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# Only when I cough? Adults' disclosure of cystic fibrosis

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## Abstract

Cystic fibrosis has traditionally been conceptualised as a fatal childhood disease. In contrast, survival age has been increasing steadily such that adults now routinely seek to gain employment and form close relationships, situations that may require telling others about the disease. Here three situations of disclosure are examined, based on interviews with 31 adults with the disease. Firstly, in a low risk situation, for example a short period of social contact, a low level of intimacy exists between the adult with cystic fibrosis and another. Here the disease may be concealed easily with little risk of discovery. Secondly, in a medium risk situation the perceived reaction of the other begins to influence the decision to disclose, as the level of intimacy becomes higher. Lastly, in high-risk situations such as employment, the consequences of disclosing or concealing CF are most severe. However, a multiplicity of factors, including perceived social support and disease progression, are seen to influence adults' decisions to disclose their disease.

Key words cystic fibrosis, disclosure, risk perception, risk management

## Introduction

Cystic fibrosis (CF) is a genetic disease most commonly found in populations of European origin; incidences of 1:2521 amongst whites in the USA (Hammond, Abmanm, Sokol, & Accurso, 1991) and 1:2415 in the UK (Dodge et al., 1997) have been reported. In the early 1930s, 70% of people with CF died before their first birthday (Anderson, 1938). By 1993, the median survival age in the USA was 27.6 years (FitzSimmons, 1993), with British children born in 1990 being predicted to live on average for 40 years (Elborn, Shale, & Britton, 1991). However, the variability and unpredictability of the disease course means that there is no particular age at which mortality rises sharply (Dodge et al., 1997).

The aim of this article is to explore through in-depth interviews with adults with CF, how decisions of disclosure of CF are made in adulthood. In interpreting the interview findings, the analysis draws mainly on the works of two sociologists; Erving Goffman and Anthony Giddens. In Presentation of Self (1959) Goffman considered the ways in which individuals present themselves in ordinary work situations; he then analysed the structure of social encounters by those with illness in Stigma (1963). Giddens built on Goffman's work in The Consequences of Modernity (1990) and Modernity and Self-Identity (1991), by perceiving the self as being constantly revised through a process of reflexivity, affecting an individual's concept of self-identity. Through applying these works and patterns of disclosure of other chronic diseases to empirical research findings, it is argued that the decision to disclose or conceal CF by adults with the disease is influenced by a multiplicity of factors including perceived social support and disease progression.

Despite extensive literature searching, there appears to be little published work on disclosure of CF by adults with the disease, a notable exception being Admi (1995). Admi's research

focused on ten adults aged 16-25 with the disease and their close relatives. Admi found that situational factors such as timing, relevance, mood, or another's interest, were all influential factors in disclosure of CF. However, many of these respondents were only just at the point of choosing partners or careers. Although insightful, issues pertinent to older adults living with the disease, such as discussing infertility issues with a potential partner or disclosing CF to an employer, were not addressed.

Factors influencing personal disclosure of other chronic diseases such as epilepsy (e.g. Tröster, 1997) and HIV/AIDS (e.g. Holt et al., 1998; Mansergh, Marks, & Simoni, 1995; Simoni, Mason, & Marks, 1997;) have been well documented in the social science literature. In the context of disclosure of epilepsy, managing information about disease is not based on an individual's general nature to conceal but instead depends more on the particular circumstances in which the issue of whether or not to disclose arises (Tröster, 1997). Similarly, Holt and colleagues (1998) have examined patterns of disclosure across stages of HIV infection, from diagnosis to AIDS, and found that disclosure was used both to facilitate self-acceptance of one's condition and to increase practical and emotional support. The impact of felt (perceived) or enacted (experienced) stigma in chronic illness has also received much attention (see for example Charmaz, 2000; Jacoby, 1994; Scambler & Hopkins, 1986, 1988).

It is possible that symptoms of CF may influence adults' disclosure of the disease. The main symptoms of the disease arise from abnormal sticky secretions in the respiratory and digestive tracts, produced by the 'CF gene' (Rommens et al., 1989). The most common symptom for both children and adults is lung disease, resulting in frequent coughing and long-term lung damage (Madden, 2000). Furthermore, most people with CF have some

degree of digestive deficiency from impaired pancreatic function, resulting in weight loss. Routine treatment is palliative, not curative and consists of daily chest physiotherapy to clear sputum, frequent courses of oral, nebulised or intravenous (IV) antibiotics, and pancreatic enzymes. Most treatment is carried out at home, with acute episodes of illness requiring hospital admission.

As health fails, organ transplantation, most commonly heart-lung transplantation, may be offered. However, the shortage of suitable donor organs in the UK means that half of adults with CF on the transplant list die before donor organs are found (Hodson, 1998; Ryan & Stableforth, 1996). Due to increased survival age, infertility is now an issue for adults with CF; the vast majority of men with CF are infertile (Sawyer, 1996) and IVF therapies have been developed to assist adults to become parents (Silber, Ord, Balmaceda, Patrizio, & Asch, 1990). Although women have a slightly better fertility rate than their male counterparts, their infertility tends to be due to amenorrhoea, brought about by poor general health and weight loss (Penketh, Wise, Mearns, Hodson, & Batten, 1987). How adults manage disclosure to partners of their possible infertility and shortened lifespan has not been documented.

### Methods and Sample Characteristics

The adults who participated in this study all attended a regional specialist centre for the care and treatment of CF in the UK, and aged between 18 and 40 years. After ethical approval had been obtained from the hospital's Ethics Committee, a list of adult patients living in southeast England was prepared from the specialist centre's CF department database, amounting to approximately 40% of the total number of adults attending the department. A meeting was held between the author and CF department staff to agree the eligibility criteria. Adults judged by staff to be in extremely poor health and those who had great difficulty in

communicating in English because it was not their first language were excluded. Two patients were ineligible on these grounds. A further fourteen patients were excluded, as they were a sibling of a patient who had already been approached to participate. This decision was taken to avoid any undue pressure on the second sibling to participate in the study, especially if their brother/sister had refused to take part.

After the staff had checked to make sure that those in the sample had not died very recently, they were written to by the author inviting them to participate in the study. Patients were informed that the focus of the study was to capture their perceptions of their health and quality of life (Lowton & Gabe, 2003), what they perceived to be the risks and benefits of their current and future treatment (Lowton, 2003), and their experiences of living with the disease and disclosing it to others. Adults were also asked to nominate a lay carer to be interviewed separately about their experiences of caring for an adult with CF (Lowton, 2002). Patients also received a letter of introduction from the CF consultant and CF Nurse Consultant.

Overall, 26% (47/183) of those approached agreed to take part, after follow-up and reminder letters. This acceptance rate was much lower than anticipated and possibly may have been to do with the subject matter of the research not involving new therapies. A similar sociological research project exploring screening for Downs' syndrome, thalasemia and CF amongst people with these diseases reported a comparable response rate of 25% amongst adults with CF (P. Alderson, personal communication, January 28, 1998).

Thirty-one respondents were subsequently interviewed in their own homes for between 1-1.5 hours on average during 1997/8, with the aid of a topic guide derived from reviews of the

medical and sociological literature concerning young adults with chronic disease, and conversations with CF clinic staff. The guide provided prompts for the researcher concerning the areas to be covered, rather than asking specific questions. Reasons for respondents not being interviewed were living out of the study area, subsequent refusal, hospitalisation, and death. Confidentiality was assured for all participants, both with the hospital and their relative. Patients were told that all interview material would be made anonymous by using pseudonyms in any reports. Each participant received an information sheet about the study and consent forms were signed by respondents to comply with the requirements of the Ethics Committee.

Interviews were tape-recorded and fully transcribed. Codes were attached to a segment of text such as a word, phrase, or sentence. These codes were then grouped into categories, providing the conceptual foundations for analysis (Dey, 1993). Coding was undertaken using the ATLAS-ti software programme for qualitative data. The majority of conceptual categories had started to be developed during the course of interviews, though discussion with subsequent participants and conversations with experienced medical sociologists in the authors' university department. These concepts were subsequently developed analytically with conceptual relations being established between them (Strauss, 1987).

Although there was a low participation rate, the findings are likely to reflect the views of other adults with CF in the UK, as between 53%-93% of all people with CF in this country are estimated to attend a specialist CF clinic in some form (CSAG, 1993). More importantly, given that the sample was theoretical, in that interviewees verified emerging theory as more interviews were conducted (Strauss, 1987), generalisability may be best judged in terms of logical inference and the plausibility of the analysis (Mitchell, 1983).

Of the 31 adults who took part in the study, 17 were female (mean age 29) and 14 were male (mean age 32). Six respondents had undergone organ transplantation, two were on the transplant waiting list (one for repeat transplantation) and one was considering assessment for transplantation. Age at diagnosis of CF ranged from birth to 22 years, although only two respondents had been diagnosed at over seven years of age; one at 15 years and one at 22 years. Nine adults had had, or attempted to have children, and 19 adults were working or studying at the time of their interview.

### Situations of disclosure

There were three types of situation identified from adults' interviews where disclosure of CF could be considered. Interviewees did not refer explicitly to these categories; rather they were identified as situations recurring throughout the interviews, suggesting that disclosure of CF was something that all respondents had to consider, if not currently then in the past or anticipated for the future. The situation categories presented here are second-order constructs of the author, although quotations from interviewees illustrate that these categories are grounded in the thoughts and feelings of the participants. In all situations disclosure was seen as a risk by adults, due to the potential consequences, both negative and positive, that telling others could present. Firstly in the 'low-risk' situation or casual encounter, identity as a 'normal' adult was usually (although not always) assured. In the 'medium-risk' situation, for example friendships, the risks and benefits of disclosure were considered more fully. Lastly, in the 'high-risk' situation, disclosure of CF to potential partners and prospective employers was perceived to hold great difficulty for respondents due to the significance of possible consequences.



In each of the three situation categories certain factors were found to be pertinent for adults. For each of them their state of health, their body and its changes with increasing illness were significant factors. For Shilling self-identity is an individual's 'sense of self as reflexively understood in terms of their own embodied biography' (1993:4), whereas social identity is the image others have of them or a group of people similar to them. How participants perceived CF as part of their self-identity and social identity was also important in deciding whether to disclose or conceal the disease and influenced their perceived (or 'felt') and experienced ('enacted') stigma of having CF. Adults' health and the effects of treatment that were seen to cause decisions of disclosure are discussed further in relation to each concept.

#### (1) Low risk situations: the casual encounter

Here existed a low level of intimacy, for example a short period of social contact (either a single or multiple fleeting contacts or a longer contact time with no desire to meet again). If CF was concealed during these contacts there was only a very slim chance of discovery of the actual disease being made by the other, either by bodily signs, for example the adults' coughing or their low body weight, or by disclosure from a third party.

'If I was meeting somebody, say, at Tesco's [supermarket], it never comes into the conversation.' [Gill]

Adults who reported concealing their CF during a casual encounter stated that they had not experienced any severe consequences, as none of them had been subsequently 'found out'. As is common for those with HIV/AIDS (Holt et al., 1998; Simoni et al., 1997), individuals' past experiences had indicated that disclosure was not necessary or called for during many encounters. However, for many respondents, the body was itself 'risky' in social encounters, as it could not be relied upon to act normally in daily situations. Goffman (1959) describes

the social processes of 'checking' the body to ensure that offence is not given to others, or the wrong signals conveyed. Nevertheless, for these adults with CF, their bodies often hinted at, or disclosed their situation for them. Usually this was through the 'CF cough', the distinctive persistent cough that was usually made more severe during chest infections and could not be controlled or 'checked'. However, respondents who spoke about their coughing during brief casual encounters, for example when in the supermarket, usually reported being quite flippant in their reply to others' concerns:

'If they say, "Oh, you've got a bad cough", sometimes if I can't be bothered I say, "Oh yes, I've got a bad cough".' [Emma]

'A lot of people do say, "Oh, you've got a nasty cough" and, "You want to give up those cigarettes" and I jokingly say, "Oh, if I had a pound [coin] for every time someone said that!" If it's like someone in a shop or something I just say, "Yes, I've always got a cough". It depends how well I know people'. [Eliza]

A socially adept individual is one habitually seen to be so by others (Goffman 1971). He or she must avoid lapses of bodily control, or signal to others by gestures or exclamations that there is nothing 'wrong' should such events occur. Eliza achieves the exclamation that nothing is 'wrong' by her insistence that her 'cough' is normal for her, relatively easy to achieve in the casual encounter. Giddens (1991) additionally suggests that a person's ease in any given situation presumes long-term experience in confronting the threats and opportunities it presents. Here Emma and Eliza's dismissals of others' concerns as purely 'a cough' in casual encounters was in keeping with their sense of self as having 'normal' health (Lowton & Gabe, 2003).

Another common response to others' questioning of symptoms during casual encounters was to attribute them to another disease or condition:

'I've got a few acquaintances round here and they don't know. They occasionally say, "What's the matter with you? You're huffing and puffing." And you know, I just put it down to being fat.' [Ian]

Some participants believed that the 'CF cough' could be confidently passed off as an asthmatic cough, and as body weight was often the same as healthy people in mild or early stages of the disease, respondents believed they did not look any more 'ill' than an adult with asthma. Passing off one disease as another more common one has been demonstrated empirically in other diseases. For example Carricaburu and Pierret (1995) found in their study of meanings and identities of men with HIV/AIDS that one man told work colleagues that he had diabetes in order to cover his frequent hospital attendance. In that study felt stigma was a strong factor in not disclosing the disease. However, in the current study, felt or enacted stigma did not appear to be an overriding factor in concealment of CF in casual encounters. One reason respondents expressed no fear of enacted stigma was because of the perceived ignorance, or 'medical blindness' (Goffman, 1963, p. 68); of the general public about adults with CF, this being in sharp contrast to the general population's awareness of HIV/AIDS and the stigma attached to the disease (Holt et al., 1998). Rather than fear of stigma it was the level of 'botherment' that adults with CF perceived they would experience in having to explain their disease to others who had little knowledge of it. Adults also reported that, as asthma was more prevalent than CF, the general public knew more about it and would enquire no more about the adult's state of health.

However, as their CF progressed it became difficult for some individuals to maintain the façade of ‘asthma’. As the following quotation illustrates, Tina reported previously telling others during casual encounters that she had asthma, but now felt that this explanation would not be believed due to her severe breathlessness and weight loss, which had resulted in her waiting for a second lung transplant at the time of her interview:

‘I used to tell people I had asthma when I used to cough because it was just so much simpler than [disclosing CF], and people had heard of asthma, so and they’d go, “Oh, right”, you know, and that was fine, without going into cystic fibrosis, “Oh, what’s that? What does that mean?” So it was just easier to do that. But then obviously I was too ill and people didn’t believe me when I just said I just had asthma [laughing], it was like, “Um, I don’t think so!”’ [Tina]

In Tina’s case the disease’s visibility or ‘evidentness’ (Goffman, 1963, p.65), i.e. that which can be told about an individual’s social identity at all times, was apparent, and communication through the body’s own expression could not be prevented (Williams & Bendelow, 1998). Disclosure in this instance is similar to that of AIDS, with physical changes in appearance often pre-empting disclosure of HIV status (Holt et al., 1998). As Kelly and Field (1996) argue, biological and physical facts (here deterioration of the body through disease) impinge directly on the self, providing signals for construction of social identity.

Graham, 40, was in the final stages of CF. Here, to use Goffman’s (1963) terminology, the discreditable became the discredited, that is the ‘stigma’ of chronic illness was now evident to others through his bodily appearance during the majority of his encounters. An ability to conceal CF during the early stages of the disease became one of full disclosure during the

later stages. During his interview Graham reported previously having attempted to give the impression to others of a sprained ankle when using a wheelchair in public. Graham stated that it was now imperative for him to disclose CF during casual encounters as he worried that his image portrayed a picture of AIDS to others; that was weight loss, poor mobility and breathlessness in a man often seen in a group of other men. This was something that Graham stated he was anxious to deny:

‘[I] tell everyone what I’ve got, because I’m scared they’ll think “bloke, AIDS”.

That has always worried me.’ [Graham]

Here Graham was not worried about disclosure of CF by a third party (this instead would have been positively welcomed by him). In effect Graham was weighing up whether it was riskier to be thought of as having AIDS or CF, because of the perceived blame associated with AIDS by the public and the risk of enacted stigma from that perception.

Many disabling illnesses such as multiple sclerosis (Charmaz, 2000) and AIDS (Holt et al., 1998) grow in severity and progress from being invisible to visible; this is also the case with CF. If, as in Graham’s case, an individual took great pains to disclose the illness for fear of reprisal from others (or alternatively expended substantial effort in keeping the illness a secret from others) it took on an enlarged meaning for their personal identity and self-concept when health became ‘distressing’ (Lowton & Gabe, 2003). In the late stages of the disease CF may be seen as the ‘master status’ (Goffman, 1963), overriding all other statuses and identities and influencing full disclosure due to its constant impact on daily life.

Other than to prevent the virtual social identity of a person with HIV/AIDS being made, active disclosure of CF in casual encounters tended to occur only when disclosure was seen

as a benefit. This benefit was either for the individual themselves or for others with CF and only took place in adults when CF being a significant part of their self-identity was secure. For example, in raising money for the CF Trust some adults were eager to tell others about their experience of having CF if it was likely that people would donate money to the charity. Alternatively disclosure was used as part of the education of others who were newly affected by the disease but were deemed by respondents to have only heard the ‘bad press’ stories from the media. In this instance disclosure of the disease was perceived as a high benefit and low risk:

‘The CF [Trust] was the major charity at the Ideal Home exhibition a couple of years ago, and I went along. I was on the stall selling whatever for half a day, and I remember just talking to a couple of young mums who’d just had CF children, [they] didn’t know anything about it apart from all the bad press stuff. And half an hour chat with them, and their whole outlook had completely changed, and I thought, "God, look, because I’m fortunately really quite well I can actually pass that [positive image] on". [Keith]

Here the perception of health as ‘normal’ or ‘controllable’ through treatment and a positive attitude to the disease (Lowton & Gabe, 2003) resulted in the individual’s self-identity reportedly influencing other’s self-identity on an individual-to-individual basis, in this instance for parents of children with CF. Other adults however regarded disclosure of CF in casual encounters as an opportunity for the wider public’s general education, in the same manner as disclosure of seropositive status in community HIV education programmes has been reported (Holt et al., 1998). However adults with CF stated that they would not disclose anything that they considered ‘personal’ but rather recount the experience of adults with CF as a group. In her job as a journalist, Emma reported frequently having the opportunity to

'educate' others about the disease. Here, although self-disclosure did take place, it was set within a wider role as an educator of the general public in an attempt to ensure that self-identity influenced the social identity (Shilling, 1993) of adults with CF as a group:

'If it comes up I tend to sort of regard it, again not so much talking about me but more as a kind of, I believe that people should in general know that there are people in general with CF that get on with life and who have jobs and who are, God help us, over 30. So it's a process of education rather than something personal about me.' [Emma]

To summarise, there was little risk of CF being discovered by others in casual situations when body image was generally good. Ill health influenced adults' decision to disclose CF, either because they were unable to pass off the disease as a minor health condition such as asthma, or for fear of being perceived by others to have a more stigmatised disease.

Disclosure of CF also took place for the benefit of others affected by a recent diagnosis or for the education of the general public as a whole. We now turn to consider disclosure of CF within friendships with others without the disease.

## (2) Medium risk situations: friendships

In this situation the perceived reaction of the other began to influence the decision to disclose as friendships were established over a period of time and the level of intimacy became higher. Past experience of disclosure to friends was used to form a decision on whether, and at what point in the relationship, CF was disclosed. Disclosure to friends was different to disclosure in the casual encounter because there was often a need for others to know, either for the respondent to be assured of empathy, medical help in an emergency, or because of a deepening friendship where self-disclosure on both sides had begun. The

chance of discovery by the interaction partner or by a third party was higher, due in part to a continuing social relationship with friends; this also made the option to conceal by referring to another disease less attractive to most individuals. Appearance of the body, state of health and self-identity again influenced the decision to disclose, or the timing of disclosure, in this situation.

Most adults stated that at certain times in life acquaintances became friends, and they thought more about disclosing their condition. Vanessa, 18, said that she told most acquaintances that she suffered from coughs and colds; this was possible because of her good body weight and mild disease that did not currently require hospital admissions. However, when friendships deepened she disclosed her disease:

'And it's only the people that I've got to know as friends, really close, and they'll say to me, "Oh, God, why are you ill?" I say, "Look, I don't want you to tell everyone, but I've got cystic fibrosis, this is what it is and that". "Oh, you never would have known", [they say].' [Vanessa]

Disclosure by a third party, usually other friends, was more likely to happen in friendship situations rather than in casual encounters. In Oscar's case, 18 months post heart-lung transplant, disclosure by friends was seen by him as due to their being 'proud' of him and wanting to 'show him off', rather than to felt or enacted stigma. As Oscar recalled during his interview:

'I did have a problem with a few friends, I think, well, it appears that they were proud of me in a way, I don't know. But they used to kind of like introduce me and say, "Oh, this is Oscar. He's had a transplant!" And they used to get me, 'cause again, I wanted to be known as a person, as opposed to the guy with the



transplant. And once I get to know someone, I really don't mind them knowing.

Um, but I'd rather not, I didn't like to be introduced as Oscar, the person who's had the heart and lung transplant.' [Oscar]

Here Oscar was unlike Graham above who was keen to use CF as a 'master status'. This was most likely due to the differences in Oscar's and Graham's health state at the time of their interviews. Oscar had made excellent progress after his organ transplant, whereas Graham's health had deteriorated to a point where he had been asked by the hospital to consider lung transplantation. However, the risk of friends making an unwanted disclosure to others already in the adult's social circle was also apparent:

'I had lunch with one chap and his wife, and I actually did tell them [about CF].

And then another man's wife about three weeks later rushed up to me. "I didn't know you had CF" [she said]. I said, "Why should you?" I was actually quite cross about it. I tell people if I feel that they need to know, or if I think they'll understand it.' [Catherine]

This suggests that the level of perceived intimacy is a significant factor that defines the moment that adults with CF decide to disclose their condition, the decision to disclose disease being made on the quality of relationship with others (Schneider & Conrad, 1980). However, the perceived reaction of friends was just as important as the degree of intimacy experienced, and tended to dictate whether only a few close friends knew, or most regular contacts. The expected reaction of friends influenced decision making both ways, either to disclose CF to heighten the level of intimacy or to conceal the disease in order to maintain closeness:

'Because the kind of person I'd be friends with wouldn't respond negatively, and I think that it's important that they do know, and I like them to know because I like that, and I also get a bit of sympathy, or empathy, and that's nice too. So no, I've never had a negative [reaction] with them.' [Clare]

'I think probably I was cautious [about telling friends] because some people get a bit funny about any disease...and then the thing I eventually realised was that if they are good friends then they will try and help, and they did.' [Barry]

In Admi's (1995) study of disclosure of CF it was suggested that respondents could 'just sense' the 'right person' to tell. Little attention was given to why respondents disclosed to some friends and not others. In the context of HIV/AIDS, Holt et al. (1998) found that protection against negative reaction of others could be made by only disclosing HIV infection to those whom individuals anticipated would be understanding. The resultant support was a boost to the individual's well being, such that disclosure became one type of coping mechanism. One likely reason for disclosure of CF to friends is the level of trust that is felt by adults to exist between themselves and their friends. Giddens (1990) typifies trust as being socially created as a commitment to something (here friendships) and as a particular type of confidence (here about friends' positive reactions). Risk and trust intertwine (Giddens, 1990), minimising here the dangers of disclosure.

Tessa, aged 21, reported not telling any friends at her current university about her CF, as she perceived a negative reaction from all of them, conveying perhaps a low level of trust in these particular friendships. During her interview Tessa reported sustaining the level of intimacy with her friends by not telling them that she had CF:

'[I] just keep it to myself. I think they'll feel sorry for me, and I think they will change, like they'll think they can't tell me anything because it's not very important in comparison to what I moan about maybe. They might think that they're just, [pauses] what upsets them is petty and rubbish, and they can't tell me. And they'll feel sorry for me'. [Tessa]

Tessa's reason for concealment is in keeping with Admi's (1995) finding that young adults with CF were dissatisfied with their disclosure to friends because they reported subsequently being treated as 'patients' in social relationships when it was not relevant. Kelly and Field (1996) argue that labelling and identity feed back directly to self-conceptions as the chronically ill person constructs and reconstructs the meaning of their bodily malfunctioning and the (perceived) responses of others to this. Here trust, as a confidence and a commitment to a relationship, is not apparent. Only for a minority of adults how negatively they felt about having CF dictated that they did not tell friends about the disease. In this case the fear of enacted stigma lead to non-disclosure (Scambler & Hopkins, 1986).

To summarise, a medium level of risk existed in disclosure of CF within established friendships because self-disclosure was more likely to occur and adults perceived a greater chance of discovery if disclosure was not made. Intimacy in friendships, the perceived level of trust, the perceived reaction of others and self and social identity were important factors in deciding to disclose. Although disclosing CF may have lead to a higher level of support and understanding from friends, there was a fear of being treated differently within their social circle.

### (3) High risk situations: potential partners and prospective employers

Much of daily life is inconsequential for the individual's long-term aspirations and is not perceived as fateful for overall goals (Giddens, 1991), seen above in respondents' experiences of casual encounters. However, Giddens argues, some avenues of activity are usually thought of by the individual as more consequential than others, for example in disclosure of CF in relation to paid employment and partnerships where losses or gains may result. Giddens terms 'fateful moments' (1991, p.113) these particular situations or episodes that are both highly consequential and problematic yet necessary for achieving an individual's required lifestyle.

There was a much higher chance of discovery of CF in high risk situations as the relationship with others was anticipated to last for a much longer period of time, or be of a much greater intensity, than in the other two situations. In deciding to disclose or conceal CF to a prospective partner or in an employment situation the consequences were perhaps most severe. Past experience of disclosure and the past reactions of others in these high-risk situations were therefore reflexively considered and used as a basis for deciding whether or not to disclose CF. Adults' age, state of health, appearance and self-identity again weighed heavily in decisions concerning disclosure or concealment of CF.

#### Potential Partners

Men with CF are usually infertile and women may also have reduced fertility (Sawyer, 1996). 'Knowing' about infertility is itself a recent phenomenon fuelled by technological advances allowing us greater insight into the body. In pre-modern cultures marriages were 'blessed' with children and certainly pre-modern couples did not discuss whether or not to have children as they might do today, therefore relationships exist more on what partners can

gain from each other (Giddens, 1991). In the current study, most adults without partners expressed concern over whether they would be able to find a partner at all, because of the ‘risks’ that they perceived asking the other to take on. These risks were most commonly infertility and death at a relatively early age preceded by illness.

As with friendships, the level of intimacy and the perceived reaction of a new partner were important factors in deciding when to disclose CF. Adults who looked well could initially conceal CF by virtue of their ‘normal’ body image and their partner’s lack of knowledge concerning CF, and participants reported often going to great lengths to do this in the early stages of a relationship. Emma described taking her nebuliser and antibiotics to work with her when she had first met her current partner Simon so that her CF could be more easily concealed. However, individuals ran the risk that discovery by a third party who did know about adults with CF might occur before disclosure was made. Again, the inability to control the ‘CF cough’ meant that the body mediated between a self-identity as an adult with CF and a social identity as a ‘healthy’ individual:

‘So I kept it quiet, and I think it was his [Simon’s] flatmate who had actually known somebody with CF, ‘cause they heard me coughing and stuff, and in the end I can’t remember whether I told him [Simon] or he asked’ [Emma]

Respondents’ knowledge of male sterility in CF (they had often been informed of this by their doctors) made infertility more of an issue for adults with CF in heterosexual partnerships as opposed to friendships. Indeed, this influenced adults to perceive potential partnerships as high risk. Although Mike’s girlfriend Nina had already known about his CF through a third party (Nina’s mother) before becoming involved with him, Mike, 33,

illustrated that infertility was an important issue that had had to be addressed at an early stage in their relationship:

'I can remember telling her fairly early on when I realised, you know, things were sort of going quite well, we were getting quite serious, the fact that I couldn't have children. 'Cause I thought, you know, if Nina thinks getting married and having children is going to be a, you know the sort of normal progress of life as it is with most people, then I'd better tell her here and now before we get down the road too far.' [Mike]

However, although Mike disclosed his infertility relatively early on in the relationship, he continued to conceal his need for physiotherapy from his girlfriend due to his embarrassment at having to perform the procedure in order to bring up sputum. Here his partial disclosure of CF was aided in part by his partner's lack of knowledge about the disease. However, this partial disclosure was different to the 'partial disclosure' reported in epilepsy whereby sufferers used ill-defined words such as 'dizzy spells' to disclose their illness (Scambler & Hopkins, 1986). Rather partial disclosure in CF involved revealing accurately some, but not all, aspects of the disease. It could be argued that partial disclosure of CF is seen across all risk situations, however it is seen most clearly when adults were applying for jobs. It is to this last risk situation that we now turn.

### Prospective Employers

In a survey of 820 adults with CF in the UK (Walters, Britton, & Hodson, 1993) those of working age achieved 80% of the employment rate of the general population. In trying to gain employment, adults with CF in this study were competing against people without chronic illness who may appear more attractive to potential employers by virtue of having

no disease. Participants appeared to work from a starting point of considering themselves less 'suitable' for employment than others without disease were, and this was an influential factor in their decision to conceal CF. Many employers in the UK use health questionnaires and medical examinations to assess the suitability of a candidate for employment; adults here appeared to be most concerned with managing this part of the application process.

As Giddens, following Goffman, argues, 'routine control of the body is integral to the very nature both of agency and of being accepted and trusted by others as competent' (1991, p.57). In the employment situation the physical body itself was seen by respondents as 'risky' in the sense that although they may have felt 'healthy' currently, future good health could not be guaranteed and the body was more likely to fail (or indeed fail earlier) than other more 'healthy' bodies. Although health cannot be guaranteed for healthy people, the risks for those others appeared to be far less, illness usually meaning sick leave from work for short periods only. While well, it was easier for adults to conceal CF, both by bodily appearance and in the knowledge that long periods of leave from work were unlikely at that time. When older and in worse health, disclosure strategies had to be changed, dictated both by bodily appearance and the amount of time spent on sick leave.

There appeared to be three distinct opportunities for adults with CF to disclose their condition to employers. Adults were often asked to write about health problems on the application form or health questionnaire; the first opportunity to disclose the illness began at this stage. The second opportunity to disclose the disease occurred at the job interview or medical. Lastly, if a successful application was made, the workplace itself presented adults with a third opportunity to disclose CF to colleagues and/or employers. Each of these opportunities for disclosure is considered in turn below. Some adults had been successful in

acquiring a job because of being employed specifically by virtue of their being a registered disabled person. The case of these adults is not considered here, but rather those with milder disease that went through more regular channels because they were not severely ill enough to be registered disabled and gain employment in this manner. It is to the application stage that we now turn.

### The application stage

When in good health, most respondents stated that they saw little requirement to disclose CF on an application form, as they did not currently need or anticipate needing time off from work. They therefore saw themselves as no different in this respect to any other person applying for the same job. Here, concealment of illness was the ‘first choice strategy’ (Scambler & Hopkins, 1988). Anna, 31, was not currently employed at the time of her interview but was thinking of applying for work in the local supermarket to fit in with her young daughter’s needs. Anna stated that she would not disclose CF on her next application form, as she perceived this would only be a hindrance:

‘I think I’d leave it blank, I wouldn’t say, "No" [she does not have a health problem], I think I’d leave it blank. ‘Cause the thing is it shouldn’t be there to hinder your progress in society and you shouldn’t have to answer that. If that question is there, why is it there? Is it so that they can discriminate against you and say, "Right, we’re not even going to give you an interview"?’ [Anna]

Past personal experience of disclosure was also used to decide whether, and in what manner, CF was revealed. Those who had declared CF in a very positive way on an application form usually changed their tactics after being consistently refused jobs. Thereafter CF was either not disclosed or the effects of the disease were minimised with the use of phrases such as



‘mild form’ and stressing the few implications for employers. However, as Simoni et al. (1997) observe in the context of HIV/AIDS in the USA, those who conceal their serostatus are deprived of the opportunity to request adjustments directed by disability law, which may compound stressors already present. Keith recalled applying to many different companies before eventually being successful:

‘Every single one of them [standard application forms] has got, "Have you got any illness?" and so I answered it, "Yes, I have, I've got cystic fibrosis". And I look back now and my first application form screamed of cystic fibrosis because I actually did some things at university involved with CF as well, and I put that down as a good thing, as a social thing that I did and I thought no, that's wrong. Reading it now I think, "God, look, I'm just advertising the fact I've got cystic fibrosis". So if you look at my application forms, through to about the 30<sup>th</sup> one, 20<sup>th</sup>-30<sup>th</sup>, have got, "Yes, I'm a very mild sufferer of CF" in tiny writing in the little box, and that's it, and no other mention of it.’ [Keith]

As Tröster (1997) argued in the context of disclosure of epilepsy, managing information about disease is not based on an individual's general nature to conceal but instead depends more on the particular circumstances in which the issue of whether or not to disclose arises. Here Keith practised ‘anticipatory preventive telling’ (Schneider & Conrad, 1980) whereby disclosing disease at a very early stage in the encounter gave the opportunity to correct in advance the negative impression that others could form when they found out, to minimise the significance of symptoms or to provide education to others. In CF, ‘medical blindness’, that is the ignorance of others, could also be used to adults' advantage by defining CF in terms of what it meant to them personally. However, it was impossible for Keith or the author to know if CF was the reason why Keith was rejected so many times, as he stated that he had not contacted companies that had not offered him an interview to find out why.

In certain jobs adults felt obliged to disclose CF immediately, as they felt that through their employer's surveillance measures it would be discovered anyway, and they would certainly face dismissal once 'found out' (most commonly in the UK an offer of employment is made subject to health clearance). Only one participant mentioned disclosure by doctors as a third party, although this certainly may be an important reason why respondents were not offered jobs. Here the influence of the seriousness of the risk of not telling was great and similar to Tröster's (1997) finding in his study of disclosure by adults with epilepsy that people were more willing to disclose their disease if their fear of the other finding out was high. Tessa, 21, chose to disclose her CF straight away when she applied for a job as a traffic warden, because she stated that she believed that the police had access to her health records and would know that she had failed to disclose CF. She used humour and exaggeration to make her point:

'Well, I worked for the police for about a year and a half and they do like a load of checks on you, and like they send special branch in to find out what you have been up to [laughs]. So I thought well, they're bound to find out, and then, and I had to take a medical, and they wanted to get in touch with the doctor and all that, so I knew there was no way I could have got into it without telling them. Otherwise I wouldn't have done, no.' [Tessa]

Adults reported that as they got older they were more likely to disclose CF to potential employers at the application stage due to increasing ill health and the absences they needed (or perceived that they would need) to take from work. During her interview Clare, 35, spoke of how disclosure of her CF to potential employers would be dependent on her health

state at that time and influenced by how much time her work would be interrupted by sick leave:

'If I was really ill then I probably would say [to prospective employers that she has CF], because I'd have to, and it would be unfair not to. But if there's nothing, where they're not going to lose out because I was having treatments and time off all the time, I probably would lie.' [Clare]

Although only a few adults in the sample could be said to be in the very late stages of CF, this finding fits with Scambler and Hopkins' (1986) conclusion that in disclosure of epilepsy to employers, those who did disclose had more frequent seizures than those who did not. The authors presumed that people with epilepsy saw anticipatory preventive disclosure as the lesser of two evils (the other option was being discovered by the other).

### The interview stage

From non-disclosure on application forms, there were two options open at an interview, to disclose CF at that point or to continue to conceal. Many respondents relied on the fact that the general public was largely ignorant of the symptoms or natural course of CF, and adults stated that they used this lack of knowledge to their advantage in gaining employment at the interview. If a prospective employer saw someone who looked fit and healthy at interview then the respondent would often see little point in informing him or her otherwise. It appeared through the study interviews that not all positions were offered subject to a satisfactory medical:

'If they had a medical and they said, "Have you got any health problems?" I'll tell them straight away. But if they don't ask, they don't want to know'. [Oscar]

'If I felt it was a job that wouldn't particularly affect my health and they didn't ask me, I don't think I would tell them'. [Jack]

A 'normal' body image was also believed to be beneficial for adults at interview, as again the 'evidentness' of CF was low and the body communicated that all was well. As respondents noted, by 'looking healthy' during job interviews they compounded the interviewer's sparse knowledge of CF by playing down the disease and only partially disclosing it, for example by referring to CF as a 'bad chest' and not mentioning the likely future health effects of the disease:

'They [interviewers] used to sit there and go "What's that? [CF]" ...and it wasn't such a problem because I looked healthy...and obviously when going for interviews that was an advantage to me, because often interviewers just look at you and think, well, she looks fine.' [Gill]

'I didn't say what I had, I just said I had a bad chest and it sometimes caused problems but was keeping on top of it.' [Barry]

However, this strategy was not always successful; at times jobs were perceived to be lost at this point of disclosure:

'And I know I got the job right up until the point where she [the interviewer] said, "Right, something totally insignificant here but just medical things, you haven't got anything wrong with you, have you?"...And then I had to say I'd got CF. You could have heard a pin drop. And I knew at that point, you could see the shutters come down over their eyes; I'd lost it. Lost the interview, I'd lost the job.' [Wendy]

## Disclosure in employment

If an individual had gained employment after concealing the full extent and implications of their CF both at application and at interview, they often felt a need to disclose their condition in case they should need to access medical services whilst at work.

“Cause I’ve moved offices, I would tell the manager there, just so the manager knows, I think it’s good to let people know...I’ve told the first aid officers.’ [Jack]

The situation varied however as to whether adults told just one person at work (this could be either their manager or a colleague) or everyone they worked with. In effect adults were acknowledging that their body was ‘risky’ and likely to let them down, and therefore needed some kind of insurance policy of telling to ensure help arrived when they needed it. This need to tell held true for most people with CF; even those who had fully disclosed it on an application form and had subsequently found the information had not reached their working environment:

‘I held off telling my immediate boss for a little while purely because I am a little bit fearful that why should a company risk taking a CF sufferer when they could have somebody who’s healthy and who won’t miss any time off work? I mean I feel I’m very much burdened by the CF stereotype, anybody who’s heard of CF, which is very few really, they know that it’s something like an extreme asthma and that people die young with it, you know. That’s the impression that I get because they watch things on TV that show the extremes. So to avoid that I let people get to know me first in a work environment and then sort of let them know [he has CF] once they see that I’m not having days off left, right and centre and that I can do 8[am] - 7[pm] every day without any problems.’ [Keith]

Respondents with CF in Admi's (1995) study also reported that they wanted their employers to get to know their employee as a person first and appreciate their work before disclosing CF. In the current study, Emma stated that it had not occurred to her that her employer might actually respect and value her more for what she had to do (i.e. her physiotherapy and drug regime) before her working day began. She noted her surprise when her employer expressed admiration for what she was able to achieve professionally after a colleague had disclosed Emma's CF to him:

'My boss at work the other day... he said, "Oh, I was told about you and what you have to do", and he was really respectful, about the fact, you know, getting up and doing physio[therapy], this, that and the other, and I sort of thought, Oh. It hadn't really occurred to me [that he might be sympathetic].' [Emma]

Some respondents said that they tended to remain in the same job for longer than might otherwise be the case (especially if colleagues were supportive of them) for fear that ill health might make it difficult for them to be successful in gaining alternative employment. For these adults, the prospect of ill health itself restricted their choice of future work as the dilemma of telling/not telling potential employers and their possible reactions were unknown. These individuals therefore found it easier to stay safely in their present employment where their employers knew them and were tolerant of their situation:

'I'd be reluctant to move really from my present employer 'cause a lot of employers aren't that understanding.' [Mike]

'I had to admit what I had because I was taking a lot of time off, but by that stage I'd already been working for them for a while and they were quite sympathetic.' [Barry]

This finding supports studies in the context of epilepsy whereby individuals reported experiencing little enacted stigma, although there was felt stigma was often reported (Blaxter, 1976; Scambler & Hopkins, 1986; Schneider & Conrad, 1980). Simoni et al. (1997) also made a similar finding; men who disclosed HIV to employers reported consequences that were substantially more positive than those anticipated by men who had not disclosed.

Total non-disclosure throughout the process of seeking employment and subsequently gaining work was a high-risk strategy in that failure to disclose CF (or the current seriousness of the disease) could lead to future problems. Total non-disclosure of CF was rare. However Ian, 36, who had not been diagnosed until he was 22, had previously worked as a telephone engineer and illustrated the risk of concealment by recalling the time when he was having a course of IV antibiotics administered as an outpatient. Previously he had taken annual leave to cover his sick leave, but on this occasion was unable to do so. Here he had to work with his 'giving set' in situ, the equipment needed by adults to administer their IV antibiotics. It signalled to his employer that something was wrong and led to his subsequent dismissal from work. Although this is a negative case (the majority of adults who were this ill would be known to have CF by their employers) it illustrates the high risk of being found out by an employer and the adverse social consequences of discovery by the other:

'I was a telephone engineer and I was trying to hide up the [fact he needed IV treatment for CF], you know when I went in hospital I'd go on leave. I had a great governor you know, but they er, they caught wind of it in the end. I had a governor come down a manhole and tread on my giving set in a manhole. So he said, "I

think you'd better come and see me". So after that they said, "I think you've done your bit and I think we've got to let you go".' [Ian]

To summarise, in telling potential partners there was a risk of rejection due to infertility, and partial disclosure of CF was common. For those disclosing their condition to prospective employers, there was a fear of not being employed on the grounds of potential ill health, as opposed to an inability to do the job. These factors influenced both the way in which CF was disclosed and the timing of disclosure. Three opportunities to disclose CF were apparent; at application, interview or once employed. Body image, increasing ill health, the amount of time off work that was anticipated and an increased likelihood of discovery all influenced adults' disclosure.

## Discussion

In adults' disclosure of CF three levels of risk situation have been identified. It is acknowledged that these situations are not discrete, but rather represent a continuum, and will not be applicable to all adults with CF. A significant influence in disclosure identified from respondents' accounts is the action of the physical body, its appearance and the amount of adults' felt control over it at different stages of the disease. Positive and negative risks of disclosure were apparent, these included the prospect of more support and empathy from friends and employers but also the risk of losing potential partners and jobs and being treated as a 'patient' by friends during periods when that was not appropriate.

Many other factors were influential in deciding whether to disclose CF. The perceived reaction of others, the level of intimacy, social consequences of telling (for example not being offered employment) and past experience (reflexivity) all influenced the decision to disclose. Partial disclosure of certain aspects of the disease was apparent, particularly in



high-risk situations. Additionally the perceived risk of detection by the 'interaction partner' or the chance of discovery by a third party was highest in situations of employment.

The sample on which this article is based is small, with all participants recruited from one specialist centre in the UK. Furthermore, there was very little published work regarding disclosure of CF by adults with the disease to inform the analysis. The analysis here depended on what participants told the interviewer they had done or would do in certain situations, rather than these events having actually been witnessed by the researcher. However, by analysing accounts from adults with varying states of health, similarities and differences in disclosure strategies could be identified. There is an unequal development of the levels of risk in this article; however this may be due to the importance for adults of gaining partners and/or employment, and managing disclosure in these situations. Further research in all of the risk situations described here would build on the findings of the current study.

All options concerning disclosure of CF are decisions not only how to act but who to be. Giddens (1991) notes that in the reflexive project of the self, self-identity is inherently fragile for all individuals. A self-identity has to be created and more or less continually restructured against a background of changing experiences of everyday life. The task of forging a distinct identity may be able to deliver distinct psychological gains (in this instance to reduce the degree of felt and enacted stigma), but it is clearly also a burden. In CF, identities are constantly being shaped based on social interaction, but also the core of ones identity is affected by the progression of the disease.

Accounts of people's health status are constantly reconstructed in different circumstances and relationships (Radley & Billig, 1996). Goffman (1959) argues that the individual adjusts the presentation of himself or herself depending on the type of situation that he or she finds themselves in and what is demanded of that situation. This, Goffman argues, does not result in different 'selves' or a fragmented self, but rather in doing so the individual is able to act differently in each situation and this is evident in the three risk situations described here. Furthermore, the meanings of chronic illness often change as they interact with different stages of the life course (Bury, 1988). This is seen in the current context by the disease's impact on adults' ability to work, to form intimate friendships and to carry out social relationships in a casual encounter, all influenced by the culture in the UK for young adults to gain employment and to have children.

Due to the low visibility of disease in many respondents, the opportunity for concealment and the ability to decide whether to disclose CF was high, as their own bodily appearance was no different to the appearance of others' 'healthy' bodies. However, with the progression of the disease the ability to conceal was lessened (either by bodily appearance or distinctive cough) and directly affected participants' decisions to disclose or conceal in much the same way that many people with epilepsy have the same choice (Schneider & Conrad, 1980; Tröster, 1997). With disease progression, a seemingly 'low risk' situation may become a 'high risk' situation to the individual with CF whose disease is severely visible and deteriorating. In HIV, evidence suggests that the rate of disclosure varies with disease state, such that disclosure increases with time from diagnosis and with an increase in symptoms (Mansergh et al., 1995), and is associated with issues of accessibility and efficacy of social support (Holt et al., 1998). In this study, respondents' perceived paucity of the level of knowledge about adults with CF on the part of the general public gave a greater

opportunity for concealment of the illness. Conversely, if adults were disclosing CF accounts could be tailored accordingly. Bodily signs could themselves disclose CF to people who were aware of the appearance of adults with CF.

Little tradition of disclosure or concealment by adults with CF exists to act as a guide for individuals in different social situations. There appears to be no 'right' approach to disclosure of CF, illustrated here by the accounts of adults. Public education, or reducing the numbers of 'medically blind' in society, may help support those with CF by building a more supportive society. Employers' greater understanding of the disease, and subsequent introduction of flexible working practices may help to reduce the uncertainty felt currently by adults over whether to disclose or conceal their disease. It is hoped that through this article adults, their families and health care providers can begin to discuss adults' disclosure of CF to others in many different contexts.

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