to devise a life that has an acceptably 'normal' quality.

Research to date suggests that worsening symptoms threaten, at least on a temporary basis, the normalising strategies which underpin psychological

wellbeing in CF. How people with CF cope with the development of the secondary complication of diabetes is unclear. This indicator of worsening health together with the stress of an additional treatment regime might overwhelm the person's coping resources. Alternatively, people who have a wealth of experience in normalising daily life within the constraints of CF might adapt well to this additional challenge.

How do people without additional health problems adapt to a diagnosis of diabetes? Diabetes presents many challenges, as its treatment includes daily medication, in the form of either tablets or insulin injections, monitoring of blood glucose levels, making dietary modifications and exercising. Qualitative studies exploring adults' or adolescents' experience of living with early onset Type 1 diabetes (unrelated to CF) reveal the impact of this condition on daily life, and identity. Dovey-Pearce et al. (2007) reviewed a range of studies that suggest that early onset diabetes, in particular, poses risks to the psychological well-being of young people, including concerns about stigma, self-image, self-efficacy, and future life plans. Negative emotional responses to diabetes tend to be associated with low adherence to treatment and poor glycaemic control. In conclusions that resonate with Robinson's view of CF management (mentioned above), these authors suggest that health professionals focus their efforts too narrowly on biomedical disease management, neglecting young people's struggles to engage in normal developmental tasks and activities despite their diabetes. Interviewing 23 young people, Dovey-Pearce et al. found that diagnosis prompted both negative emotions and positive relief. Diagnosis often led initially to negative redefinitions of self, and resentful feelings of difference from others.



Participants commonly encountered dilemmas concerning who to tell, and how to limit other people's interference in their illness self-management. With experience, young people described moving to a state of accepting their condition. Schur et al. (1999) conducted an interview study guided by the principles of interpretative phenomenological analysis and found that when their participants learned to 'depersonalise' their diabetes, they were better able to deal with it. As one young man said, "It's just something I have to do" (p.227). Participants described striking a balance between managing their diabetes and managing their lifestyles. "Control involved taking practical steps to manage diabetes and keep it in its place so that participants could get on with the rest of their lives" (p. 229).

In summary, both CF and diabetes are complex diseases that require demanding daily treatment schedules which affect all aspects of daily life. However, several qualitative studies have shown that people live positively with each of these conditions by preserving a balance between illness self-management and normal daily activities, as well as by limiting the impact of illness on their identities through self-presentational strategies (such as limiting the disclosure of the illness to others, and taking medications in private). Concerns with difference, stigma and social rejection are common among people living with each of these conditions. Possibly because CF is usually diagnosed in early life, there is less shock and uncertainty apparent in qualitative accounts of CF, and possibly greater emphasis on successfully leading 'ordinary' lives. In some contrast, diabetes onset in adolescence and

early adulthood often seems to provoke an extended period of anxiety about loss of control and social acceptance.

However, in the absence of published research, it is unclear whether people already living with CF respond to a diagnosis of diabetes in similar ways as those for whom diabetes is a first chronic illness, whether people respond to their new diagnosis of CFRD by applying their existing coping and illness management attitudes and strategies, or whether they feel overwhelmed by the additional burden of illness.

## **METHOD**

### **Aim**

The focus of this paper is to examine the experiences of adults with CF in adapting to a diagnosis of diabetes, a second chronic illness. This work is part of a larger study investigating the experience of living with diabetes and CF, and aims to inform health professionals working with these patients.

### **Design**

A qualitative method was appropriate for exploring the complex 'insider' experiences of adjusting to a second chronic illness, particularly as previous research is lacking and there are likely to be individual differences in meanings and coping strategies. A qualitative single-occasion interview design was used, guided by the principles of interpretative phenomenological analysis, IPA (Smith et al. 1999). This approach was chosen in order to obtain a rich analysis of the experience of living with CFRD.

## **Participants**

Adults with CFRD were identified from a local NHS Trust CF database. A letter explaining the aims of the study was sent to 47 adults with CFRD who lived in London and Southeast England, inviting them to participate. Twenty-two adults volunteered to be interviewed (10 females, 12 males), aged 24-55 years. Mean time since diagnosis of diabetes was 8 years 4 months (range 1yr - 35 years 10months). The sample was relatively large for an IPA study, but this enabled experiences of males and females to be explored.

## **Data collection**

Semi-structured interviews were conducted at the end of 2004. Twenty participants agreed to be interviewed within the hospital, usually when already attending for a routine appointment. The remaining two were interviewed at home.

Semi-structured interviews enabled participants to speak freely on a common set of topics whilst giving the opportunity for further elaboration on issues of personal relevance. The participants were encouraged to discuss freely and spontaneously their experiences, attitudes, behaviour and feelings about living with CF and diabetes. The interviewer (first author) was trained in counselling skills and was sensitive to the needs of the participant. No participant experienced any emotional distress when interviewed, as indicated by de-briefing afterwards. Interviews were digitally recorded and transcribed verbatim. Two interviews enabled piloting of the topic guide to identify any limitations. These two interviews were included in the final analysis, as no changes were required.

## **Ethical Considerations**

The proposal, information sheet, consent form and interview guide were approved by Ethics Committees at Brunel University and the relevant NHS Trust. Confidentiality was maintained throughout this study and pseudonyms are used when quoting from transcripts.

## **Data analysis**

Interviews were fully transcribed and analysed using the process of IPA. IPA seeks to discover participants' meanings, but proponents accept that through a process of interpretative activity the researcher uses personal experience and professional or academic concepts to make sense of the participant's personal world. IPA recognises the research process as dynamic as one is trying to take an insider's perspective while recognising this cannot happen completely. The process of analysis involves systematic coding of individual transcripts, identification and analysis of shared themes, searching for connection, patterns, and tensions. Analysis is a cyclical process, with stages repeated several times. The master theme list from one particularly rich interview transcript is a starting point for analysing subsequent interviews. Where new themes emerge they are tested against earlier transcripts. Six transcripts were independently analysed by the second author; the high degree of agreement offered validation of the identified themes.

## **Findings**

Four recurring themes were inferred: emotional responses to diagnosis of diabetes; looking for an understanding; learning to live with diabetes, and limiting the impact of diagnosis.

### **Emotional responses to diagnosis of diabetes**

The initial diagnosis of diabetes was met with many reactions, not all negative. Whilst many participants described feeling shocked, devastated, upset, annoyed, or 'gutted', some were also relieved they had an explanation for their new health problems .

I didn't understand diabetes and there's varying degrees of it and how it could be sort of fairly well controlled and um I was just upset. I thought, I thought that was kind of the end of my life, that I wouldn't be able to work blah-blah, I was very upset. (Andrew).

When they told me I was diagnosed diabetic it was a shock because I thought it was going to affect my life, and in a way it did (Nick).

Feelings about diabetes were complicated by the presence of CF. In some cases, diagnosis brought CF into the foreground of awareness again.

Participants found that they were confronting feelings about both chronic conditions, not just diabetes:

I think I was quite distraught actually and found it really difficult to have that on top of... I mean not that I'd been ill with the CF before, but you know having to sort of actually deal with something else. It made me think about CF more (Debbie).

However, some participants described relief at the diagnosis of diabetes because they had been suffering from puzzling symptoms and because they saw the condition as treatable:

I think that if anything I was probably relieved because I'd been going through symptoms that I really didn't understand, I was very thirsty, I was weeing a lot and although those are really obvious symptoms because I wasn't diabetic and didn't really know any diabetics, I didn't really realise (Karen)

However, there was also recognition that the diabetes would create additional burdens of monitoring and treatment. For some, this created feelings of frustration and powerlessness:

So in some ways when I was diagnosed, there was an element of relief because I knew that this awful feeling was going to go. But I also was annoyed that I had another condition that I knew was going to be for the rest of my life and that was going to take yet more time and involve various treatments every day. So I was really, ahh, frustrated (Paula).

The experience of developing diabetes when health was already seriously compromised by CF was an extremely negative experience for one participant. Kevin, who was on the transplant waiting list, reported the most negative initial emotional response to being diagnosed with diabetes:

As my health dropped, as it did at that point because my sugars were so high, I suddenly became prone to infection... I was in

Hospital X for about 4 weeks. I was really quite poorly, I was really quite fed up, so there was only 2 times in my life I'd ever say I was clinically depressed ... I think that was one of the times (Kevin).

Like previous research into the experience of diabetes (as a single condition), participants already coping with CF reported a range of emotions, mostly negative but also positive relief, when diagnosed with CFRD. The presence of CF complicated feelings about diabetes, though, with some participants finding themselves confronting feelings about both illnesses, some fearing or resenting the extra restrictions imposed on their daily lives, and some responding emotionally to a marked overall decline in their health.

### **Dealing with uncertainty - Looking for an understanding**

Only five participants described having a prior awareness that CF could lead to diabetes. Most did not know the symptoms, and had no contact with others affected by diabetes. Some who were aware of CFRD did not realise that it could develop when CF was well controlled:

I mean looking back you knew things were happening but you just couldn't figure out why because you felt fine, as far as the CF side you felt fine (David).

Many expressed uncertainty about treatment options, the size of needles used for injecting insulin, and whether they would be able to inject themselves.

You've got a concept of something which is completely ... I sort of imagined these huge needles and syringes (Andrew).

Even though participants were in a sense 'expert patients', familiar with the large array of medications and physical therapies used daily for CF, they nevertheless encountered uncertainty and anxiety about the specific regimes required to manage diabetes. For nearly all participants, the diagnosis of diabetes brought similar uncertainties, as with other patients unaffected by CF who confront this illness.

### **Learning to live with diabetes**

Most participants described adjusting to diabetes, and their initial feelings of shock, upset and frustration transmuted to more positive attitudes and acceptance:

By the time I came out [of hospital] um, yeah obviously I'd regretted that I had it ...but I wasn't really in despair in anymore, I'd come out of that (Andrew).

Again I thought it was, oh another thing I've got to deal with, but at the time that was when...my CF was quite under control and it was just like, right I can deal with another thing, that's fine...and I just coped with it ...and yeah I got positive about it. Although it was an extra hassle, I could deal with it (Emma).

CF is a condition which requires meticulous daily treatment just to maintain baseline health, and sometimes despite carrying out all the required



treatments health can deteriorate. In contrast, commencing treatment for CFRD was quickly associated with symptomatic improvements. The acceptance of diabetes seemed to be facilitated by this experience of successful control.

When you have treatment and feel much better that obviously you know makes you feel much happier about things. (Karen).

In addition to symptom control, learning to live positively with diabetes seemed to be associated with being older, having a more stable daily routine already because of CF self-management, and treating illness as a problem to be managed in a depersonalised way. Some participants seemed to apply their CF coping strategies, lifestyle patterns and attitudes to the new challenge of managing diabetes:

I think if I lived a more, a more spontaneous lifestyle or my dietary habits were more spontaneous or more... exotic, that may [make it difficult], but like I said it is quite...mundane and quite rigid. (Kevin)

I'm not ...an outgoing ...running around type person therefore the problems of trying to fit that into regular dosage of insulin or whatever else, I mean doesn't arise ...it's fairly easy for me to work to a schedule. (Paul)

Although some described soon developing a positive problem-solving attitude to diabetes, this did not immediately guarantee good glycaemic control:

I think I cope well in terms of my attitude and so on, you know, I don't get down about stuff. But, umm, yeah on a practical level I think I've

made a lot more mistakes with diabetes in terms of ... my sugar levels being too high (Matthew)

Various factors seem to hinder adjustment to diabetes, including being younger at diagnosis, living alone, seeking to preserve a more active lifestyle, and having insufficient skills for managing blood sugar levels. However, only one participant indicated very poor adjustment, describing diabetes as being worse than CF, because it inconvenienced him more. This could be partly attributed to his younger age, and the negative impact of diabetes on his lifestyle at the time of diagnosis:

I wasn't happy about being tied to the regime and um, having to eat, having to watch what I do, because I mean I was in my early 20's, you know and I liked going out and I liked partying and such like and that interfered with that. It interfered with it big time (Colin)

Four of the participants were diagnosed with diabetes when they were children (aged 10-17years) and their memories of this event were somewhat distinctive. Two of these participants described coping with diabetes in the early stages by rebelling against it; this involved not carrying out the insulin injections or not adhering to a low sugar diet which was advised at that time.

I ate everything that had sugar in as much as I possibly could, and ... it became a drug, it didn't do me any favours at all; I went on like that for about 5 years (Liz).

One of the biggest barriers in the early stages of adjustment to diabetes was injecting insulin:

What was making it hard, I guess... it wasn't, I guess, so much the pain, although there was the possibility of hurting... you know inflicting pain on myself, although I knew that it didn't always hurt, it was just the sort of psychological, I found it hard to stick something in me (Brian).

However, changing from oral hypoglycaemic agents to insulin led some to take their condition more seriously, promoting acceptance and compliance with treatment (as also noted by Phillips 2007).

There's quite a lot of responsibility with the insulin... not with the tablet (Matthew).

An important barrier to adjusting to diabetes related to the conflicting demands of CF. Good nutrition and optimising weight by following a high energy diet is a priority for many affected by CF whereas healthy eating is an integral part of diabetes management. Difficulties and uncertainty in balancing diet and controlling blood sugars were experienced by several participants. Moreover some complained that there was a lack of clarity in advice about dietary and medical management amongst health professionals.

If I didn't have CF and weight wasn't such an issue, the sugar side of the diabetes wouldn't be so bad because I'd, I could just eat a healthy diet and not worry too much about ... trying to eat a lot of food with the CF side of things and trying to keep my sugars balanced as well. You know, it's very difficult to do both. (Matthew)

Lack of energy associated with CF also made it difficult for some to live with their diabetes:

If I didn't have Cystic Fibrosis and I was just diabetic, and I didn't feel so shitty all the time then I probably could do it, but because I find my CF sort of takes over, and that makes me feel ill and there's stuff I can't do and I can't cook my dinners and ... I want to just lay in bed and feel like I'm dying. Then my diabetes you know, just kind of takes a second ... thing (Jen)

So in summary, the diagnosis of diabetes presented a range of challenges. As noted in studies of people facing diabetes as a single chronic condition, adaptation was facilitated by being older, feeling less personally threatened or 'different' because of the diagnosis, and taking the illness seriously. However, CF was also relevant as it had already imposed a regimented way of life into which diabetes self-management could readily be incorporated. Positive problem-solving attitudes, acquired from coping with CF were also helpful. Hindrances to adapting to diabetes concerned the unpleasant paraphernalia such as needles, pen injection devices, and prioritising an active 'normal' lifestyle out of the home (this tended to be found in the younger participants whose CF was less debilitating). Specific to CF, was the dilemma of how to meet the apparently conflicting dietary demands of CF and diabetes, and the limited professional advice available.

### **Limiting the impact**

Some participants initially minimised the impact of diabetes by regarding it as a temporary problem, assuming that it might disappear if their CF was better controlled:

At the time I started having, needing insulin whilst I was in [hospital], and that was quite psychological blow, but it was softened by the fact that there was always the hope that it would only be a temporary thing and I would recover and so I wouldn't need to inject (Brian).

The most common way in which participants seemed to limit the impact of their diabetes was by comparing it favourably with CF. Many participants did not view the diagnosis of diabetes as being as significant as living with CF and this appeared to help lessen its impact.

To be honest it's the least of my worries, I think (Stuart).

It [diabetes] hasn't... in itself, it hasn't stopped me doing anything... but the CF is starting to as a whole. (Brian)

Whilst most participants felt that diabetes was a nuisance, presenting a further burden, they reported an attitude of having to 'get on' with their lives and deal with it.

I've got it, I've got to do this and, and you get on with it (David).

I quickly learnt that really, it's more of a nuisance as opposed to really a debilitating illness so far (Kevin).

Attitudes and strategies previously developed to cope with the rigours of CF, seemed on balance to help participants to adapt to the onset of diabetes. Many of the participants seemed able to view diabetes more as a nuisance or problem to be solved, rather than a sinister threat to identities or lifestyles.

## Discussion

Initial feelings after diagnosis of diabetes included shock, anxiety, uncertainty, loss of spontaneity and relief; these are feelings already noted among people diagnosed with diabetes as a first chronic illness (e.g. Kelleher 1988, Ternulf Nyhlin 1990, Callaghan & Williams 1994, Everett 2001, Gillibrand & Flynn 2001). A new finding is that the diagnosis of diabetes led some to confront difficult feelings about CF, which until then may have seemed well controlled and 'normal'. Initial feelings about diabetes were also shaped by experiences with CF, as the prospect of two sets of restrictions was daunting for some participants. Worsening CF at the time of diagnosis also challenged coping.

After the diagnosis of diabetes, participants sought to resolve uncertainties. Most were unfamiliar with the possibility of this secondary complication of CF. Health professionals need to be aware that despite participants' status as 'expert patients', highly experienced in the management of CF, they were not equipped with knowledge and confidence for managing this second chronic illness.

Participants described various helps and hindrances in learning to live with their second condition. Factors previously noted in diabetes studies were influential, such as age, whether they lived alone or not, and lifestyle priorities. For younger people whose CF was relatively well controlled, permitting a 'normal' lifestyle, the onset of diabetes created more of a biographical disruption (Bury 1982). In such cases, participants resented this illness and

failed to cooperate fully with treatment, seeking instead to maintain pre-existing lifestyles and identities. Previous studies of young diabetics have also noted rebellion against treatment and prioritising similarity with peers above diabetes self-management (e.g. Badlan 2006, Schur et al. 1999, Dickinson & O'Reilly 2004). However, familiarity with CF also promoted positive coping with diabetes. The regular routines and lifestyle restrictions of CF helped some to cope with the new demands of diabetes. But some found that poor health, limited advice and perceived conflicts between the dietary demands of CF and diabetes made adaptation more difficult.

Most participants described making appropriate adjustments after diagnosis without a protracted period of struggle, as captured in the theme 'limiting the impact'. They did not describe intense preoccupations with negative self-concept or feelings of difference from others, unlike the findings of other qualitative studies into experiences of diabetes (e.g. Dovey-Pearce et al. 2007, Schur et al. 1999). Possibly participants' considerable experience of coping with CF resulted in CFRD being perceived less as a biographical disruption, and more as an additional practical demand on their health-management strategies. Most participants described learning to view diabetes as a problem to be solved effectively through medication and diet, a nuisance rather than a serious threat to identity or lifestyle. The main exception occurred when diabetes coincided with a serious worsening of CF, provoking feelings of powerlessness and depression.

Treating diabetes in a depersonalised way is effective for young diabetics (Schur et al. 1999). Participants (with one exception) viewed diabetes as less

serious than their CF and this minimising attitude also helped limit the emotional impact of the diagnosis of diabetes. This is a form of downward comparison, where contrasts are made to others worse off (as noted by Schur et al. 1999) or in this case, with an illness experienced as worse.

### **Study Limitations**

The sample was small (though large for IPA studies). All participants lived in London and the South East of England. Some were recalling responses to a diagnosis that occurred some years previously, and emotions may have been reinterpreted. The experiences of patients who attend a specialist CF centre may not be readily generalisable.

Interviewing within a hospital setting also risks gaining less personal stories. But disclosures of highly negative feelings within the interviews suggest that participants were not engaging in artificially positive self-presentation.

Participants volunteered for this study; they may therefore have been highly motivated, managing their illness well, and more willing to share their experiences. However, alternative strategies of recruitment are unlikely to be acceptable ethically.

There may also be some bias from the lead author both carrying out the interviews and also the data analysis because IPA puts researchers' own interpretations centre-stage. However, the different professional background of the second author, and use of independent coding and discussion ( for a subset of transcripts), helped reduce any professional bias in the interpretation of the themes.



## **Conclusion**

In this study, we found a lack of awareness of diabetes amongst adults with CF, both as an illness and as a secondary complication of CF. An implication is that healthcare professionals should seek to educate people with CF about its secondary complications, show understanding of the emotional responses to diagnosis, and offer ongoing support to help affected people maintain as normal a life as possible in a context of deteriorating health. There is an urgent need to plan a clear structured evidence-based programme about managing CFRD, as standard advice and education programmes for diabetes patients do not meet the needs of people having also to manage CF.

This study provides those who work with patients affected by CF with an 'insider' perspective. Participants' accounts indicate that initially negative feelings about diagnosis tended to dissipate, leaving less emotional ways of dealing with diabetes. However healthcare professionals need to appreciate that initial feelings about diagnosis in this patient group may be complicated by resurfacing concerns about CF and mortality.

Previous lengthy experience of managing CF did not provide knowledge or confidence to manage diabetes initially, but participants' regular daily routines and problem-solving attitudes already developed in the context of CF, appeared helpful for limiting the impact of diabetes. Conflicting demands of weight management and diet for each condition concerned participants, and they required better professional advice.

## References

- Admi H. (1996) Growing up with a chronic health condition: A model of an ordinary lifestyle. *Qualitative Health Research*, 6 (2), 163-183.
- Badlan K. (2006) Young people living with cystic fibrosis: an insight into their subjective experience. *Health and Social Care in the Community*, 14(3), 264-270.
- Berge J., Patterson J., Goetz D. & Milla C. (2007) Gender differences in young adults' perceptions of living with cystic fibrosis during the transition to adulthood: A qualitative investigation. *Families, Systems and Health*, 25 (2) 190-203.
- Bury M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4 (2), 167-82.
- Callaghan D. & Williams A. (1994) Living with diabetes: issues for nursing practice. *Journal of Advanced Nursing*, 20, 132-39.
- Charmaz K. (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers University Press: New Brunswick, New Jersey.
- Christian B.J. & D'Auria J. (1997) The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing*, 12(1) 3-12.
- Cystic Fibrosis Foundation (2006) Patient Registry 2005 Annual Report. Bethesda, MD: Cystic Fibrosis Foundation.
- Cystic Fibrosis Trust. (2008) <http://www.cftrust.org.uk/aboutcf/whatiscf/>
- Cystic Fibrosis Trust. (2004) *Management of cystic fibrosis related diabetes mellitus: report of the UK cystic fibrosis trust diabetes working group*. Kent: Cystic Fibrosis Trust.
- Dickinson J. K. and O'Reilly M.M. (2004) The lived experience of adolescent females with type 1 diabetes. *The Diabetes Educator*, 30 (1), 99-107.

Field Code Ch

Formatted: F

- Dodge J.A., Lewis P.A., Stanton M. & Wilsher J. (2007) Cystic fibrosis mortality and survival in the UK:1947-2003. *European Respiratory Journal* 29, 522-6.
- Dovey-Pearce, G., Doherty Y., May C. (2007) The influence of diabetes upon adolescent and young adult development: A qualitative study. *British Journal of Health Psychology*, 12, 75-91.
- Everett J. (2001) Qualitative study of the impact of type 1 diabetes on everyday life. *Journal of Diabetes Nursing*, 5(5), 151-55.
- Gillibrand W. & Flynn M. (2001) Forced externalization of control in people with diabetes: a qualitative exploratory study. *Journal of Advanced Nursing*, 34 (4), 501-10
- Gjengedal E., Rustoen T., Wahl A. & Hanestad B. (2003) Growing up and living with cystic fibrosis: everyday life and encounters with the health care and social services – a qualitative study. *Advances in Nursing Science*, 26(2),149-59.
- Kelleher D. (1988) Coming to terms with diabetes: coping strategies and non-compliance in *Living with Chronic Illness*. (Anderson R. and Bury R., eds). Unwin Hyman Ltd: London.
- Koch C., Rainisino M., Madessani U., Harms K. H., Hodson M. E., Mastella G., McKenzie S. G., Navarro J. & Strandvik B. on behalf of the investigators of the European Epidemiologic Registry of Cystic Fibrosis. (2001) Presence of cystic fibrosis related diabetes mellitus is tightly linked to poor lung function in patients with cystic fibrosis: data from the European Epidemiologic Registry of cystic fibrosis. *Pediatric Pulmonology*, 32, 343-50.

- Lannig S., Hansen A., Thorsteinsson B., Nerup J. & Koch C. (1995) Glucose tolerance in patients with cystic fibrosis: five year prospective study. *BMJ*, 311, 655-659.
- Lannig S. (2001) Glucose intolerance in cystic fibrosis patients. *Paediatric Respiratory Review*, 23: 253-259.
- Lowton K. (2004) Only when I cough? Adults' disclosure of cystic fibrosis. *Qualitative Health Research*, 14 (2) 167-186.
- Lowton K and Gabe J. (2003) Life on a slippery slope: perceptions of health in adults with cystic fibrosis. *Sociology of Health & Illness*, 25(4), 289-319.
- Phillips A. (2007) Experiences of patients with type 2 diabetes starting insulin therapy. *Nursing Standard*, 21 (23), 34-41.
- Robinson CA. (1993) Managing life with a chronic condition: the story of normalization. *Qualitative Health Research*, 3 (1), 6-28.
- Schur H.V., Gamsu D.S. & Barley V.M. (1999) The young person's perspective on living and coping with diabetes. *Journal of Health Psychology*, 4 (2), 223-36.
- Smith J, Jarman M & Osborn M. (1999) Doing interpretative phenomenological analysis. In *Qualitative Health Psychology* (Murray M & Chamberlain K., eds). Sage Publications: London.
- Ternulf Nyhlin K. (1990) A contribution of qualitative research to a better understanding of diabetic patients. *Journal of Advanced Nursing*, 15, 796-803.
- Tracy JP. (1997) Growing up with chronic illness: The experience of growing up with cystic fibrosis. *Holistic Nursing Practice*, 12(1), 27-35.

Williams B., Mukhopadhyay S., Dowell J., & Coyle, J. (2007) Problems and solutions: Accounts of parents and children of adhering to chest physiotherapy for cystic fibrosis. *Disability and Rehabilitation*, 29 (14) 1097-1105.

Table one: Interview topic guide

<b>Topics for discussion</b>	Brief overview of experience of living with CF(overall attitude to living with CF, impact on daily life, coping etc)
	Tell me about when you were diagnosed with diabetes (thoughts, feelings, behaviour)
	Management of diabetes (additional demands, treatments).
	How is your life affected by having diabetes (home, work, family/relationship, health, treatment).
	How do you cope with the additional demands of having diabetes?
	The future? (do you see diabetes having an impact on your future)?