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Cystic fibrosis adults' perception and management of the risk of infection with *Burkholderia cepacia*

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Abstract

The risk of infection for cystic fibrosis patients from *Burkholderia cepacia* complex pathogens is of increasing concern to doctors and scientists. This paper reports on how these patients perceive and manage the risk of cepacia infection using Douglas and Calvez's (1990) typology of four cultures of the community (the central community, dissenting enclaves, isolates, and individualists) and Douglas' works on pollution, risk, and culture. We attempt to develop Douglas's cultural theory in the light of the data, which were drawn from in-depth interviews with 31 adults with cystic fibrosis attending a specialist treatment centre in the UK. We found that our respondents' group membership depended on their health state and contact with the hospital. The central community of adults was found to be dispersing to form a series of isolates, perceiving others who may potentially have infection as individualists. Due to the nature of cepacia infection, no dissenting enclave was identified for this group. Medical and lay uncertainty in testing for infection and managing the risk of its spread was expressed by the majority of adults, many of whom admitted that they limited hospital attendance as a part of managing such risk.

Key words: cepacia, cystic fibrosis, risk, risk management

Introduction

The ways in which perception and management of risk are socially constructed has been of particular interest to anthropologists and sociologists. Douglas, for example, has made a major contribution to theories of risk. In 1966 she argued in *Purity and Danger* that many classes of risk avoidance in tribal societies could be explained in terms of their role in creating order out of contradictory experiences and moral confusion. Beliefs about defilement, animal taboos, and forbidden food helped maintain a sense of order (Krimsky 1992, Gabe 1995). In 1982 Douglas shifted her attention to Western industrialized societies and the way in which groups and institutions in such societies respond to risk in functional terms as a consequence of the need to maintain a chosen form of social organization. She formalized her argument in an analytic scheme that has come to be known as grid/group analysis, a typology of social structures and perceptions of risk involving the identification of four distinct world views or 'cultural biases' which justified different ways of behaving towards a hazard. Later, with Calvez (1990), Douglas renamed two of the world views or cultures when she considered risk in the context of AIDS. The four types of culture demonstrated when using the group/grid axes are shown in Figure 1. The group axis is defined in terms of with whom an individual interacts, i.e. 'the outside boundary that people have erected between themselves and the outside world' (Douglas and Wildavsky 1982: 138) and the grid axis in terms of how they interact with others (Ostrander 1982), i.e. 'all the other social distinctions and delegations of authority that they use to limit how people behave to one another' (Douglas and Wildavsky 1982: 138). The group axis ranges from a cohesive, clearly bounded cultural group (high group) to isolated individuals engaged in limited interaction with others (low group); the grid ranges from a strict hierarchy (high grid) to no hierarchy at all (low grid).

INSERT FIGURE ONE ABOUT HERE

The central community consists of members of an ordered and centralized group that back agreed norms of behaviour. The central community is hierarchically structured; having set up established professions (for example health care professionals) it continues to respect them (Douglas and Calvez 1990). In the case of HIV/AIDS, dissenting enclaves develop 'solidarity in shared adversity' (Douglas and Calvez 1990: 460) by fighting against the establishment, science and treatment, and the views of the lay public who are not infected with HIV. Douglas and Calvez define isolates as people whose autonomy is constrained by the 'predatory expansion' of others. In this case there is limited interaction with others (low group) but a hierarchy enforced by boundaries imposed either personally or by others (high grid). Lastly there are individualists who do not belong to any exclusive group and do not abide by rules made by society, so their loyalty to others tends to be suspected by others in the community. Douglas' cultural theory is useful in that it demonstrates that judgements made about danger, pollution, and threat are dependent more upon a wider social context than individual design (Tansey and O'Riordan 1999). The emphasis is not only on how individuals think but also on how groups and institutions think and set boundaries (Bellaby 1990). Certain dangers that make sense to a particular culture, and are therefore selected for attention as a 'risk,' are based on that culture's shared values and concerns (Douglas 1992).

However, problems have been identified with Douglas's cultural approach. Marris et al. (1998) have highlighted an ambiguity in cultural theory and whether it emphasizes 'stability' or 'mobility.' In the former version individuals are assumed to conform to the same 'cultural bias' whatever the social context and to do so over time. In the mobility version individuals are assumed to adopt different cultural biases as they move between institutions. Similarly, Bellaby (1990) has suggested that 'Douglas was unable to explain why individuals might move from one risk culture to another,' presenting serious implications for developing methods to test the theory. It has also been suggested that Douglas was not clear about whether cultural groups should be classified in terms of group and grid on the basis of their own (emic) concepts or those of the analyst (etic) (Wight 1999).

Although influential at a theoretical level, there have been few attempts to apply Douglas' cultural approach empirically. One recent example is that of Wight (1999) who explored how far a cultural approach could explain the variability in risk perception and behaviour of young heterosexual men with respect to the risk of HIV infection, by focussing on occupation and partnership history. He concluded that perceptions of HIV risk are shaped in part by these men's partnership careers and occupational paths. Likewise, Bellaby (1990) has applied Douglas's theory to understand risk acceptability among managers and workers in the pottery industry and among motorcyclists and car drivers. Of particular interest is his focus on life course transitions and the way such transitions influence risk perceptions and behaviour.

This paper aims to contribute to the small literature on cultural theory of risk by considering how the perception and management of risk of cepacia infection among a community of cystic fibrosis (CF) sufferers attending a specialist treatment centre could illustrate Douglas and Calvez's typology. CF is Britain's most common autosomal recessive genetic disorder, affecting approximately 1:2500 births of European origin in the UK (Dodge et al. 1997) and the USA (Hammond et al. 1991). Abnormal sticky secretions produced by the defective gene identified in 1989 (Rommens et al. 1989) cause lung inflammation and infection and problems with digestion. Other symptoms that may also be experienced include infertility (Sawyer 1996) and CF-related diabetes (Dodge and Morrison 1992). Currently, survival age is 31 years (Dodge et al. 1997), although those born in 1990 are predicted to survive into their 40s (Elborn et al. 1991).

The wide range of symptoms of the condition requires adherence to an array of treatments aimed at most of the major organs if health is to be maintained. Chest infections, one of the most common symptoms, are routinely treated with oral antibiotics; when this fails to eradicate infection intravenous antibiotics are administered. Although much daily treatment can be self-administered at home, clinical guidelines for care recommend that treatment co-ordinated by staff working in specialist centres is required for this group (Cystic Fibrosis Trust et al. 1996), through outpatients' appointments and/or inpatient stays. Research suggests that patients treated at specialist centres have a better outcome following treatment in terms of body mass index and lung function than those treated at local hospitals (Mahadeva et al. 1998).

Recent outbreaks of methylene resistant *Staphylococcus aureus* (MRSA) in the UK have led to many patients, not just those with CF, being nursed in hospital isolation rooms to prevent the spread of infection (Solberg 2000). Another organism that causes infection and is proving difficult to eradicate among this group is *Burkholderia cepacia* complex, formally classified by scientists as *Pseudomonas cepacia* (Holmes et al. 1998). Although *cepacia* has been identified as causing infections in patients without CF since the 1950s, albeit rarely, it is only since the 1980s that it has become problematic for people with the condition (Isles et al. 1984, Holmes et al. 1998).

Cepacia is an organism that is found naturally in soil and river sediments, surviving and proliferating in water-based environments (Holmes et al. 1998). Highly transmissible strains of the bacteria appear to emerge randomly and uniquely raising concerns for human health (Holmes et al. 1998). Originally, scientists believed that *cepacia* was not transmissible by social contact between patients or between those with and without CF (Dy et al. 1999). Currently it is acknowledged that transmission occurs through both environmental and social contact, for example by contamination of surfaces, through medical equipment, and by social contact with infected others (Govan et al. 1993); the most important risk factor therefore being hospitalization (Tablan et al. 1985). Many people without CF may harbour *cepacia* with no long-term effects. However, for people with CF, the effects of infection, currently resistant to all known antibiotic therapy, can be a sharp decline in lung function and death (Webb and Govan 1998).

A study at one specialist CF centre during 1987 – 1990 found the prevalence of *cepacia* to be between 4.1 – 5.9% of patients (Taylor et al. 1993), comparable to the 6% prevalence of patients in the UK and 5% of patients in Europe (Webb and Egan 1997). The spread of *cepacia* by social contact prompted all specialist clinics to begin segregation of *cepacia*-infected patients (Ledson et al. 1998). At the time the research was conducted, medical uncertainty was apparent regarding the best way to segregate patients with and without *cepacia*. Initially, *cepacia* infected patients were segregated as one group, away from those who had not been infected. However, scientists now think that patients with different strains of the organism can re-infect each other and patients should be further segregated according to their strain (Ledson et al. 1998). Faced with the prospect of infection, patients at specialist centres can be expected to develop views about the risk to themselves from other patients and how to minimize it. This in turn is likely to have an impact on the wider community of these patients of whom they are a part. The ability to prolong patients' good health by the avoidance or eradication of dangerous infection through the development of treatments and care policies is a value shared to some extent by patients and hospital staff alike.

Wight (1999: 741) has argued that some 'theoretical leaps' are necessary in cultural analysis, as 'when dealing with cultural factors, one is often going beyond respondents' conscious understanding of their lives.' Here, we bring to the analysis of cultural theory both an emic approach, by considering participants' own concepts of boundaries and hierarchies, and our own, etic approach, to account for

differences between the individuals that reside within a specific institutional context. By using illustrations from interview data from adults attending a specialist centre, the paper develops an analysis of how these community members perceived and responded to the risk of cepacia infection at a time when medical knowledge of the infection and organization of care in response to it were continuing to develop.

Methods

The adults involved in this study all attended a specialist centre for treatment and care in the southeast of England. This centre, in common with others (Govan et al. 1993, Millar-Jones et al. 1998), was recognized by centre staff as harbouring the risk of cepacia infection for these patients. The hospital in which our clinic was based began a segregation policy of scheduling appointments for patients with cepacia on separate days in a separate clinic area, although other areas in the hospital appeared not to be subject to such segregation. As such, boundaries in time and space were established both by the clinic and some patients to try to contain the infection. This presented a fortuitous time for us to study an emerging pathogen and the development of responses to it.

Adults attending the centre aged 18 and over and living in the southeast region (around 40% of the total number of patients) were written to by the first author and invited to participate in the study. This proportion was selected in view of time and financial restraints on the study. Only 16 adults were excluded from the study, on the grounds that the hospital staff thought they were in extremely poor health ($n = 1$), were not fluent in English ($n = 1$), or were a sibling of a patient who had already been approached to participate in the study ($n = 14$) (see Lowton and Gabe 2003) for further details about sampling). Confidentiality with the hospital was guaranteed and assurance was given that pseudonyms would be used in all research reports. Patients also received a letter of introduction from the CF consultant and CF nurse consultant. Overall, 26% (47/183) of those approached agreed to participate, after follow up and reminder letters. This acceptance rate was much lower than anticipated and may have been to do with the subject matter of the research; patients might have responded more positively to research involving new therapies, from which they might benefit personally, than to a sociological study.

Thirty-one respondents were interviewed. Reasons for respondents not being interviewed were subsequent refusal, living outside the study area, hospitalisation, and death. All interviews were conducted in respondents' homes and lasted for around 1 – 1.5 hours. Lung function, height, and weight were measured as part of the larger study. A Vitalograph lung spirometer was used to record participants' forced expiratory volume in one second (FEV1). This value was then expressed as a percentage of that predicted for a 'healthy' person of the same sex, age, and height (FEV1% predicted). Interviews were conducted with the aid of a topic guide and focused on the respondent's health, their perception of the risks of routine, selective and future treatment and care, and how they and others (e.g. formal and informal carers) managed such risk. In particular, respondents were

questioned about what they knew of cepacia, and how they perceived and managed the risk of infection. All interviews were tape-recorded and transcribed verbatim.

Coding of interview transcripts was undertaken using the ATLAS-ti software programme for qualitative data. Codes were attached to a segment of text such as a word, phrase, sentence, or paragraph. These codes were then grouped into categories, providing the conceptual foundations for analysis, as described by Dey (1993). The majority of the conceptual categories were initially constructed during the course of the interviews, through discussion between the authors and respondent interviews. Categories were subsequently developed analytically with conceptual relations being established (Strauss 1987). The data were used to test our ideas about how to classify different types of patients' perceptions of risk of cepacia, in light of the grid/group theory.

All respondents in this study were registered with the clinic for their treatment and care, and all were aware that during their early childhood their survival age had been predicted to be less than 20 years. Of the 31 patients who were interviewed, 17 were female (mean age 29) and 14 were male (mean age 32). Mean FEV1 was 50.7% of that predicted for a 'healthy' adult (SD 26.3, range 17 – 115%).

Socio-economic status was not measured in these respondents because of difficulties in assigning a social class category to adults whose choice of occupation and ability to continue working is driven largely by the limitations of the condition. At the time of interview, half of the sample were not in paid work, due mainly to ill health. Of the remainder, most were in sedentary jobs such as clerical work, having sought employment where risk of lung infection was minimal. Table I shows the social and health characteristics of respondents.

INSERT TABLE ONE ABOUT HERE

Although there was a high non-participation rate, we believe that we have sufficient data for theoretical development. We were not aiming to achieve representativeness in this instance, as we were interested in capturing the range of experiences and meanings for patients faced with the risk of cepacia at a time when the clinic was changing its outpatient policy from group to individual segregation, in order to develop theory of patients' risk perception and management. We interviewed all of those who were willing and able to take part in an interview in addition to completing health questionnaires; being mindful of the burden that ill health poses for many adults with this condition and the expressed desire of many patients to have minimal contact with specialist services.

Below we employ Douglas and Calvez's grid/group typology to explain different perceptions of the risk of cepacia and ways of managing it among adults in this community. Evidence from patient cases will be used to illustrate the value of the typology and also its limitations. We will argue that two factors, patients' health state and frequency of contact with the clinic, shape their perceptions and management of the risk of cepacia infection. The analysis is made more dynamic by emphasizing how

group membership in the community, and hence risk perception, changes over time as health state alters.

Findings

Only one patient in the sample, Gill, 30, said she was infected with cepacia at the time of the interviews. Of the other 30, five stated that they were not at all concerned about this or any other infection while the remaining 25 patients stated that they were concerned about cepacia to varying degrees. Those adults who were concerned about the threat of infection saw it as coming from two main sources: other patients with CF who may have cepacia and the environment that these patients inhabited. Only one patient was concerned that health care staff may harbour cepacia; to our knowledge transmission of cepacia from staff to patients has not been reported in the medical literature (Dy et al. 1999). The patients who discussed the threat of cepacia infection referred to the need for strict boundaries to be created by the hospital staff and/or patients to protect themselves from possible infection.

In terms of Douglas' typology, we considered those patients who stated that they were not concerned about infection as continuing to belong to a central community. The majority of this group had good lung function and required regular but limited contact with the hospital. We considered those patients who reported concern about infection to varying degrees to be isolates, hesitant to form any type of group, but looking for the hierarchical structures to continue, perceiving others who may carry infection as individualists in need of restraint. This group had poorer lung function and had started to visit the clinic more frequently than those in better health. It is these isolates that form the main focus of the paper; all had been inpatients and all were regular hospital attendees, with a history of receiving intravenous antibiotics. From respondents' accounts, we were unable to classify any patients in a dissenting enclave; we discuss the reasons for this below. No patients' accounts of their own behaviour led us to classify them as individualists; this may be because patients who receive care from a specialist clinic may be more likely to believe in a hierarchical structure. However, patients appeared to speak of others with CF in terms that led us to believe that these participants perceived others as individualists, with declining health and increasing hospital contact. It is to the central community that we now turn.

The central community

As noted above, only five out of the 31 patients in the sample could be identified as continuing to belong to a central community, a community that had apparently been thriving at the specialist centre before the advent of cepacia infection. Traditionally, there had been high group cohesion with a high structure, the CF adult group being one layer within a wider hierarchy of clinicians and research scientists. For example, clinic staff had for many years organized regular social events for inpatients such as visits to city attractions. Both the hospital and the Cystic Fibrosis Trust had held meetings for patients and their families to discuss the latest treatment and care advances; in this respect the knowledge of the medical profession was (and still is) accepted and respected. Those in the central

community were unconcerned about the need to maintain personal boundaries; their trust in the hospital led them to believe that it would protect their interests.

By definition, those in the central community were in relatively good health when compared to other patients, and so had minimal yet regular contact with the hospital through either outpatient or inpatient admission. Of the five patients who the authors identified as being part of the central community, Jack, diagnosed at birth, and Tessa, diagnosed at age 15, stated that they had never had intravenous antibiotics and had an FEV1% predicted of 68% and 57%, respectively. Both had ongoing contact with the hospital for discussion or treatment concerning the possibility of having children. Two others, Vanessa (FEV1 102% predicted) and Rose (FEV1 91% predicted), had had only one course of intravenous antibiotics each; Vanessa having had hers at home as a child. This compared favourably with other respondents who tended to experience an acute episode of illness at least annually. All except for Brian, who was crippled with CF-related arthritis, stated that they were enjoying a very good quality of life with minimal effects of the condition, and their lung function values, between 57% and 102% of that predicted, reflect this. Their relatively good health state, together with their regular yet minimal clinic contact, may explain why the threat of cepacia infection was not deemed by them to be a risk.

For example, Vanessa, an 18-year-old student, had transferred to the adult clinic at the specialist centre from her local hospital paediatric clinic only in the past year. She had not yet learnt about the prevalence of cepacia in the hospital or the risks of becoming infected and had no concerns about attending the clinic:

KL: Do you worry about cepacia? Have you heard much about pseudomonas cepacia?

Vanessa: No, I haven't. I've heard about pseudomonas. I know it's the, it's one that basically stays in your lungs, you can't get rid of it. I don't really, I know that it's the worst one, strongest, you can't kill it. Well, you can, but it's very rare that you do. I mean, it's recurring, isn't it? But it hasn't really given me that much problem. I don't really know much about it, I'm just, it's another bug.

Likewise, Jack, a 35-year-old civil servant, who had had well-controlled CF-related diabetes for the past 4 years and who, with his partner, was beginning a programme of in vitro fertilization, also stated that he was not worried about the risks of cepacia infection and so continued to attend educational meetings and hospital outpatient appointments without concern. He had not been admitted to the hospital for lung or stomach problems since childhood. As he explained:

I mean I read the [CF Trust] magazine and I see it [cepacia] in there and I think about it at the time and then when I go to the clinic, quite honestly, I totally forget

about it. I don't think that would really put me off. I don't know if I'm ignorant of the facts but, no, that doesn't put me off and that doesn't cross my mind really.

Brian is an unusual member of the central community in terms of his poor health. However, his professed ignorance about cepacia, his trust in the specialist centre, and his willingness to mix with other patients suggest we can include him, at least at that point in time, as a member of that community. In considering those who could also be considered high group, we turn our attention next to whether a dissenting enclave can be found among these adults.

The dissenting enclave

As the central community becomes fragmented in response to the perceived risks of acquiring cepacia, patients potentially have the opportunity to create what Douglas and Calvez (1990) term a dissenting enclave. This is a culture where the knowledge base and authority of professionals are suspected and rejected and the group develops its own theories, creating a social division between themselves and the central community. For inclusion, we were looking for reports of those infected with cepacia, a poorer state of health, and requiring a higher level of hospital treatment than those in the central community. A dissenting enclave could conceivably have been established to disseminate information among those already infected with cepacia, challenge current segregation policies, act as a support group, and raise funds specifically for research and treatments for cepacia. In the present study, however, no dissenting enclave was identified from the first author's dealings with the hospital, either before the advent of cepacia or afterwards, or from the patients' interviews. This may have been because only around 6% of patients have cepacia, a low proportion of patients but who present a high threat to others. Our inability to identify a dissenting enclave may not be due to ignorance or apathy among patients but to real material barriers that often limit collective opposition to risk (Williams et al. 1995). In this case, fear of social contact with others who may have cepacia, and the resultant health effects that cross-infection with other strains of cepacia was perceived to bring, would be the barriers to patients forming a dissenting enclave.

The quotation below is from Gill, a 30-year-old ex-receptionist, who stated during her interview that she had been infected for 6 years with cepacia, and who currently had poor lung function (FEV1 30% predicted). Her quotation demonstrates why we could not identify a dissenting enclave, as all those with cepacia infection need to be segregated from each other to prevent cross-infection with different strains. During her interview, Gill recalled asking the Nurse Consultant at the centre whether a teaching session for hospital nurses could be arranged using only patients with CF as the teachers. Instead of the patient-teachers that were usually invited, Gill suggested asking only those infected with cepacia to take part, so that their point of view could be put forward more clearly:

I said, "Why don't you just have [organise] a day for cepacia patients then, in that case?" "Oh, well, you've all got different DNA [strains of cepacia], so you're all at risk" [the Nurse Consultant replied]. I said, "Are we?" See, I didn't know that.

According to Douglas and Calvez (1990), the knowledge of experts (here the health professions) is distrusted in the low grid position of a dissenting enclave. This was not the case with Gill who trusted the Nurse Consultant's knowledge. Furthermore, these adults are a highly medicalized group of patients, supported by a specialist clinic, with access to a charity with a very medicalized approach to managing the condition, so it is not surprising that they should continue to adhere to norms of a high grid.

When a community is attacked from the outside it encourages solidarity from the members within it (Douglas 1966). However, when the attack is internal it is possible for the actions of the community to be self-defeating. Patients' movement away from the central community to form a dissenting enclave may be prevented so far by their declining health and fear of infection by others damaging their already compromised health state. They could therefore only challenge the risk of infection by minimizing interaction with others, in adopting a low group position as isolates or individualists. In our analysis we categorized as isolates those patients currently without cepacia but with poor lung function, or less than 2 years post lung transplant, restricted in their activities by the impositions of others with cepacia (who they appeared to conceptualize as individualists), yet who continued to acknowledge the hierarchy of the wider community. The case of the isolates and their perception of others as individualists is now considered.

The isolates

Both Wight (1999) and Marris et al. (1998) question how people can, in practice, be isolates; combining the characteristics of minimal interaction with others (low group), while adhering to the community's hierarchical structure (high grid). In the context of the threat of cepacia, however, being an isolate was perfectly possible. Such people had deteriorating lung function, were cautious to minimize their contact with other people, but due to their deteriorating health found themselves visiting the clinic on an increasing basis, either to attend outpatients appointments or for inpatient admission. Of our sample, the remaining 25 patients without the infection could be categorized as isolates on this basis. The mean FEV1 of this group was 48.0% of that predicted for healthy adults (FEV1 ranged from 17% to 115% predicted). Although a wide range, patients who had gained the two highest scores had received lung transplants 18 months previously. As a group they were generally in poorer health (those post transplant were at risk of rejecting donor organs) than those left in the central community. Isolates said they generally spent time on their own, choosing not to participate in CF-related activities such as conferences or making friends with others with the condition, yet they continued to attend hospital and adhered to treatment plans decided by expert clinicians. For these respondents, the risk of cepacia infection was related to concerns about medical and lay uncertainty and perceiving the hospital to hold a different level of acceptable risk. In particular, respondents focused on the risks to their health posed by others and the need for hospital segregation of patients.

During their interviews, those whom we identified as isolates spoke of others who had cepacia as being responsible for its spread, through the latter's negligent behaviour. As such, they appeared to be treating these others as individualists, that is as people whose loyalty to the patient community and their professional careers was not vouched for and whose actions tended to be suspected (Douglas and Calvez 1990). Respondents perceived these others as being unconstrained by the rules of an institution (in this case the hospital) or the demands of society (here all others with CF or those involved in their care). Indeed, the attribution of transmissible lethal disease to the behaviour of culturally different others is a paradigm that has existed in societies since ancient times (Glick-Schiller et al. 1994).

Despite the medical profession's early claim that only about a fifth of patients infected with cepacia will suffer severe symptoms and probably early death (Isles et al. 1984), most patients who stated that they were concerned about acquiring cepacia thought that untreatable lung damage would befall them if they were to become infected. As Douglas notes of lay risk perception, 'the number crunching does not matter, the idea of risk is transcribed as unacceptable danger' (1992: 39). Cepacia could therefore be perceived as an 'at risk' status (Kenen 1996) for these adults, despite their already suffering from a chronic disease. Indeed, Douglas (1992) notes that to be 'at risk' is to be vulnerable to the events caused by others; adults with CF must now adhere to approved behaviour, role performance, and norms (i.e. segregation) to reduce that risk.

Zara's account of other patients known to have cepacia was typical of isolates' comments about such others. In this instance, patients are known to have cepacia because of the isolation rooms they are allocated during in-patient stays. Zara, a 25-year-old part-time personnel officer, had been experiencing deteriorating health. She reported that she had been an in-patient eight times over the past year in order to receive intravenous antibiotics and said that she preferred a single room (of which there were only a handful at the centre) during her in-patient stays to lessen her risk of infection. The risk posed by others not staying in isolation was evident:

When I'm actually in hospital you walk past [other patients], I mean I hate being in hospital purely because of that reason, because it's so hot in there and germs are spreading. You see rooms that say isolation, then you see people walking around who are actually in the rooms, and you think, "They shouldn't be doing that". And one of the boys [without cepacia] who was in there said to me he was really cross because this person had cepacia and she walked out of her room and went into the canteen bit to get a bit of milk, and he said to her, "Why are you out of your room?" and she said, "Oh, I was just bored, I've just got to get out". And I thought that was really bad 'cause she's walking around, so I prefer to be at home, doing my IVs.

Segregation appeared to be the hospital's and patients' main method of creating a boundary and ensuring safety from the risk of infection from cepacia. The system of boundary maintenance ensures

the purity of social contacts and the exclusion of people and objects that do not belong (Douglas 1966). Where boundaries are clear-cut, safe and familiar spaces appear inside the boundary, protecting the group from the dangers outside (Bellaby 1990). However, it is difficult to discriminate between danger and safety where an institution lacks boundaries (Bellaby 1990). As Douglas and Calvez (1990) note, 'blaming procedures' support the organizing effort to control epidemics whereby the population is divided into those needing care and protection (the isolates) and those needing forcible detention (the individualists). If infected patients had been reported by respondents to be adhering strictly to hospital segregation requirements we would not have considered these others as individualists, but as isolates. The notion of whether those needing forcible detention should be classified as individualists or isolates is discussed further below using interview data from the one participant in the sample who was infected with cepacia.

Zara also echoed Armstrong's (1998) account of the risk of infection from the 'dirty' hospital itself as 'germs were spreading.' This fear was not only apparent among inpatients, but also among those waiting for outpatient appointments. Matthew was a 32-year-old ex-craftsman whose FEV1 was just 42% of that predicted and who required 3-monthly outpatient appointments. He recounted how he waited for his appointment:

I try to distance myself. I try and wait round the corner [of the clinic], away from it. And I occasionally go outside and take a few deep breaths and come in and breathe very shallowly.

Friendships (both potential and ones that were well established) with others with CF were also affected for isolates by the risk of cepacia transmission. According to Clare, a 35-year-old health professional who had been admitted for intravenous antibiotics a few months before her interview, the dangers involved in making new friendships were now too great:

Cause like with AIDS, you know, the whole thing of, "Don't treat people like lepers 'cause it's not catching", and here's something that's quite unique. But it is there in my mind, even not cepacia, just generally, what infections will you pick up? So I always do sit a bit separate. 'Cause it's just a real reality. It's very nice to be sort of sentimental but if you're going to walk away with some terrible infection, it's [befriending others] not worth it.

Established friendships between patients could have survived if patients had been able to stay within the central community or move into a dissenting enclave, thereby maintaining high group cohesion. However, patients themselves found that the boundary drawn by the hospital between isolates and those already infected was not always easy to implement, as noted above. As Lupton (1995) contends in the context of HIV infection, models of rational behaviour ignore the role of pleasure and unconscious desire in emotional expression. Furthermore, in the same context of HIV infection,

individuals who have the power to control their behaviour will not always follow expert advice for emotional reasons (Hart et al. 1992). Here the circumstances surrounding segregation may change, leading isolates to judge the risks differently on each occasion. For instance, Caroline, a 22-year-old special needs assistant, spoke during her interview of her friend Samantha who had had cepacia and had recently died. Caroline had been receiving disability living allowance for the previous 2 years due to difficulty getting around and was attending clinic appointments every 3 months. She stated that they used to have unrestricted social contact before Samantha was diagnosed with cepacia. However, after Samantha's diagnosis, Caroline had to weigh up the social versus health risks of their regular meetings. Despite expert advice, they were not always able to maintain physical boundaries between themselves:

[Samantha] had cepacia and it was awful actually because I knew she had it, she was very upfront with me and sometimes we'd give each other a hug or something, but some days I just panicked, I thought, "I can't be near [her] in case I get it". So I would stand away from her and she would say, "Go and sit over there and I'll sit over here". So it depended what mood I was in. Sometimes I'd say, "Oh, it doesn't matter because I just want to be with [Samantha] and I'm sure it'll be okay", and other days I thought, "Oh, gosh, I really don't want it".

Cultural theory facilitates the understanding of lay people's risk perception by considering the widest range of goals that a person is trying to achieve (Douglas 1992); in Caroline's case this includes both the maintenance of health and the continuation of an established friendship. Grinyer (1995) suggests that not only are risk perceptions multi-dimensional (for example, covering both health and social risks) but that at any given time, people may be managing a number of different agendas that may conflict with official ones. As Caroline's quote illustrates, people are managing agendas that may conflict with the 'official position' and are often contradictory. In this context of social and health risk, Bloor (1995) suggests that normative expectations (here the immediate movement away from an infected patient) may be a less important determinant of risk behaviour than certain aspects of the situation (in this case maintaining an established friendship). Indeed, Douglas and Calvez (1990) argue that there is more to risk assessment than the disclosure of information (for example about infection) and more to the perception of risk than the rational weighing up of impartial technical information. From Caroline's quotation we can also consider that Samantha was not deemed to be irresponsible; she was 'upfront' about her infection, and so may be classified as an isolate herself, willing to try to maintain a boundary between herself and other patients.

Medical and lay uncertainty

The case of cepacia infection provides an excellent example of Giddens' (1991) assertion that experts (in this case doctors and scientists) often do not agree on emerging risk issues. They may dispute both what the risk is and how it is to be managed. This uncertainty was apparent in the medical literature concerning the perceived impact of evolving infections on these patients and the

consequences for their medical management. For example, conflicting opinions have been expressed about the effects of untreatable *Burkholderia* infection in lung transplantation (Kanj et al. 1997, Khan et al. 1998) and, more generally, whether patients with other infections should be refused transplant surgery (LiPuma 2001).

One established way for the clinic to assess the risk of infection between patients is to test them routinely for cepacia. As Bellaby (1990) notes, risk involves uncertainty, and knowledge may remove that uncertainty. Indeed, Lupton suggests of screening in general, that:

[h]aving a test, of any kind, is conceptualised [by those being tested] as offering control, of being a way of "doing something" in the face of the incipient disorder created by the presence or potential of disease (1995: 78).

Kenen (1996) states that some people have a symbiotic relationship with testing to assess their risk of disease. However, testing for the presence of cepacia was not generally perceived by those we classified as isolates to minimize the risk of infection, despite tests being carried out at every outpatient's appointment. For example, Mark, aged 38, a part-time shop assistant and part-time management consultant, was experiencing more frequent chest infections at the time of his interview and achieved an FEV1 of only 35% predicted. He emphasized his uncertainty not about the accuracy of the test (i.e. knowledge) but about the timing of testing versus infection (i.e. management). As with many other infections, most notably HIV, a negative past result did not indicate current freedom from infection:

Well, cepacia [worries me] because you don't know you've got it until you've been tested, and if you're sitting next to a guy who's got it, but he wasn't tested positive last time, and he's tested positive this time, it's too late, you're already there.

Therefore, as the knowledge he gained from hospital testing did not bestow enough control, the safest way to manage the risk for Mark was to treat everybody else as potentially having cepacia, that is as individualists who were seen by other patients as a threat to the community. Lupton (1995) suggests that testing offers personal knowledge or control, although here it was knowledge about the other that was as important to isolates as knowledge about their own health status. For the isolates, even the idea of socializing with other patients was now often considered to be too great a risk to take, illustrating the current low group cohesion of these patients. For example, Nicholas, a 37-year-old office worker who stated that he had recently been investigated for CF-related diabetes, spoke of the risk of infection that was inherent in meeting other patients from the hospital socially, thus highlighting the influence of both medical and lay uncertainty in risk decisions. His quotation draws together Zara's concern about irresponsible infected patients and Mark's worry about the limits of testing:

Nobody could say whether people had it [cepacia]. Apparently the controls that were in operation were all, if people had this they were instructed not to meet with other patients because [of the risk of passing on infection]. Well, that's fine. One, they could say, "Well, sod that, I'm going out anyway", and secondly, they might not know [that they had cepacia]. So I thought, "Well, what's the point of having the risk?" I wouldn't take that risk, so I didn't. So it [socialising] died a death as it was.

Førde (1998) suggests that people obsessed with risk aversion are socially impaired. Here, although not necessarily 'obsessed' with risk aversion, that impairment is evident through patients minimizing social contact with other patients in order to avoid exposure to cepacia.

The active use of ignorance as a defensive strategy against the threat to psychological health through cepacia infection was reported by some isolates, although there was nothing that could differentiate those isolates who sought information from those preferring ignorance. Indeed, as a fragmented group, these isolates were bound to follow different strategies. For instance, during her interview, Nicola, a 38-year-old university employee, illustrated the notion that ignorance was bliss. She had suffered from repeated chest infections since the birth of her son 2 years ago and now required frequent intravenous antibiotics. During her pregnancy, the hospital staff had informed her of many of the adverse effects of pregnancy for this group and she had also been able to access information through her university employment. Now Nicola felt that she was too informed:

Yeah, I do [worry] a bit, but I've decided I don't want to know what happens when you've got it [cepacia] because I think I've almost become too informed [about CF generally] recently and I want to become less informed because I think I survive better not knowing, to a certain extent. So I think it's something I don't really want to get, but I'm not sure what, I know that you can't, that it's resistant to antibiotics and I'm sure that's not very good [laughing] but you know, I don't really want to [know].

In the context of a lay response to 'expert' science, ignorance cannot be treated as a simple deficit, but rather it entails active construction (Michael, 1996). In the process of this construction people reflect on the epistemological status of knowledge, and this is reflected in Nicola's quotation. However, isolates' management of the risk of cepacia was also directly affected by their perception of the hospital as 'dirty' and some hospital staff as incompetent managers of risk. It is to these issues that we now turn.

Perceptions of the hospital's level of acceptable risk

Transmission of cepacia can be seen as making individuals ritually impure; it is infectious and dangerous and generates risks that the hospital needs to manage. Failure to do so turns the hospital into a risky, dirty, and dangerous environment. Control of cepacia was not only restricted to the

construction of hospital boundaries but was apparent throughout the wider CF community. For example, conference organizers began prohibiting patients with cepacia attending conferences, and advised people to maintain personal boundaries such as remaining at least 3 feet apart, not shaking hands with others with CF, and not handling multi-use soap bars; all activities that have been labelled as 'high-risk' (Cystic Fibrosis Foundation 2003). This should have reassured isolates that the medical hierarchy was continuing to develop boundaries between patients, although patients themselves should also be responsible for maintaining those boundaries outside the hospital that were serving to isolate them from the risk of infection.

For those patients that we classified as isolates, attending hospital outpatient appointments was beneficial to ensure that correct treatment was given. However, the perception of the hospital as dirty and a source of infection lead most of them to declare that they either tried to limit the number of outpatient visits made or to have intravenous antibiotic therapy at home. Thus Barry, a 39-year-old bookkeeper who had recovered from a successful heart – lung transplant 18 months prior to the interview, stated that he continued to view the hospital as dirty and attended the hospital as little as possible:

I don't go to the [hospital] very often these days ... I suppose as much as anything it's probably defensive because hospitals are full of bugs, and if you go to [the CF] ward it's even more full of bugs.

Recently many specialties have begun to treat people who would previously have required hospital in-patient stays in their own home through 'hospital at home' programmes (Shepperd et al. 1998a, b). For adults with CF, intravenous therapy for severe chest infections can thus now frequently take place at home rather than in hospital (Bramwell et al. 1995). Moves towards providing hospital at home services have been primarily financially driven due to the demand on hospital beds across all specialities (Shepperd et al. 1998a) although in CF, healthcare staff have acknowledged the reduced risk of hospital-acquired infection from home treatment (Bramwell et al. 1995). As Armstrong (1998) notes, the hospital was once a place of safety, protecting patients from the dangers of the outside. Now, however, danger is felt to exist even within the hospital.

Although many of those patients classified as isolates who received intravenous antibiotics preferred to have them at home, Mark, 38, emphasized the importance of regular lung physiotherapy during chest infections to clear sputum; a benefit that meant admission to the hospital for antibiotic administration was necessary. During his interview, Mark illustrated how he balanced the risk of hospital-acquired cepacia infection with the benefits that antibiotics and physiotherapy would bring:

If I have to go in, I go in. And I go in because then I get the physio[therapy] and the drugs. But it worries me sick when I'm in there. And also I spend a lot of time out of the hospital when I'm in the hospital. So I go out for meals, I'll go out in the

afternoon, I'll go out in the morning, I'll be back for physio[therapy], back for the drugs.

Mark was very carefully balancing the risks and benefits of hospital admission by getting the essential treatment (physiotherapy and medication) but not staying in hospital otherwise. Indeed, patients' most common response to the perceived failure of the hospital to segregate infected patients properly was to manage the risk on an individual level. This gave emphasis to the idea that patients were isolates by their reluctance to attend the hospital as needed but to continue to respect the knowledge of the hospital staff and scientists working in the field. Førde argues that the 'risk epidemic, the revelation from epidemiological research of new hazards and risks' (1998: 1155), enhances health care dependence and health care consumption by increasing anxiety regarding disease. However, it seems that in the context of cepacia the converse is also true: the risk epidemic and a perceived poor hospital management may actually force patients to reduce their dependence on health care delivered in the hospital.

However, it is not knowledge per se (here regarding the segregation of patients at clinics) that is important in risk perception but rather people's confidence in institutions and the credibility of information or management that is at issue (Wildavsky and Dake 1990). The evolving policy of boundary setting at the time of interview contributed to the uncertainty among patients as to where these boundaries lay; separation of patients in time as well as space added to their confusion. Isolates' perception of hospital staff's uncertainty in the practical management of patients with cepacia was voiced and frequently questioned during the interviews.

Graham, a 40-year-old ex-hospital ancillary worker, was in very poor health at the time of his interview and stated that he had been asked by staff at the clinic to consider assessment for a lung transplant. During his interview he recounted how hospital staff had previously expected him to share a room with a fellow patient, who Graham assumed was admitted with an unknown infection at a time when doctors were unaware of the risks to patients of cross-infection. To avoid the risk of transmission of infection Graham decided to leave his shared room and take shelter in the day room:

Graham, a 40-year-old ex-hospital ancillary worker, was in very poor health at the time of his interview and stated that he had been asked by staff at the clinic to consider assessment for a lung transplant. During his interview he recounted how hospital staff had previously expected him to share a room with a fellow patient, who Graham assumed was admitted with an unknown infection at a time when doctors were unaware of the risks to patients of cross-infection. To avoid the risk of transmission of infection Graham decided to leave his shared room and take shelter in the day room:

The guy who was brought in to me, next door [in the next bed], they [hospital staff] don't know what he's growing. What do I do? I'm in a complete panic. They don't know what he's growing; he could be growing cepacia for all I know. So I said to

[Nurse Consultant] at the time when she was passing, "I'm ever so sorry but I can't stay in that room". So she said, "Why?" So I explained why, "I couldn't help overhearing that they don't know what he's growing". "Oh", she said, "It's probably the same as you, Graham". And that wasn't good enough. So that night I stayed in the day room and it really didn't go down well with the nursing staff. And I tried to explain, "I've got nothing against the poor bloke", I said, "'Cause I feel sorry for him, that's how I was a week ago, but why put us together when you don't know what he's growing on his chest?" I said, "He's coughing like anything, how do you think I feel?"

The ability to define risk and make pronouncements as to how people might avoid or minimize risk is central to the reinforcement of experts' standing as dominant in high-status institutions (Lupton 1995). The Nurse Consultant, in her role as the human face of biomedicine and the medical institution, was therefore seen by Graham to be forcing him to question his perception of the centre's standing as a 'dominant high-status institution' protecting him from the risks of infection. Although those that were classified as isolates accepted the status of medical knowledge regarding infection, those in poor health held no special respect for the management of boundaries by the hospital based on that knowledge.

Unfortunately for the purpose of our analysis there was only one patient in this sample, Gill, who was infected with cepacia. However, in our consideration of emic and etic methods in developing cultural theory, it is valuable to consider how we as sociologists would classify this person, whom others with CF were likely to perceive as an individualist, breaking the rules of the community, and exposing them to the risk of infection, and how Gill perceived herself. From Gill's interview, it became clear that other patients appeared to perceive her, and others like her, to be an individualist. However, we would classify her as an isolate, as indeed Gill herself appeared to do, for despite being excluded from all contact with other patients she continued to respect the hierarchy. It is to the case of Gill that we now turn.

The Individualist

Douglas's cultural theory suggests that individualists do not belong to any exclusive group and do not abide by rules made by society, and so their loyalty to others tends to be suspected by others in the community. As we have shown above, this was the perception of other patients. However, if infection with cepacia results in segregation in hospital and conference spaces, and from other sufferers, it is evident that these individuals would also be positioned as isolates.

Gill, a 30-year-old ex-receptionist, had had cepacia for at least 6 years prior to the interview, with an FEV1 only 30% predicted. She attended outpatients appointments every 3 months, with her last admission being 9 months prior to the interview, although rather unusually she had lived with the infection with little adverse effect on her quality of life. Contrary to the reports of the isolates without

cepacia, Gill did not perceive herself to be putting the health of others at risk through her attempts to maintain a boundary between herself and other patients. During her interview she emphasized the responsibility she felt in maintaining her distance from other patients because she did not perceive the hospital to have taken on that obligation:

The onus is very much on you, obviously we're all adults. I take myself away from people. But you shouldn't really have to bother yourself.

Gill also saw management of the risk of cepacia as needing individual organization as she did not perceive the hospital organization to be reliable. Gill also stated that she felt excluded from all CF-related meetings, social events, and conferences as well as hospital outpatient's appointments and inpatient stays, all places where she had previously met other people with the condition. Gill stated that she was torn between recognizing the need to stay away from others and the emotional effects of being excluded from the group of patients:

Like what, do we wear badges round our [necks], we've got cepacia? You know, it's a catch twenty-two because you know you have to be excluded but do you really want to be excluded? You know, does segregation have to mean exclusion?

Both Gill and those patients without cepacia who were considered isolates appeared to agree that those with cepacia would be classified as low group. The difference in perception was in whether Gill, and those like her, were high or low grid. Individuals with cepacia would appear to place themselves as high on the grid whereas those without known infection would place them as low grid. That is, the expectation of others (i.e. that patients with cepacia are individualists) does not always fit with the reported reality of the self (that these patients are also isolates). Gill's quotes suggest her expectation of a high structure (others in the hierarchy making provision for segregation) was not realized, yet a low group cohesion through not being in contact with others in her attempt to limit the spread of cepacia. This would suggest to us that Gill is also an isolate, and not an individualist, as others perceive those with cepacia to be.

Discussion

Wight (1999) argues that it is important that researchers investigate the wider social-cultural context of people's lives when studying perceived health risks and their management. In his study of HIV risk perception among young heterosexual men, the role of cultural meanings associated with lifestyle, and friendship groups largely resulting from their occupation, played a large part in shaping risk perception. In this paper we suggest that while occupation may shape some cultural perceptions of risk, health status and the risk of infection may be much more significant in shaping such perceptions and behaviours when a declining health state has displaced an individual's occupation as their central source of identity. The significance attached to health status is reflected in our operationalization of Douglas and Calvez's grid-group model, which we suggest can provide significant insights about how

people make sense of risk. Using an etic approach we have demonstrated how those with CF are located as members of different cultural groups depends on their health status and resulting contact with the hospital. Those who belong to the central community (high grid and high group) have good lung function and thus regular but limited contact with the hospital and its health care professionals. Isolates (high grid/low group), the majority of those in this study, have poorer health yet still maintain contact with the hospital to manage their condition. The very existence of such isolates contrasts with the findings of Marris et al. (1998) and Wight (1999) who could find no evidence of members of such a social group. Individualists (low grid/low group) are those with the poorest health, who may have developed cepacia infection, and who attend the hospital yet do not respect segregation policies.

In our study there was only one individual who was known to have cepacia, but she did not fit the model of an individualist, as she indicated that she had internalized the rules of the medical hierarchy (high grid) and had perceived the lack of enforcement of boundaries by the hospital, and segregated herself from others with the condition. This highlights a tension between employing an etic approach, where individuals are located according to the researcher's criteria, and an emic approach, where individuals' own concepts of boundaries, hierarchies, and others in the wider community are emphasized. Furthermore, how those with CF perceive others (i.e. as individualists) do not always correlate with how those 'others' see themselves (as isolates). Douglas and Calvez fail to note this tension and how it might be resolved. In our case we weighed up the evidence and eventually classified the individual with cepacia on the grounds that while the socio-cultural context shapes the choices available to individuals (Tansey and O'Riordan 1999) it does not determine them. Respondents' own concepts therefore need to be taken seriously. We could not find any evidence in support of Douglas and Calvez's fourth cultural group, a dissenting enclave (low grid/high group). This was explained as stemming from the fact that the risk of the spread of cepacia prevented such a group from forming.

One of the criticisms of Douglas' typology of group/grid is that it is static and not designed to show the process of change (Bellaby 1990, Tansey and O'Riordan 1999, Bellaby and Lawrenson 2002). By focusing on changing health status and the emergence of a devastating and untreatable bacterium we have shown how it is possible to explain people's movement away from the central community into isolation. In developing the theory, we considered putting forward a case for the risk averse being members of the central community and patients unconcerned by the risk of cepacia transmission being part of a dissenting enclave. However, we found that the risk averse could not be classified as a high group because of the risk of cepacia infection, and 'carefree' patients had no motive to join a dissenting enclave.

Although Douglas and Calvez's model has been shown to be useful in explaining how risk perception is shaped by membership of a particular cultural community it does not explicitly consider the place of the institution (in this case the hospital) in the making of cultures. As we have demonstrated, the threat of pollution (infection by cepacia) was not only from others in the community (individualists) but also

from the hospital itself. In the absence of perceived rigorous risk management from the hospital the patients were their own risk managers, taking individual responsibility for the containment of cepacia, although there were difficulties in managing the risk, most notably social versus health risks. Rather than risk awareness enhancing health care dependence as suggested by Førde (1998), in this case it seemed to encourage patients to reduce their dependence on the hospital management of care. Even so they continued to trust medical knowledge regarding the effects of the bacterium.

There is currently no sociological literature on the perceptions and management of the risks of cepacia (or indeed any other) infection by adults with CF and it is hoped that this paper has made a start in the understanding of this issue. The analysis here is of course based on one-off interviews involving retrospective accounts of the lives of adults. It should be noted that the low response rate to our invitation to participate in the study may have affected the results reported here. The lack of evidence of a group of patients who distrusted medical experts may be explained in part by the fact that the research was explained to potential respondents by medical experts who then invited them to participate. Those who were critical of clinicians or orthodox care might have been more likely to refuse. Furthermore such people are unlikely to have attended the clinic in the first place. Other explanations for our low response rate include the possibility that those who are concerned to minimize any infection risk refused to participate, that many adults with a relatively rare disease might feel overburdened with research requests, or indeed feel disinterested in the subject of the research. The significance of these methodological factors, and the implications for the findings and our interpretations, may best be checked by undertaking a longitudinal study of risk perception among a larger group of adults, for example by examining how risk perception and management interact with evolving hospital policies.

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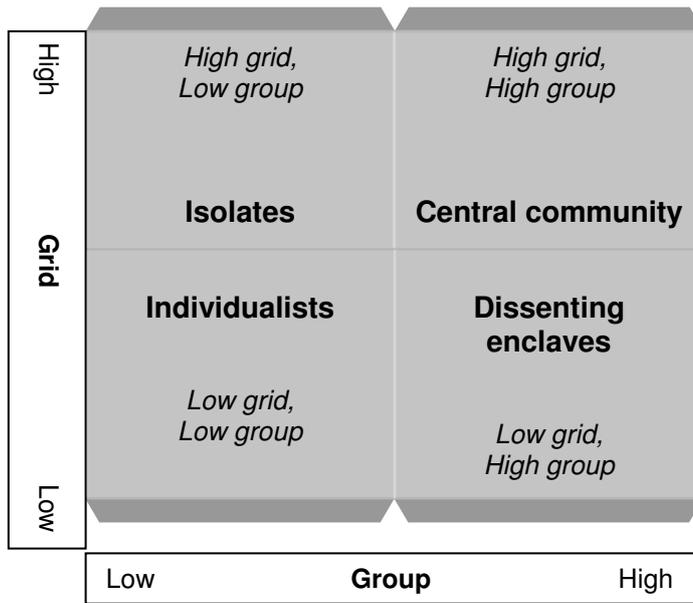


Figure One. The four cultures within Douglas and Calvez' community

Table one: Social and health characteristics of respondents at time of interview¹

Respondent	Gender	Age	Marital status	Occupation	Diagnosed	FEV₁ % predicted
Vanessa	Female	18	Single	Student	At birth	102
Tessa	Female	21	Single	Student	8 months	57
Lauren	Female	22	Single	Ex nursery worker	Infancy	22
Caroline	Female	22	Single	Special needs worker	5 years	37
Wendy	Female	23	Living with partner	Ex hairdressing assistant	10 weeks	58
Zara	Female	25	Single	Part-time personnel officer	18 months	29
Tina	Female	26	Married	Part-time charity worker	10 months	17
Rose	Female	27	Married	Part-time health care worker	15 years	91
Ashleigh	Female	30	Married	Ex shop assistant	2 years	29
Gill	Female	30	Married	Ex receptionist	3 months	30
Eliza	Female	31	Married	Ex secretary	3 days	34
Anna	Female	31	Married	Ex shop assistant	2 years	80
Emma	Female	33	Living with partner	Writer	2 years	36
Harriet	Female	34	Married	Ex council worker	6 months	62
Clare	Female	35	Married	University professional	At birth	78
Nicola	Female	38	Married	University professional	4 years	58
Catherine	Female	40	Living with partner	Trained legal worker	In infancy	35
Victor	Male	20	Single	Part-time veterinary assistant	In infancy	46
Darren	Male	21	Single	Student	At birth	26
Keith	Male	26	Living with partner	Trained book keeper	5 years	33
Oscar	Male	26	Single	Computer worker	4 years	87
Matthew	Male	32	Married	Ex craftsman	In infancy	42

Brian	Male	32	Single	Never worked	In infancy	23
Charles	Male	33	Single	Ex ship worker	7 years	26
Mike	Male	33	Married	Engineer	18 months	52
Jack	Male	35	Married	Civil servant	At birth	68
Ian	Male	36	Married	Ex engineer	22 years	57
Nicholas	Male	37	Married	Office worker	3 months	83
Mark	Male	38	Married	Part-time shop assistant, part-time management consultant	3 months	35
Barry	Male	39	Married	Trained book keeper	In infancy	115
Graham	Male	40	Married	Ex hospital ancillary worker	2 years	22

¹ Precise employment details are not given in order to protect participants' identities.