

AN EXPLORATION OF THE FACTORS INVOLVED IN LIFESTYLE
DECISIONS IN YOUNG PEOPLE WITH CYSTIC FIBROSIS USING
DECISION MAKING VIGNETTES, AND THE ROLE OF PERCEIVED RISK
OF INFECTION

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The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others

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ABSTRACT

This study explored the factors involved in lifestyle decision making in young people with Cystic Fibrosis, specifically the role of infection risk. Certain pathogens present a high risk of infection to people with Cystic Fibrosis, and can significantly affect their health. It is therefore important that people with the disease attempt to minimise the risk of contracting these infections. There was limited literature relating specifically to infection risk and decision making in this population. However, this study drew on decision making literature from other areas, with regard to engaging in risk-taking behaviours. The study employed a vignette methodology, presenting a series of lifestyle situations to eight participants and asking them to think aloud whilst deciding whether to engage in the activity. This was followed by a brief interview. An interview was also conducted with a Consultant Microbiologist, offering a detailed understanding of the level of risk presented in each vignette. Thematic Analysis was used to interpret the results, highlighting a number of important themes. Participants frequently chose to engage in activities that would present an increased risk of infection. It was often important to find a balance between maintaining their health and engaging in a fulfilling life. However, at times, participants lacked an adequate understanding of the level of risk or the nature of the infections to make an informed decision. Implications for future research and clinical practice are discussed.

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ABBREVIATIONS

Bcc: Burkholderia Cepacia Complex

CF: Cystic Fibrosis

ERCP: Endoscopic Retrograde Cholangio-Pancreatography

MRSA: Methicillin-Resistant Staphylococcus Aureus

MSSA: Methicillin-Susceptible Staphylococcus Aureus

PsA: Pseudomonas Aeruginosa

1. INTRODUCTION

Overview

This chapter will provide an introduction to the study. It is divided into four sections. Section I will begin by introducing Cystic Fibrosis (CF), the impact of the condition on lifestyle, and the role of infection in clinical health outcomes. Section II will then examine quality of life in more detail, specifically the factors that are important in determining the impact the condition has on an individual's quality of life. Section III will then explore the role of decision making in young people, exploring career choice decision making, models of decision making, the use of information in making choices, and the influence of parents and healthcare professionals. Finally, Section IV will discuss the clinical implications of the evidence presented in the preceding sections, as well as the aims of the current study.

Section I

Cystic Fibrosis

Cystic Fibrosis (CF) is the most common transmitted genetic disease affecting Caucasians. It is associated with numerous pulmonary and digestive problems, requiring life-long treatment. Symptoms include chest infections, and difficulty in gaining weight. The treatment involves a life-long complex regimen of physiotherapy, medication, and a specific diet. Eventually the individual with CF may require lung and heart transplantation. Although the disease is life-limiting, advances in treatment have led to

significant increases in life-expectancy. For many years considered a paediatric condition, life-expectancy has now increased to over 38 years for more than half of people with CF (CF Trust website, 25/07/10). Moreover, Dodge, Lewis, Stanton, and Wilsher (2007) note that children born with CF in 2000 can be expected to live past 50 years of age. This change has led to an increase in focus on the impact of the condition on psychosocial functioning in adulthood.

Infection Risk

As young people with CF move into adulthood, they must begin to consider making decisions regarding lifestyle choices themselves. This is an important area to consider as certain activities may carry greater risk of infection and subsequent ill-health. Significant risks are posed by infections such as *Burkholderia Cepacia* complex (Bcc) and *Pseudomonas Aeruginosa* (PsA). These infections are highly contagious, and for people with CF they are associated with an exacerbation in respiratory symptoms, and increased morbidity (e.g. Frederiksen, Lanng, Koch, & Hoiby, 1996; Pamukcu, Bush, & Buchdahl, 1995). These infections are now considered to be so harmful to people with CF, that patients who have these infections are segregated from those who do not when they attend clinics. This can involve using an alternative entrance, a different room, and attending at different times. The UK Cystic Fibrosis Trust Infection Control Group (2004) developed guidelines for best practice in prevention and control of Bcc complex. These

guidelines note the increased risks to health in people with CF who have contracted Bcc infections, including chest problems, increased morbidity, and decreased life-expectancy. The guidelines note that whilst the infection is most often transmitted from person to person, there may also be a risk from environmental sources, specifically Jacuzzis, soil and freshwater environments. The group indicate a reduction in the number of cases of Bcc following the introduction of segregation, where the opportunity for close personal contact with another individual with the infection has been reduced. The guidelines recommend that all individuals with CF are aware of their Bcc infection status and avoid Jacuzzis in order to minimise the risk of infection from this bacterium.

The guidelines also recommend the use of infection status information to determine the risk of cross-infection with other patients. This allows clinics to plan for segregation to reduce the risk to those who are currently free from the infection. The UK Cystic Fibrosis Trust Infection Control Group (2004) suggest that a greater understanding of the Bcc bacterium is required to determine whether segregation for the different strains is necessary to further reduce cross-infection. Although there is little research exploring the use of infection risk information by people with CF, it may also be a factor in making lifestyle decisions.

The UK Cystic Fibrosis Trust Infection Control Group (2004) produced guidelines on the prevention and control of PsA. They note that this pathogen is the most prevalent source of infection for people with CF, and

indicate that it is related to poorer health outcomes for patients. These guidelines outline the potential sources of PsA. Environmental sources of the pathogen include plants, soil, environments contaminated by human or animal waste, surface water, and spa baths or Jacuzzis. They also note that sinks and drains, particularly those in hospitals, can be a source of infection. In addition, cross-infection is also a means of transmission, and the guidelines suggest that segregation measures should be taken. The guidelines make a number of recommendations to help prevent the spread of PsA, which include promoting hygiene measures, avoiding spa baths and Jacuzzis, and avoiding contact with other people with CF. Moreover, they recommend that people with CF are aware of their infection status and consider the risk of cross-infection when planning for further education and entering a workplace.

Another potential source of infection for people with CF is *Aspergillus*. This is a fungus that can cause infection with the potential to significantly affect lung function, as well as a serious allergic response in some people with CF (O'Sullivan & Freedman, 2009). Littlewood (2007) offers guidance on the environments in which this fungus can be found. He states that *Aspergillus* is found in warm, damp environments and damp straw, and recommends people with CF should avoid greenhouses, stables, horse riding and “mucking out.”

Razvi, Quittell, Sewall, Quinton, Marshall, and Saiman (2009) note the change over time of the patterns of infection in people with CF. They

reviewed the USA CF patient registry between 1995 and 2005, evaluating the rates of infection over the period. Overall, the authors found a significant decrease in the prevalence of PsA, particularly in children and adolescents. In addition, there was a significant decrease in the prevalence and incidence of infection from Bcc. Razvi et al. (2009) suggest that these decreases are the result of the use of antibiotic eradication strategies for PsA, and the implementation of segregation policies to reduce cross-infection for Bcc. Conversely, the authors note a significant increase in the prevalence and incidence rates of Methicilin-Resistant and Methicillin-Susceptible Staphylococcus Aureus (MRSA and MSSA respectively). It is suggested that this increase might be related to better detection of the infection, and possibly due to an increase in community-acquired infections. The authors note that the pattern of infections amongst people with CF should be monitored in order to explore any relationship with clinical outcomes and care practices.

The risk factors involved in the acquisition of MRSA were explored in a study by Nadesalingam, Conway, and Denton (2005). The authors retrospectively reviewed fifteen CF cases, where respiratory cultures had tested positive for MRSA, and compared these with age-matched controls. The study found acquisition of MRSA was significantly related to a higher number of inpatient days, and greater use of certain antibiotics. In addition, patients with MRSA were more likely to also have Aspergillus fungi, which is also resistant to certain antibacterial agents used with people who have CF.

It is therefore important that steps are taken to avoid acquiring this infection. The UK Cystic Fibrosis Trust infection Control Group (2008) recommend that patients who have CF and are MRSA positive should be segregated from those without the infection, and hygiene procedures should be in place. Moreover, they recommend that people with CF are aware of their infection status, and should be made aware of the additional risks of working in a healthcare setting.

Although these infections present few difficulties for people without CF, adults and parents of children with the condition are advised to consider the risk of infection and subsequent consequences for their health when making lifestyle choices. Given the key role of avoiding infection in remaining well with CF, consideration must be given to the potential exposure to infection risk in decisions about lifestyle and career. Gjengedal, Rustoen, Wahl, and Hanestad (2003) carried out focus groups with patients with CF and their families and asked for views about infection status. They found that change to infection status was considered by patients as a significant stage in their condition. For many of these patients, PsA infection presented in adolescence. This resulted in changes to treatment, including longer and more frequent inpatient visits to hospital. The authors note that patients felt there were restrictions placed on them socially following infection acquisition, with the need to prevent exacerbation of symptoms. This may indicate some relationship between lifestyle and infection status.

As previously noted, certain environments carry greater risk of contracting an infection, such as soil, plants, areas contaminated by human or animal faecal matter, stagnant water, and Jacuzzis. Planning for certain activities, including horse riding, swimming or gardening, should involve an evaluation of the risk of infection. Ideally these risks should then be calculated against the possible health benefits, as people with CF are advised to take part in physical activities and sports. Many careers carry a higher risk of contracting an infection as a result of exposure to certain environments, including healthcare professions, veterinary or farm work. Gjengedal et al. (2003) note that patients diagnosed with PsA recognised the need to avoid smoke-filled environments and avoid contact with people who may carry infections. Further exploration of the use of infection risk information is required in order to understand how important this is in making choices about career and lifestyle. This might include an evaluation of whether current infection status impacts on the use of risk information. Table 1 below summarises the potential sources of these four common pathogens.

Table 1 Sources of Infection

Infection	Potential Sources
PsA	Cross-infection, plants, soil, surface water, environments contaminated by human or animal waste, hospital environments, and Jacuzzis (The CF Trust Infection Control Group, 2004).
Bcc	Cross-infection (person-to-person contact), soil, freshwater environments, Jacuzzis (The CF Trust Infection Control Group, 2004)
MRSA	Cross-infection, hospital environments (The CF Trust Infection Control Group, 2008).
Aspergillus	Warm, damp environments, greenhouses, straw, stables, horses (Littlewood, 2007).

Living with Cystic Fibrosis

Cystic Fibrosis is associated with a range of physical symptoms, demanding a varied and complex treatment regimen. Treatment for the condition includes physiotherapy, which can be carried out at home by the individual or by a parent. Physiotherapy aims to reduce the risk of chest infection caused by a build up of mucus in the lungs. It is usually carried out a minimum of once per day to reduce this build up. This mucus can also present a problem for the digestion of food, leading to malnutrition. Medication is therefore usually taken to aid digestion and ensure nutrients from food can be absorbed. In addition, a high calorie diet is usually recommended in order to ensure a healthy weight can be maintained by the individual. With regards to medication, a variety of drugs may be given to relieve respiratory difficulties, including steroids and antibiotics, and therapeutic oxygen may be used. Individuals may also regularly attend Cystic Fibrosis clinics as an outpatient, to monitor their health. Where

infections occur or respiratory health deteriorates, inpatient stays in hospital may be necessary. Compliance with the treatment regimen was explored by Gudas, Koocher, and Wypij (1991). They interviewed patients with CF between the ages of 5 and 20 years, and their parents and physicians, to determine the perceived level of compliance with treatment. The study focussed on the use of medication, chest physiotherapy, and diet. Information was obtained from self-reports by the patients, and reports by the parents and physicians. Participants were asked to rate compliance with these items, and an average from the three reports was taken. The authors used an average of all three respondent groups, as they believed this would allow a more accurate representation of compliance with treatment than a single report. The study found older children tended to be less compliant with their medication regimen than younger children. A good level of knowledge of the condition was associated with compliance in younger children, but taken alone it could not account for compliance in older children. Higher levels of optimism were found to be related to better levels of compliance. The authors note that with age, treatment regimens may become more demanding as the child's condition deteriorates. They suggest that this might make compliance more difficult for older children, and knowledge of the condition may not be helpful at this stage. They note that optimism may reflect resilience amongst this group, who appeared to have developed adaptive coping strategies to manage their condition. The issue of compliance to the treatment regimen explored in this study does not take

into account the impact of the condition on lifestyle, social activities, or career choices. However, the demands of the regimen may make it difficult to become involved in certain activities.

In addition to the treatment regimen and hospital appointments, people with CF are advised to take part in physical activities and sports that will offer the opportunity to exercise their heart and lungs. As well as the benefits for lung function, exercise and a high calorie diet can help to build muscle, gain weight and boost strength. As previously noted, decisions regarding participation in certain activities may be effected by the level of infection risk the activity presents. However, there is little research exploring this topic.

Section II

Quality of Life

Due to the complex and often demanding nature of the treatment regimen, as well as restrictions on certain recreational and career choices, it is important to consider quality of life in Cystic Fibrosis. Staab et al. (1998) explored the factors involved in quality of life outcomes in people with CF. The study included two samples; one comprised of the parents of children with CF, and the other comprised of adults and adolescents with the disease, who had a mean age of 24.2 years. A number of measures were used to evaluate quality of life, including measures of perceived disease severity, and ways of coping with living with a chronic illness. The authors developed their own measures for this study. Staab et al. (1998) used an 'Every day life' questionnaire, which consisted of 48 items exploring various aspects of quality of life and satisfaction with treatment. The authors note that the six sub-scales were significantly correlated with the total score, so this was used as the overall measure of quality of life.

The results of this study indicate quality of life outcomes in patients were related to the individual's perception of their health, their coping style, and disease severity. Staab et al. (1998) note that although most of the participants accurately rated their health status, those with good health outcomes who perceived themselves to be in poor health were more likely to have poorer quality of life outcomes. The authors suggest that this indicates the importance of addressing patients' perceptions of their health, and

exploring the individual factors related to the variance in these perceptions. For parents of children with CF, quality of life was found to be negatively associated with the length of time spent on daily therapy, as well as the coping style employed. Staab et al. (1998) found that social comparison and self encouragement were correlated with positive quality of life outcomes, and report that child disease severity and parental perception of disease severity was unrelated to quality of life outcomes. It may be useful to consider how the disease severity interacts with social comparison and whether lifestyle factors are important. As coping style appeared to be the most important factor in determining parental quality of life, the authors of this study suggest that this might be promoted by attending to the relationship between parents and healthcare professionals in clinics. In this way, adaptive coping styles might be promoted, to help parents adjust to the demands of caring for a child with CF.

Havermans, Vreys, Proesman, and De Boeck (2006) evaluated the relationship between perception of quality of life by children with CF and their parents' perceptions. This study administered the child and parent versions of the Cystic Fibrosis Quality of Life Questionnaire-Revised Version (CFQ-R; Quittner, 2003). This measure has both broad and disease-specific domains, with variable reliability from 0.40 to 0.85.

The authors found that parents and children had a moderate level of agreement regarding physical aspects of quality of life, although children reported poorer respiratory and digestive outcomes than did their parents.

They suggest this may result from either parental optimism regarding their child's health outcomes, or from a degree of under-reporting of symptoms by children. The results of this study also indicate differences between parent and child perceptions of psychosocial dimensions of quality of life. Better ratings were given to this aspect by children than by their parents, indicating that children view this aspect of their quality of life more positively than do their parents. Havermans et al. (2006) also note a difference in perceived illness burden, with parents rating this more highly than their children. The authors suggest that this may indicate that parents view the illness as having a greater impact on their child's life than their child does. They propose that this may stem from the demands placed on the parent by the treatment regimen, and difficulties they may encounter in helping their child adhere to the regimen. Havermans et al. (2006) also suggest that children may report a lower impact on their quality of life, using denial or avoidant strategies to cope with the demands of the treatment regimen. They also consider parental distress and the knowledge differential between child and parent, as possible sources of variance in quality of life scores. The authors conclude that whilst there are differences in the quality of life perceptions of parents and children, both accounts may provide the clinician with information regarding the suitability and appropriateness of certain treatment regimens. It might also be interesting to explore the young person's view of their infection status and the role this might play in making lifestyle choices.

These studies indicate a number of factors involved in the quality of life outcomes of children and adults with CF, and their parents. They draw attention to the coping strategies employed by parents and people with CF, as well as the perception of illness burden. Both of these factors relating to quality of life may be involved in the process of decision making when making lifestyle choices, and may indicate the degree to which the individual feels inhibited or constrained by their condition. A higher level of quality of life may indicate low levels of perceived illness burden, as suggested by Havermans et al. (2006). In this way, individuals who do not view their illness as restrictive may be less likely to adapt their lifestyle to accommodate the condition. This may lead to limited consideration of illness or health related risk issues when making recreational or career choices, and reduce the effect of Cystic Fibrosis on the individual's quality of life.

It is clear that CF can impact on an individual's quality of life. However, it is unclear as to the degree to which quality of life outcomes are considered important in making decisions regarding lifestyle or career choice. If experience of illness burden is low and quality of life high, health-related risks may be less important in the decision making process. However, as noted by Staab et al. (1998), perceived illness burden is not necessarily a measure of clinical health outcomes. For instance, an individual who is free from PsA and is in relatively good respiratory health may experience a greater illness burden than someone who has intermittent PsA, as they may attempt to avoid contracting the infection, and feel their

quality of life deteriorates as a result. In addition, whilst coping style has been found to be related to perception of quality of life, the relationship to lifestyle decision making is unclear.

Section III

Decision making

Patients and parents of children with CF are required to make decisions regarding treatment, lifestyle and career choices. Individuals must make decisions relating to whether to attend clinic, take medication, administer or receive physiotherapy, and adhere to the dietary and exercise requirements of their treatment regimen. Decisions are made relating to health and infection status, with certain choices affecting these outcomes. As particular activities are associated with a greater risk of Bcc or PsA infections, this may influence decisions made relating to career and lifestyle choices, such as avoiding working with animals or in certain outdoor environments.

Career Choices

There is limited exploration of career or lifestyle decision making processes in young people with CF. However, decision making regarding career choice in healthy young adults was investigated in a study by Wang, Jome, Haase, and Bruch (2006). In this study, the authors explored the impact of personality and decision making self-efficacy on commitment to career choice. Participants were undergraduates with a mean age of 20 years. The study administered the NEO-FFI (Costa & McCrae, 1992) to measure scores on neuroticism and extraversion. Questionnaires measuring

career decision making self-efficacy, career commitment, and level of career indecision were also given.

The authors of this study found that career indecision was related to gender, with males demonstrating higher scores on indecision. They also note significant effects of race, with black and minority ethnic (BME) students demonstrating lower scores for extraversion and self-efficacy, higher scores for neuroticism and career indecision. For white participants, there was no relationship between neuroticism and self-efficacy or career commitment. The reverse was true for BME participants. For both groups of participants, the authors note that higher scores on the measure of extraversion were related to higher levels of career decision making self-efficacy. The authors suggest that this relates to the social nature of making career choices, the need to draw on others for support and advice, as well as seeking out opportunities for employment. This raises the issues of the psychosocial impact of living with Cystic Fibrosis and the impact this may have on these factors, particularly as young people with CF are advised to avoid socialising with one another because of the risk of cross infection.

Puffer (1999) investigated career decision making, specifically looking at its relationship between factors such as family relationships and career choice commitment. In this study, questionnaires exploring family environment and attachment, and vocational identity and career commitment, were administered to undergraduates. Relationships between these variables were found for female participants. Puffer (1999) found that

those participants with high levels of parental attachment and family cohesion, and those who were encouraged to exert personal autonomy, were more likely to demonstrate greater career choice commitment and less anxiety or indecision regarding their career choice. The author proposes that these results indicate a need to consider the contextual and developmental factors involved in career decision making, particularly for young women. It might be interesting to consider this in young people with CF, particularly if there may be issues relating to attachment or personal autonomy as a result of the need for additional physical care.

These studies indicate a number of stable and fluid factors important in making career choices, including personality, self-efficacy, parental attachment, and family support. It is important to consider the impact of chronic illness on these factors when examining career decision making in CF. It is also necessary to look at the psychosocial impact of CF, and how this in particular might affect an individual's decision making self-efficacy. Additionally, it is important to consider the factors that may affect the individual's knowledge base about their health, if they use this information in making decisions.

There is a paucity of research exploring the role of infection risk information or perceptions in making career choices. Indeed, the factors involved in the decision making process in career choice in people with CF have not been explored. Further investigation of the process is required to

explore the factors considered important to young people making these choices.

Models of decision making

It is generally acknowledged that adolescence is a life-stage at which risk-taking behaviours are common (Reyna & Rivers, 2008). As previously noted, there is little research exploring decision making and risk in young people with CF. For these individuals, decisions regarding risk encompass the usual range of risk-taking behaviours found in healthy young people, with the added component of risk of infection. In addition, it is of note that young people without CF generally overestimate rather than underestimate their risk of mortality (Jamieson & Romer, 2008). This should be considered when thinking about how young people with the condition evaluate or utilise information about risk of infections. It is important to consider the reason why risk-taking behaviour is typical of this particular age group, particularly when risk of mortality is overestimated.

Gerrard, Gibbons, Houlihan, Stock and Pomery (2008) posit a dual-process model of risk-taking decision making, known as the Prototype-Willingness Model. They suggest that decisions regarding risk are comprised of two components; factors relating to reasoned action, and factors that are reactionary or unintended. The authors suggest that the reasoned action component of decision making centres around previous experience of the behaviour, using beliefs and values regarding the behaviour as well as intention to act in making the decision. Conversely, the

reactionary path to risk-taking behaviour focuses on willingness to perform the behaviour. They note that both of these pathways can be engaged at the same time. However, willingness has been found to be a stronger predictor of risk-taking behaviour compared with intention in young people (Spijkerman, van der Eijnde, & Engels, 2005). With regards to health-related risk-taking behaviours in young people with CF, it may be interesting to explore the degree to which these decisions are intentional or reactionary, and how this might relate to the Prototype-Willingness Model.

Hollen (2000) proposed a multifactorial model to predict risk taking behaviours and the quality of decision making, exploring the impact these may have on health outcomes and quality of life. The model was developed specifically for adolescents who have survived cancer, as a means of identifying those who present a high risk for engaging in substance misuse. The author suggests that risk taking behaviour is associated with a lower standard of decision making. She suggests that young people surviving cancer may be more likely to make poor quality decisions as a result of cognitively harmful treatment for their condition. In a study with adolescents who had survived cancer, Hollen and Hobbie (1993) found a significant relationship between poor quality decision making and previous cancer treatment, where treatment may have affected cognitive functioning. Hollen (2000) suggests that cognitive deficits resulting from cancer treatment may impact on the young person's ability to make appropriate decisions. However, the author acknowledges that decisions to engage in risky

behaviours are moderated by the individual's attitude towards the behaviour. This is similar to the model proposed by Gerrard et al. (2008), where previously developed attitudes may affect the young person's willingness to engage in the behaviour, thereby affecting their decision making. In young people with CF, the issue of cognitive deficits affecting the ability to make good quality decisions may not be important. However, their decision making, whether considered to be of a high or low standard, may be mediated by their attitudes towards particular behaviours.

The relationship between personal values and the decision to use alcohol was investigated by Shim and Maggs (2005). In this study, healthy college students were surveyed to obtain information about their personal values, attitudes towards using alcohol, and their intention to drink alcohol. Personal values were classified into self-actualising (e.g. self-respect), and social-hedonistic (e.g. sense of belonging). The students were then re-interviewed a week later to determine the amount of alcohol use since the previous interview. The authors found that participants with more self-actualising values were more likely to state negative attitudes towards alcohol use. For those who held more social-hedonistic values, more positive attitudes towards alcohol use were found. The study also found a relationship between intention to use alcohol and actual use. The authors suggest that these results indicate the importance of personal values on the decision making process, and emphasises the importance of attitudes towards an activity in the decision to engage in this.

Langer, Zimmerman, Warheit and Duncan (1993) evaluated the impact of sense of directedness on healthy adolescents' decision making. The authors explored knowledge, beliefs, attitudes, skills and behaviours relating to decisions around risk taking in sexual behaviour. They asked young people to rate themselves on each of these factors, as well as determining whether their decisions are directed by their peer group, parents or by themselves. High risk attitudes, beliefs and behaviours were found to be associated with peer-directed decision making, rather than self-directed or parent-directed. The authors place this in a developmental framework, as young people initially centre themselves within their family, drawing on parental views to guide their decisions. As the young person places increasing value on their social network, the views of peers become more important than those of parents, and in turn influence the decisions made by the young person. According to the results of this study, this results in a higher level of risk in the attitudes, beliefs and behaviours relating to sexual behaviour held by the young person. The authors suggest that as the young person develops, individuation occurs. This allows the young person to become independent from the values of parents and peers, and become self-directed in their decision making. Langer et al. (1993) note that there is no significant difference between the level of risk in decisions made by parent-directed or self-directed adolescents. This study suggests that young people who are immersed in and driven by their peer group may be more likely to

engage in risk taking behaviours, suggesting a role for social network in the process of decision making.

Fischhoff (2008) has suggested a Behavioural Decision Making Framework in exploring the risk-taking behaviours in adolescence. The model acknowledges the process of assessing decisions against social norms, the individual's beliefs and values relating to the behaviour, as well as the impact of individual cognitions and emotions. Fischhoff (2008) suggests that skill in decision making varies according to the individual, and highlights the importance of context and framing when evaluating beliefs and values about the behaviour. In CF, it may be important to explore context and framing effects in decision making around infection risk.

There are a number of different models of decision making regarding risk-taking behaviour. However, there is limited research into the models employed by people with CF in making decisions regarding their risk of infection in certain activities or careers.

Use of Information

There is little research exploring the sources of information about health and risk in young people with CF. Two possible providers of health and risk information may be parents and medical staff (Janse, Sinnema, Uiterwaal, Kimpen, & Gemke, 2005). Information may also be obtained from the Internet or pamphlets available in clinics. The provision of information in pamphlet form has been investigated by Loeben, Marteau and Wilfond (1998). In this study, the authors evaluated the content of a number of

pamphlets available in the UK and the USA. Although the majority of these were neutral in tone, there was considerable variability in the information presented regarding life expectancy, reproduction, and the disease itself. The authors consider the implications for the messages given to patients and their families, if varying and conflicting information is presented in these pamphlets. It is important to consider the nature of information given to patients and their families in these pamphlets, and the impact this may have on future ability to make informed lifestyle choices. It is also important to consider the availability of information on the Internet, which may not always mirror information given by healthcare professionals in Cystic Fibrosis clinics.

Parent and Healthcare Professional Influence

Parental involvement in the daily treatment regimen of a child with CF can be considerable, and can involve the provision of medication and physiotherapy, as well as attending hospital and clinic appointments. Additionally, parents of children with CF are faced with making lifestyle choices for their child, considering the various infection risks present in certain activities and in the home. It is therefore important to consider the longer-term effects of parental involvement on a young person's decision making skills.

The relationship between parental perceptions of child vulnerability and the child's level of social anxiety and school absence, were explored in a study by Anthony, Gil and Schanberg (2003). This study recruited participants with either rheumatic or pulmonary conditions, including those

with Cystic Fibrosis. Physicians provided information relating to the child's disease severity, and school records offered information relating to attendance levels for each child. Parents were asked to complete the Child Vulnerability Scale (Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996), to establish their opinion of their child's vulnerability to health related difficulties. In addition, children completed the Social Anxiety Scale for Children - Revised (SASC-R; La Greca & Stone, 1993).

The authors found that 61% of parents perceived their child to be vulnerable to health problems. These ratings were related to fewer years of parental education and higher levels of child disease severity. Anthony et al. (2003) note that children who were rated as more vulnerable by their parents were more likely to be socially anxious than those with low vulnerability ratings. After controlling for disease severity and the child's age, the authors found a significant relationship between the vulnerability rating and the Generalised Social Distress and Social Avoidance aspects of the SASC-R. However, the level of school absence was unrelated to parental vulnerability ratings. These results indicate a relationship between parental perceptions of the chronic illness, and the child's social functioning. It is important to consider the implications of this study in terms of lifestyle and career decision making, as social functioning may be an important factor in this process. It may prove necessary to consider the impact of parental involvement in future ability to make decisions affecting career and lifestyle.

Section IV

Clinical Implications

It would appear that the change in life expectancy in people with Cystic Fibrosis has led to an increased focus on the impact of the condition on psychosocial functioning in adulthood. As young people with CF move into adulthood, they must begin to consider making decisions regarding career and other lifestyle choices themselves. As yet, however, this aspect has received little attention in the literature. Whilst studies have examined issues of quality of life in people with CF, the relationship between lifestyle decisions and infection status has not been explored. In addition, there is a paucity of research exploring the decision making processes around infection risk in people with CF. It is therefore important to consider the implications for clinical practice, in order to evaluate the level of information and support that may be beneficial to young people in making decisions. It is necessary to develop an understanding of the factors young people consider to be important when making lifestyle decisions. This would allow the healthcare professional to enable the young person to make appropriate choices for them, providing a suitable amount of information in a supportive environment.

Aims of the current study

The current study explores the factors involved in the process of decision making in young people with CF, with a specific interest in lifestyle and career choices, exploring the impact of CF on these choices. It

investigates the factors important to young people when assessing risk in the process of decision making. Finally, it explores whether infection status impacts on the decision making process and the use of infection risk information.

Objectives

- To examine the process of decision making in young people;
- To examine the factors most important to young people when making decisions regarding lifestyle;
- To evaluate the role of infection risk information in lifestyle decision making.

2. METHODOLOGY

Aim

This study will examine the factors involved in making decisions about lifestyle and career choices, and explore the impact of CF on these choices. It will investigate the factors important to young people when assessing risk in the process of decision making. It will also explore whether infection risk affects the decision making process, and how young people use of infection risk information.

Ethical Approval

Ethical approval for this study was granted by the Leeds Research Ethics Committee (East) on 09/09/2009. A copy of the approval letter can be found in Appendix 1. Copies of the information sheet and consent form, given to participants, can be found in Appendix 2 and Appendix 3 respectively.

Participants and recruitment

The study recruited young people with CF, aged between 16 and 25 years, who attended the adult outpatient clinic at St. James's University Hospital, Leeds. This age group was selected as young people are beginning to become more autonomous in their decision making over 15 years (Wray-Lake, Crouter, & McHale, 2010). This would allow us to assess the factors important to the young person in reaching a decision. Those older than 25 years may be more likely to have a greater awareness of Bcc,

through direct or indirect experience of the infection as a result of its prevalence during the 1980s and early 1990s (The UK Cystic Fibrosis Trust Infection Control Group, 2004). However, this study aimed to investigate the decision making process for young adults, who are beginning to make lifestyle choices independently. It was therefore thought that participants should be recruited in the 16 to 25 years range.

With regards health status, it was important that participants were well enough to be involved in the study. Therefore interviews were only conducted with participants with a sweat chloride greater than 60 and lung function above 30%. The advice from a consultant adult CF physician and a consultant paediatric CF physician indicated that those with poorer lung function would already be facing a number of treatment demands. It was therefore felt that this would be an addition, unnecessary demand on their time. Whilst it would be interesting to explore the relationship between lung function and assessment of risk, this did not form part of the research question in this study. As this study specifically examined the impact of CF on lifestyle decision making, it was felt that excluding this group would not adversely bias the results. In addition, interviews were not conducted with inpatients. Again, it was felt that this would be an additional, unnecessary demand, for those potentially already engaging in a number of procedures. Participants were recruited by staff in the unit, who acted as gatekeepers to the study. A Cystic Fibrosis consultant from the adult service led the

recruitment of participants from the clinic. Individuals who met the above criteria were informed of the study, and provided with an information leaflet. During the recruitment period, between 01/03/2010 and 31/05/2010, 294 patients attended outpatient appointments at St. James's University Hospital, Leeds. All those who met the criteria for this study were informed of the study and offered an information pack. It is not possible to accurately state how many patients met the criteria for this study. However, approximately 30 information sheets were given to patients who were interested in the study. They were then asked if they would consent to the researcher contacting them by telephone to provide further information and arrange a convenient time to be interviewed. A total of 11 patients consented to this. The consultant collected their contact details and passed these to the researcher, providing the participants with a consent form and pre-paid return envelope. Information regarding the participants' infection status and respiratory health was also given to the researcher. Feedback from the consultant physician indicated that this patient group were reluctant to be involved in another research project, following their involvement in a number of other projects in the recent past. Although the study originally aimed to recruit 10 participants to each of the 'non', 'intermittent', and 'chronic' PsA infection status groups, this was not possible due to small numbers of willing participants.

Study protocol

The researcher made contact with those agreeing to participate via telephone to provide them with further information regarding the study, answer any questions, and arrange a convenient time for the interview. The researcher was able to make contact with 10 out of 11 of those patients who agreed they could be contacted. Eight patients gave their consent to participate, and they were asked to return the consent form they were given in the clinic if this had not already been returned.

Interviews. All interviews were conducted by telephone. This offered participants greater flexibility in arranging an interview time, and reduced the risk of cross-infection as they were not required to attend hospital for the interview. Moreover, all participants were able to be interviewed in a place where they felt most comfortable. At the agreed time of the interview, the researcher reiterated the information previously provided, stressing the importance that the participant remain comfortable throughout the interview. The participant was then instructed that they could withdraw from the study at any point, and confidentiality and anonymity were assured. Participants were also instructed that confidentiality would only be breached if there was particular concern for their or someone else's well-being. Had any of the participants become distressed, the researcher could provide the contact details of clinical psychologists attached to the unit. However, none of the participants became distressed during the interviews. The researcher also

acknowledged that they were independent of the Cystic Fibrosis clinic, and that information discussed would not affect their treatment in any way.

The researcher then verbally presented seven vignettes based around decisions relating to recreation, socialising, and family. These were devised by the CF research team, and were divided into high and low infection risk. The team was comprised of a Consultant Microbiologist, a Consultant CF Physician, a Consultant Paediatric CF Consultant, two Consultant Clinical Psychologists, and the researcher. The level of infection risk was assessed by the Consultant Microbiologist, to provide as accurate an assessment as possible. These vignettes are detailed in Table 2. A full outline of these vignettes can be found in the interview script, in Appendix 4.

Table 2 Level of risk presented by Vignettes.

Vignette	Situation	Source of Risk	Level of Risk
1a	Family wedding	Cross-infection	Average
1b	Over 100 guests attending wedding	Cross-infection	Average
2a	Going swimming with friends	PsA	Slightly increased
2b	Using a Jacuzzi with friends	PsA	Significantly increased
3a	Going camping with friends	PsA, Aspergillus	Average
3b	Using communal shower/toilet	PsA, Aspergillus	Average
4a	Going horse riding	Aspergillus	Increased
4b	Visiting stables	Aspergillus	Significantly increased
5a	Meeting someone with CF	PsA, Bcc	Significantly increased
5b	Close-proximity to someone with CF	PsA, Bcc	Significantly increased
5c	Close-proximity to someone with CF	PsA, Bcc	Significantly increased
6a	Visiting a friend in hospital	MRSA	Increased
6b	Visiting a friend who has MRSA	MRSA	Significantly increased
7	Visiting a relative in a nursing home	MRSA	Increased

Participants were asked to 'think aloud' whilst they reached their decision about whether or not they would participate in each proposed activity. Gilhooly and Green (1996) describe this 'think' aloud' technique as a process that allows the interviewer access to thoughts that might not ordinarily be articulated. The interviews were audio recorded and transcribed. All records of the interviews were carefully anonymised and kept in a secure place to ensure confidentiality. After the vignettes were presented, the researcher asked the participants to speak about their career choices. Where the participant was currently in education, they were asked to describe their plans for their future careers, and the reasons for making these choices. If the participant was in employment, they were asked to speak about their occupation and why they chose it. Participants were also asked to describe how important they felt it was to consider infection risk when making lifestyle and career choices, as well as the extent to which their parents have influenced these choices. Finally they were asked if they had heard of PsA and Bcc infections, and whether they have always been aware of segregation in clinics for those with these infections. This allowed an exploration of the role of segregation on perception of infection risk. As segregation occurred less than ten years ago, some participants may not have experienced it in the paediatric clinic, and may therefore have a different view of infection risk. The length of the interviews was in part led by the participants, and varied according to the length of the responses given.

However, as there were a limited number of vignettes, the length of the interviews was between 20 and 45 minutes.

Design

Use of Vignettes

Vignettes have been widely used in a number of studies exploring medical decision making by healthcare professionals (e.g. Bachmann, Muhleisen, Bock, ter Riet, Held, & Kessels (2008); Holmes, Rovener, Rothert, Schmitt, Given, & Jalongo, 1989). The methodology involves presentation of a fictional case study that requires clinical judgement or medical decision making. Participants are asked to evaluate the information given in the vignette in the process of making their decision. It is important to consider the validity of this methodology, as well as the process of developing and using vignettes to explore decision making.

Validity. The vignette methodology has been found to have a high level of internal validity and consistency amongst participants in a number of studies (Ryan, 2004). However, there has been limited exploration of the external validity of this process. For instance, Holmes et al. (1989) attempted to compare the judgements made by physicians in case vignettes for hypertension with outcomes taken from medical charts of patients diagnosed with the condition. Whilst the vignettes detected the use of decision making strategies amongst the physicians, the authors found they were unable to effectively compare the reliability of physicians' decisions in the vignette task and clinical practice. They indicate that such a comparison

was impossible in this case, due to the limited number of clinical charts available.

Shea, Asch, Johnson, Staroscik, Mallet, Pollack, et al. (1997) presented vignettes in a survey to explore the importance of particular clinical indicators on the clinical judgements made by surgeons and gastroenterologists for the diagnosis and treatment of bile duct stones. The survey presented eight types of clinical information, and asked participants to divide 100 points between them in order of importance in their judgement on whether to treat bile duct stones using Endoscopic Retrograde Cholangio-Pancreatography (ERCP). The survey then required participants to make a judgement on clinical case vignettes. The authors found that the most and least important indicators were the same for surgeons and gastroenterologists. However, there were differences between the two groups on the level of rated importance for other indicators. In addition, they discovered gastroenterologists were significantly more likely than surgeons to carry out ERCP as a matter of routine, regardless of the indicators. Conversely, surgeons were significantly more likely than gastroenterologists to never conduct ERCP for the treatment of bile duct stones. Where these differences may affect treatment, Shea et al. (1997) suggest that patients may receive varying treatment depending on who examines them, with the possibility of unnecessary investigation. This study highlights the value of exploring the use of certain indicators in making decisions. Using vignettes

as a choice exercise allowed the authors to explore the factors important in decision making that might have been difficult to achieve from clinical records. The study indicated patterns of decision making emerging within groups, but did not tackle the issue of external validity.

A conjoint analysis study of clinical decision making for surgery to treat aortic stenosis was conducted by Bouman, van der Meulen, van den Brink, Smidts, Cheriex, Hamer, et al. (2004). They evaluated the validity of medical case vignettes in exploring the decisions made by cardiologists to treat the condition with aortic valve replacement surgery. The vignettes required clinicians to rate on a six-point scale the likelihood that they would recommend surgery. The ratings ranged from 'certainly yes' to 'certainly no.' For the purpose of analysis, these were then divided into 'yes' or 'no' responses. Medical records for patients recently diagnosed with the condition were then coded using the same model as used for the vignettes, to allow comparison. The study found a high level of agreement between the decision making for the vignettes and the decisions made for patients, with three common factors considered important in deciding on surgery. Gender was an additional factor considered important in the decision to treat with surgery in actual patients. Despite this, the authors conclude that this methodology offers a reliable means of exploring clinical decision making, and could be considered to have a high level of external validity.

McKinlay, Burns, Durante, Feldman, Freund, Harrow, et al. (1997) attempted to control for problems in external validity in their study of medical judgements and decision making. They presented two vignettes in video format individually to physicians. To help improve external validity, they asked physicians to view the videos during their clinic, between seeing patients. Physicians were asked to view the women in the vignettes as patients. They were also asked to rate how typical they thought the cases presented in the vignettes were, and if they were not typical, to explain why this was. Finally, the physicians were asked to rate how typical their planned management of the patient was, when compared to other patients they have seen with similar presentations. The authors hoped that this would allow a more accurate representation of the decisions made by clinicians in their usual practice, and improve the external validity of the study.

Although there are limited studies exploring the external validity of the vignette methodology, Bouma et al. (2004) note that the method is a well recognised means of quantitatively evaluating the use of particular information by healthcare professionals when making medical judgements and decisions about treatment. The studies noted above do indicate a high level of internal validity, so whilst it is difficult to ascertain whether participants reliably behave in a similar manner in reality, it is clear that patterns in decision making can be discerned from vignettes. In this study, it will therefore be important to explore actual career and lifestyle choices or

plans at the end of the interviews. This will offer a means of comparison for the coded information from the decision making task, and may offer a means of exploring external validity.

Number of vignettes. Bachman et al. (2008) conducted a systematic review of recent vignette studies analysing medical decision making. They note that whilst this is a popular methodology, some studies may be adversely affected by the large number of vignette cases included. There is little evidence to suggest an optimal number of vignettes, however, the authors suggest that those studies involving large numbers of decisions may bias outcomes. Bachman et al. (2008) indicate that attention may be compromised by the presentation of large amounts of information, and participants may be unable to appropriately process and respond to the vignettes. This study will therefore limit the number of vignettes presented to participants to seven vignettes. In using this number of vignettes it is hoped attention will be unaffected, and a range of infection risk situations may still be presented without overwhelming the participants.

Developing appropriate vignettes. Holmes et al. (1989) proposed a method of selection for cues to include in developing vignettes. Their study explored decision making strategies for diagnosing hypertension, specifically the ordering of additional tests, and used cues to inform the decision. Initially, they evaluated the literature to gather frequently reported signs and symptoms of hypertension. This was then followed by work with an expert

panel to investigate additional cues to developing the diagnosis. Finally, they presented a focus group with the information they had collected, in order to determine whether other factors would influence the decision to order tests.

Vignette presentation was used by Denk, Benson, Fletcher, and Reigel (1997) in a study exploring public opinion on the continuation of treatment in terminal or serious illness. The authors of this study presented participants with 11 vignettes describing a medical case in a telephone interview, and asked them to decide whether they would continue treatment. Vignettes were constructed by randomly combining six variables. These variables, including for instance patient characteristics, prognosis, and insurance information, were generated from two focus groups asked to explore the important factors in making decisions on continuation of treatment in medical vignettes. The authors found a consistent relationship between decision to stop treatment and two variables. The first was the patient's wishes, with an advance directive to terminate treatment considered important in the decision by 80% of participants. The second was the potential benefit of treatment to the patient. This included whether their life could be prolonged with treatment, with a greater increase in life expectancy associated with the decision to continue treatment. Whilst there was no interaction between the variables in the vignettes and the personal characteristics of the participants, personal characteristics did affect the

decision to treat. Ethnicity, age, and level of education significantly affected the decision to treat. The authors found that these differences were the result of differences in the way in which people rate markers of quality of life, derived from ratings of four markers of quality of life presented in the interview.

The above studies make use of expert panels or focus groups to generate the important components of their vignettes. This study drew on this method, developing the vignettes based on the expert knowledge of members of the adult and paediatric CF teams. The vignettes offer decisions to participate in high and low infection risk situations. The expert panel provided accurate information on infection risk.

Influence of personal characteristics. It is important to consider the impact of personal characteristics on the process of decision making. A number of the studies noted above use the vignette methodology to determine whether particular attributes noted in the vignette alter the decisions made. However, McKinlay et al. (1997) explored the impact of physician characteristics on medical decision making. They evaluated the impact of physician speciality, their years in practice, and their concern over malpractice, in making decisions regarding the diagnosis and treatment of breast cancer in women. Following the presentation of two vignettes, one depicting a case pre-diagnosis and one post-diagnosis, physicians were asked to provide a description of the case, as well as a diagnosis and plan

for treatment. The authors found that surgeons were significantly more likely to diagnose breast cancer than non-surgeons, and less likely to recommend tissue analysis to aid their diagnosis. In addition, surgeons were significantly more likely to recommend breast reconstruction than non-surgeons. With regards to years of experience, the study revealed that physicians with less than 15 years experience were significantly more likely to request tissue analysis to aid their diagnosis than those with more than 15 years experience. Similarly, they were more likely to offer full primary therapy than their more experienced counterparts. The authors also found a significant relationship between concern over malpractice and the recommendation for extensive metastatic evaluation and axillary node dissection, suggesting a more cautious approach to treatment.

The study by McKinlay et al. (1997) demonstrates the suitability of the methodology in assessing the relationship between decision making strategies and personal characteristics. This study will therefore utilise the vignette decision making task to analyse the impact of experience of infection and previous history of segregation in clinics on risk-taking behaviour.

Analysis

The interview transcripts will be analysed using Thematic Analysis. This will allow an evaluation of the factors involved in the decision making process for each participant, as well as any themes that emerge across the

group. In addition, it will help determine whether a particular model of decision making can be applied. Qualitative research methods are widely used to elicit detailed information on personal experience from participants, accessing thoughts and feelings on a deeper level than quantitative research methods (Strauss & Corbin, 1998). These methods have frequently been used in health psychology research as a means of assessing the individual, personal experience of illness, which cannot be accessed by quantitative methods (Lyons, 1999). There are a wide variety of methods within qualitative research, as a result of the wide variety of philosophical and theoretical backgrounds (Henwood, 1996). Thematic Analysis is a method of identifying and analysing themes that occur within a data set, without attachment to any specific theoretical framework (Braun & Clarke, 2006). Braun and Clarke (2006) suggest this allows a greater degree of flexibility of application, compared with methods grounded in a particular theoretical background. The authors describe 'inductive' Thematic Analysis, whereby themes emerge from the research data, rather than focussing on themes that fit with the interests of the researcher. This method of analysis will be used in this study, allowing an exploration into an area that has been little researched. Thematic Analysis is comprised of a number of stages, outlined below and summarised in Table 3. This is based on the outline given by Braun and Clarke (2006), which aims to make the process of Thematic Analysis more explicit.

Following the research interviews and transcription, a process of familiarisation is required. This allows the researcher to become immersed in the data. In this study, the researcher will also carry out the transcription, facilitating this process of familiarisation. Initial codes are then generated, which can be numerous. This helps ensure the researcher draws out all possible meaningful codes from the data set, in line with the inductive approach. The researcher then searches for themes amongst these codes, with codes grouped together to form meaningful themes. The next stage involves reviewing these themes, to evaluate the supporting evidence for the theme within the data set. This is an important stage as it verifies that each theme is distinct from the others. The final stage in the process of analysis is to return to the data set, evaluating the themes in relation to the original data. This helps to ensure that each theme is clearly defined.

Table 3 Process of Thematic Analysis

Step	Description
1	Familiarisation with the data
2	Generate initial codes
3	Group codes into themes
4	Review themes and evaluate supporting evidence
5	Define themes with reference to the original data

Research Question

Although there is limited literature exploring the impact of CF on lifestyle choices, this study aims to highlight the factors that impact on the decision making process in young people.

3. RESULTS

This chapter is divided into four sections. The first section outlines the participant demographics, specifically age and PsA infection status. The second illustrates the decisions made by the participants. The next section provides details of the results of the Thematic Analysis, outlining each theme and providing illustrations from the transcripts. The final section explores the results of the interview with the Consultant Microbiologist.

Section I: Participant Demographics

Details of the participants' PsA infection status and age are outlined in Table 4 below.

Table 4 Participant Demographics

Participant	Age	Gender	Pseudomonas Status
1	21	Female	Intermittent PsA
2	18	Male	Intermittent PsA
3	24	Female	Intermittent PsA
4	18	Female	Non-PsA
5	17	Female	Chronic PsA
6	23	Female	Chronic PsA
7	21	Female	Chronic PsA
8	24	Male	Chronic PsA

Section II: Decisions Made by Participants

The decisions made by the participants in the vignette task are outlined in Table 5 below.

Table 5 Participant Responses to Vignettes

Vignette	Microbiologist Risk Rating	Participant 1	2	3	4	5	6	7	8	Total
1a	Average	✓	✓	✓	✓	✓	✓	✓	✓	8
1b	Average	✓	✓	✓	✓	✓	✓	✓	✓	8
2a	Slight Increased	✓	✓	✓	✓	✓	✓	✓	✓	8
2b	Sig. Increased	✓	✓	✓	x	✓	✓	x	(x)	5
3a	Average	x	✓	✓	✓	x	✓	✓	✓	6
3b	Average	x	✓	✓	✓	x	✓	✓	✓	6
4a	Increased	✓	✓	✓	✓	x	✓	✓	(x)	6
4b	Sig. Increased	x	✓	x	✓	(x)	x	✓	✓	4
5a	Sig. Increased	x	✓	✓	x	x	-	x	-	2
5b	Sig. Increased	x	✓	✓	x	x	✓	x	x	3
5c	Sig. Increased	x	✓	✓	x	x	✓	x	x	3
6a	Increased	✓	✓	✓	✓	✓	x	x	✓	6
6b	Sig. Increased	x	✓	x	✓	x	x	x	x	2
7	Increased	✓	✓	✓	✓	✓	✓	✓	✓	8

'Sig. Increased' indicates 'significantly increased risk, '✓' indicates a decision to engage in the activity, 'x' indicates a decision to avoid engaging in the activity based on risk to health, '(x)' indicates a decision to avoid engaging in the activity unrelated to risk to health, and '-' indicates no decision was made.

In order to understand these responses, an interview was conducted with a Consultant Microbiologist, who rated the level of infection risk in each of the vignettes. These ratings are also detailed in Table 2. It is of note that none of the participants chose to avoid the risk in vignettes 2a or 7. In addition, at least half the participants said they would engage in the activities

in vignettes 2b, 4a and b, and 6a, all of which were identified as posing an increased level of risk to people with CF.

These results suggest that the participants made choices in this task that would represent an increased risk to their health. It is unclear from the quantitative data whether this was because they were unable to assess the level of risk in each situation, or whether they chose to act despite an identified risk. It was therefore important to qualitatively analyse responses to the vignettes, to explore the reasons for these choices.

Section III: Decision Making Vignettes and Interviews

Analysis

Thematic Analysis was applied to responses to the decision making vignettes and the interviews that followed, using the process outlined by Braun and Clarke (2006). Interviews were transcribed by the researcher, and read multiple times in order to become familiar with the data set. Initial codes were generated across all participants, before being separated into potential themes. These themes were then reviewed with reference to the original extracts from the transcripts, and drawn out to explore relationships between themes. Clear definitions for each theme were then generated, and a final analysis of the selected extracts was conducted. These verbatim extracts were then used to provide a detailed account of the themes, providing an insight into the way in which young people with CF make lifestyle and career choices.

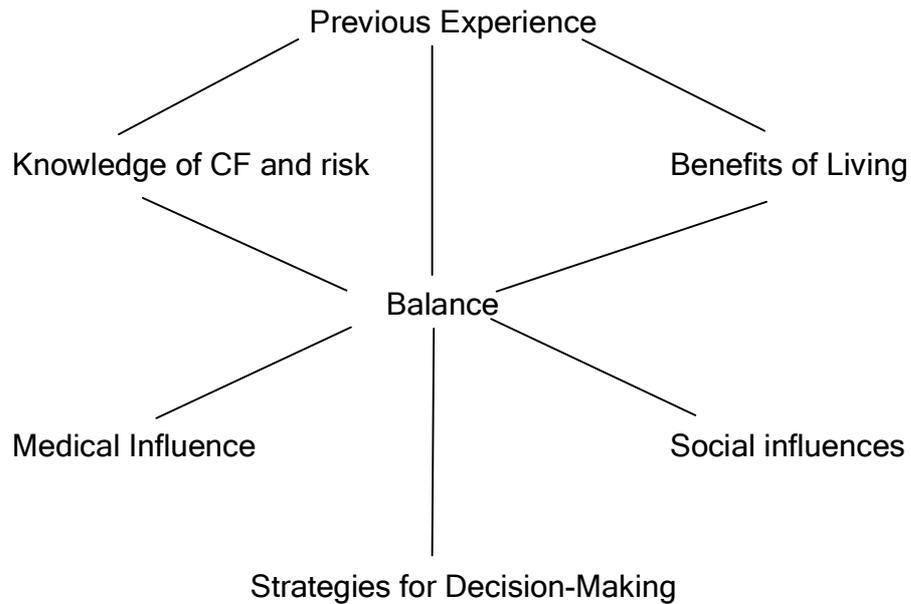
Credibility and Validity Checks

During each of the steps noted above, the researcher met with an academic supervisor, to ensure the process of analysis was accurate and appropriately conducted. This allowed both the researcher and supervisor to check the validity of the analysis at each stage, and helped to ensure the credibility of the results.

The analysis revealed seven main themes. These themes are detailed individually, with extracts from the interviews given in illustration.

The way in which the themes relate to one another is outlined in Figure 1 below.

Figure 1 Main Themes from Analysis



Each of these themes was present in nearly all participant transcripts, as outlined in Table 6 below.

Table 6 Themes Present in Participant Transcripts

Theme	Participant	1	2	3	4	5	6	7	8
Previous Experience		✓	✓	✓	✓	✓	✓	✓	✓
Knowledge of CF and Risk		✓	✓	✓	✓	✓	✓	✓	✓
Benefits of Living		✓	✓	✓	✓	✓	✓	✓	✓
Balance		✓	x	✓	✓	✓	✓	✓	✓
Social Influence		✓	✓	✓	✓	✓	✓	✓	✓
Medical Influence		✓	✓	✓	✓	✓	✓	✓	✓
Decision-Making Strategies		✓	✓	✓	✓	✓	✓	✓	✓

'✓' indicates the theme was present, 'x' indicates it was not present.

Previous Experience

This theme is central in understanding how participants might have acquired information about their health, infections, and risk, and how they utilise this knowledge. This theme was comprised of two sub-themes: experience of segregation and previous experience of infections.

Experience of segregation. This sub-theme detailed participants' previous experience of segregation from other patients with CF. As illustrated in the extracts below, participants were aware of the need for segregation but did not always find this easy. Also, many noted mixed experiences of segregation in the past. Some have a sibling with CF, others attended clinics before segregation was in place or had experience of services where segregation was not rigidly enforced.

"[...] I suppose it can be quite, quite strange for me to think other people, other people with CF don't mix, cause I obviously spend time with my brother [...] and growing up together, we lived in the same house and things like that [...] so I might have a different view on it that some people [...]"

Participant 3 - interview

"[...] I only started going to St. James's when I was eighteen. And it's always been segregated, but when I was at x hospital, yes they used to try and avoid taking two CF in at once, but sometimes it was unavoidable[...]"

Participant 1 - interview

“Segregation? Does that mean by yourself?[...] Oh, yeah, well when I was on the paediatric children's ward [...] I was allowed to like, keep my door open and talk to the other CF patients like across the room, but I was never allowed, we had a green line on, across our door and we were never allowed to cross that [...] But on the adult CF ward you're so enclosed and isolated by yourself [...]”

Participant 5 - interview

These extracts demonstrate a mixed experience of segregation from other people with CF. Whilst all the participants had experienced segregation in the adult clinic at St. James's Hospital in Leeds, with the exception of participants 4 and 2, they had not experienced segregation as children. This, coupled with the experience of siblings with the condition, may have influenced participants' views of the risk of interacting with people who have CF. Moreover, none of the participants were able to articulate a detailed understanding of the reasons why segregation has been enforced.

Previous experience of infections. A number of participants commented on their previous or current experience of infection, referring to this when making decisions. Direct experience of specific infections varied amongst participants. However, as illustrated in the extracts below, participants drew on this experience when completing the decision making task.

“[...] maybe in the past five years I've been in hospital nearly every year with the erm, pseudomonas germ, and it's come down to like maybe I'm stuck with it [...] I don't really know much about the germ itself, but I know it can be around like a lot of drains [...]”

Participant 7 - V3b

“[...] I grow MRSA like in my spu, in my cough sputum. I grow it, I mean it doesn't really affect me [...] It's kind of obviously other people can catch it from hospitals and things and it can be really harmful, but as far as I know, that, I think I've grown it for years and it's never, never really affected my health.”

Participant 4 - V6a

“I'm not really, I don't really know any bugs. I've got my pseudomonas, but unless I get it...I'm not really even gonna pay attention. Cause I probably couldn't tell you what tablets I'm on to be honest.”

Participant 8-interview

It appeared that where participants had direct experience of an infection, they used this experience to make a decision regarding the risk in particular situations, and whether their health would be affected. However, this risk assessment was not always accurate, with some underestimating the impact of an infection on their health. Participant 4 provides a clear example of this. She describes having direct experience of MRSA, and believes that it has not had an adverse effect on her health. She was therefore willing to visit a friend in hospital where there was a significant risk of contracting MRSA, as she felt this would not present a threat to her health.

Where there was no direct experience of an infection participants appeared to have limited knowledge and understanding of where it might be found or the impact it may have, illustrated in the extract from Participant 8 above.

Knowledge of Cystic Fibrosis and Infection Risk

This theme emerged as participants described their understanding of cross-infection, feelings of vulnerability, and their understanding of CF and infection risk in both the interview and the decision making tasks. There were three sub-themes: risk of cross-infection, understanding of Cystic Fibrosis, and sense of vulnerability.

Risk of cross-infection. Participants described some awareness of the risk of cross-infection when meeting someone else who has CF, illustrated in the extracts below. However, as can be seen, this understanding was not particularly detailed, and indicated limited knowledge of the process of cross-infection.

"[...]I wouldn't worry for me, I'd worry for them as well, because we could both give each other bugs and it's just not fair."

Participant 5 - V5a

"[...]due to like cross-infection. Erm because there's, because there's like two different types of major bugs, and if I have one and they have the other, then for us to catch it off each other would be a big no no kind of thing."

Participant 6 - V5a

"It's, it's to do with erm, just because erm, well, our, our like immune system, I don't know, like we can catch bugs easier can't we [...] and we can easily catch it and then between us we can easily cross-infect."

Participant 7-interview

These extracts illustrate the limited level of understanding held by the participants regarding cross-infection. The example from Participant 7 clearly indicates the lack of detailed knowledge about the process of cross-infection. Whilst there was some degree of concern surrounding mixing with other people who have the condition, the exact nature of the infections or their route of transmission was not discussed. Participant 6 acknowledged an awareness that it was important to avoid cross-infection, describing it as *"a big no no."* However, she was unable to explain the exact implications of mixing with other people with CF, or describe in any detail the infections from which she may be at risk.

Understanding of Cystic Fibrosis and infections. A number of participants demonstrated a limited level of understanding of their condition and harmful infections. These extracts highlight the lack of detailed understanding as well as misconceptions surrounding infections and CF. Some comments appear to demonstrate an inappropriate extension of common beliefs about infection and resistance to their own situation.

"Whereas if you go out every now and again and you get mixing with people with bugs, then it's gonna sort of (...) they're not really bad and you

don't really catch it, then you're going to sort of build your immune system a little bit, aren't you?"

Participant 1-interview

"I think it's, I think it's, briefly bits about it in the, in the news about people picking it up in hospital I suppose (...) that's probably about it, it's just eh, an infection, but obviously, you know, I wouldn't know how that would affect me [...]"

Participant 3 - V6b

The example from Participant 1 illustrates a belief commonly held within the general population: it is important to be exposed to bacteria in order to improve your immune response. Whilst there may be some truth in this in certain circumstances with healthy individuals, it is clearly not true for those at risk, such as individuals with CF. In addition to misconceptions and a lack of understanding around infection risk and CF, a number of participants were confused about the nature of different infections, with a number unable to describe Bcc and one participant confusing Bcc with a different bacterium:

"What is that like (...) [...] Is, is that um, is that where you have it [Pseudomonas] really badly?"

Participant 7 - describing Bcc

It was clear that participants did not have a sufficient understanding of their condition or possible infections. This may have affected their ability to make an informed choice regarding risk in the decision making tasks.

Sense of vulnerability. Although there was limited understanding of the common infections that are harmful to people with CF, the participants emphasised a sense of vulnerability and need to protect themselves. The

example below acknowledges the vulnerability arising as a result of CF. However, there appears to be a limited understanding of the precise nature of this vulnerability.

"I've got a low immune system. I pick things up really, really easily."

Participant 1 - V4b

Compounding these feelings, participants also acknowledged their vulnerability in different environments to particular infections. Where they were aware of risks of infections, some articulated concern that they might be at risk, as illustrated by Participant 3.

"[...]And eh, I think it's eh aspergillus which is, is quite frequent in stables and such like, which I don't currently have, so I wouldn't want to pick it up anywhere, and, or put myself in the position where I'm more likely to, to get it."

Participant 3 - V4b

In addition, participants' level of understanding of infections had an impact on these feelings of concern. In this extract from Participant 5, there is a sense that the PsA infection is unpredictable and she feels she has no control over when it will have an effect.

"[...]and I try my best to like, stop infection, but with chronic pseudomonas it creeps up on you now and again, and you try your best but it just still creeps up on you. It's frustrating, you can't control infection. You just, it just comes up when it feels like it."

Participant 5-interview

All participants described some sense of vulnerability as a result of their condition. However, despite this a number still made decisions in the

vignette task that could compromise their health. Given their concern for their health, this may indicate a lack of understanding of the actual relative risk in these situations.

Benefits of Living

Benefits of living were seen as the positive aspects of making decisions based on personal or social reasons, and included the participants' plans for the future. As all the decisions surrounded lifestyle choices, the potential benefits of making the choices were a significant component of the decision making process, and were often cited before infection risk or health were considered. There were three subthemes: benefits to self, social benefits, and planning for the future.

Benefits to self. Benefits to the self were cited in participants' responses to a number of vignettes, detailed below. Whilst these varied for each individual, they centred on personal interest and enjoyment, and influenced lifestyle and career decisions.

“Erm, well I've always, I've always loved English [...] and then the same with films really, I've always loved films and I had, I was just going to do English [...] and then when I found out you could do the both of them together that pushed my decision towards doing both of them [...]”

Participant 6-interview

“Eh, I've sort of been to see elderly relatives in nursing homes, and you're generally surrounded by quite mad old people, which I find quite amusing, so it's for my own entertainment really.” *Participant 8 - V7*

“Erm (...) It would be good to try [...] And something different to do (...) erm (...) yeah, I'd probably go.” *Participant 2 - V3a*

These extracts highlight the importance of personal benefits in decision making. For Participant 6, the decision to study English and Film at university was solely driven by her personal interests. Similarly, the decisions made by Participants 8 and 2 focussed on personal benefits, without considering health or risk issues.

Social benefits. Social benefits were commonly cited by participants as forming part of their decision making. These included supporting friends and family, and feeling involved in peer group and family activities, illustrated in these extracts.

“[...] I'd want to get in, obviously again cause it's all about not missing out. And, well, my friends are all going to university, so like I want to see them and stuff, and spend some time with them before they go for all that time.” *Participant 7 - V4a*

“You know, it would be fun and if my friends were going I could mess about with them. I'm also, eh, I'd probably try and compete with them in some things as well, like if it was (...) how fast we could go across the pool. I'm quite a competitive person really.” *Participant 8 - V2a*

It was evident that feelings of social inclusion were significant to the participants in making decisions, with Participant 7 explicitly acknowledging the need to avoid “missing out.” In addition, a number of participants

focussed on the importance of family in making decisions, illustrated here by Participant 5.

“Erm, well I think about my family. I really do get on well with my family, and anything involved with family, I’m there straight away because I’m a big family person. I come from a massive family.” Participant 5 - V1a

It was clear that social factors were important to all participants when making decisions in the vignette task. It is also important to note that these influences came from both friends and family.

Planning for the future. A number of participants discussed their plans for the future, indicating clear goals or desires for their lives. The extracts here indicate career plans, and aspirations for the future, emphasising a desire for life.

“Em, eventually I want to do erm, like marketing but within the film industry [...] I’m very interested in stuff like that. So yeah, a job in that really.”

Participant 6 -interview

“Because erm, having CF, I don’t know if you know if you have CF that your like, life expectancy is not as good as someone else. Do you know what I mean? And I would like, like I’m 18, coming up 18, and I want to have a kid when if I’m 18 or 19, it means I can grow up with my kid, see them going to college and see them like have kids and stuff like that. So I can see more of my child’s life and not have them miss out on their mum.”

Participant 5 -interview

"I'd like to be in the games industry [...] Erm (...) because it interested me really." *Participant 2 -interview*

All participants were able to articulate their plans for the future, although there was wide variation in the nature of these plans. In the examples noted above, Participants 6 and 2 are focussed on achieving a career, whilst Participant 5 would like to focus on starting a family. It was clear that these plans had an effect on the choices the participants made in their lifestyle, education, and career.

Balance

This theme emerged as participants attempted to evaluate and reduce risk in decision making, whilst still participating in activities they find enjoyable. This balancing process was often mediated by input from others. There are three sub-themes: assessing risk, weighing the benefits to self with the risks to health, and input from others.

Assessing risk. Participants frequently attempted to make an assessment of the level of risk to their health involved in the vignettes, noted in the extracts below. Often this proved difficult, with participants demonstrating limited understanding of the level of risk.

"[...] I know that the hospital don't quite like us all mixing up, because obviously one bug is more dangerous to one person than another. And I don't know enough about what sort of strain of CF and things that I've got, to be able to sort of make an accurate evaluation of whether it'd be safe or not."

Participant 1 - V4b

In this example from Participant 1, she is unsure of her ability to accurately assess the level of risk, and indicates that a lack of knowledge of her condition contributes to this difficulty. Participants 6 and 8, below, highlight the difficulty presented by the unknown; they acknowledge problems in assessing risk when they are unaware of which infections might be problematic and where these can be found.

"[...]I would be aware of other infections, cause you don't know what every other patient has. So I would be aware of it, but it wouldn't stop me from going to see them."

Participant 6 - V6b

"[...] Then if I knew that [MRSA] was there, then I'd avoid it, but ...or someone with CF and I don't know what infections I could give them or they could give me. I'd probably avoid it. But if I don't know (...) or going to social events or camping or whatever, it's not something what really crosses my mind."

Participant 8-interview

Again, this indicates an insufficient level of understanding of their condition or the risk posed by some infections, to make an accurate assessment of the level of risk. Although participants' choices were based on their assessment of risk, it would appear that these were not informed choices due to the gaps in their knowledge of this area.

Weighing the benefits to self with risk to health. Participants spent time considering how best to balance their desired lifestyle with the need to maintain their health. There was an almost philosophical nature to these

reflections, exploring the importance and costs of having a fulfilled life relative to having a healthy life.

"[...] is it something to do with, like, you, you live to have a life, or you're just, I, I don't know, something like that. Where you, something to do with like medication and stuff, where people, patients could like really like could look after themselves, and erm, do all their nebulisers and stuff like that, and then realise at the end of the day, erm, you're like not allowing yourself to do as much. Whereas in some ways I feel, it's kind of a bit naughty maybe, but I'd rather do like, go camping, and maybe like if I get, if there's something else going on I might miss out on a nebuliser or something like that [...]"

Participant 7-interview

"[...] I think it's like we were saying before, it's about getting the balance between having, having a life, and rather than stopping yourself doing things that you, that you otherwise would do (...)"

Participant 3-interview

A number of participants discussed this balancing process. It is clear in the extract from Participant 7 that this process is used when making lifestyle decisions, with a focus on the message that *"you live to have a life."*

"I try not to let my illness stop me doing anything, like I don't, everything like my friends do. But I suppose there is times where I can't do everything when I'm not well, and, but apart from that, when I'm fine, I don't, I don't limit myself to doing every, anything. I try to do as much as I can."

Participant 4-interview

“But at the end of the day you can't sort of shut yourself away to try and avoid things [...] So in a way I think it's really important to think about infection, but I think some people could take it too far.”

Participant 1-interview

The majority of participants described this balancing process when they made decisions, holding an awareness of the need to stay healthy, whilst engaging in activities they find enjoyable. The importance of not focussing entirely on preventing infection, and still feeling able to engage in enjoyable activities is described by Participant 1. However, Participant 4 inserts a caveat to the rule of not letting *“my illness stop me doing anything,”* acknowledging some difficulties when she is feeling unwell.

Input from others. Within the theme of balance, it was clear that input from others influenced the way in which participants evaluated the importance of risk compared with having a fulfilling life in decision making. This varied between participants, and appeared to be related to the message they felt they had been given from parents. Participant 3 described parental input that encouraged her to find a balance between assessing risk and engaging in the activities she finds enjoyable. However, Participant 8 described less of a focus on risk, with more emphasis on living his life as he desires.

“[...] they've explained to me that they wouldn't stop me doing things and they would want me to live life to the full and things like that. But equally, obviously still being aware of what the risks are and being able to

make an educated decision about whether, whether that risk is worth taking or not.” *Participant 3-interview*

“Yeah and they want me to be independent and they don't, my mum's always encouraged me, well they've both always encouraged me to go and do things. They haven't sort of kept me locked inside and oh you can't go out in case you get an infection, go out and do as you please(...) well up to a certain point anyway.” *Participant 8-interview*

Whilst input from others was important to all participants, they often indicated the difficulty in following advice. This is clearly illustrated by Participant 1, below.

“[...]She could see that it was making me ill, but I was too stubborn to listen to her. Erm, but even when I did manage, did finally get ill, she didn't say haha, told you so, she was quite supportive about it, and she was just like well, it's a learning curve.” *Participant 1-interview*

These extracts demonstrate the value placed on family members in providing guidance in making balanced decisions. Whilst difficulties in taking advice from parents were acknowledge the supportive role of family members was emphasised by participants.

Decision making Strategies

It was clear from the response to the decision making vignettes that participants employed various strategies to help them arrive at their decisions. These included placing the responsibility for the decision with someone else, reducing the impact of the risk to their health, and focussing

exclusively on the potential benefits of the decision with a move towards hedonism.

Externally placed responsibility. Participants employed this strategy in making decisions most commonly when their behaviour also entailed a risk to another person with CF. This is illustrated in the extracts from Participants 6 and 2. Although both acknowledged the risk presented by meeting another person with CF, they said they would leave the final decision to the other person.

"[...] if I liked the person really well, and we'd been talking for a long time, erm, I would leave it up to their decision, I would tell them what I thought, but leave it up to their decision as to whether we met up or not."

Participant 6 - V5b

"[...] I could make them ill if (...) [...] I probably would go [...] because they've invited me to go [...] because they want me to go."

Participant 2 - V5b

Placing responsibility externally was also apparent where participants had difficulty in reaching a decision. An example is presented from Participant 7, who was aware of the risk of Aspergillus but wanted to spend time in stables. In this case she said she would outline the risk to the other person, and ask them to make a decision based on their knowledge of these particular stables. This allowed her to feel less responsibility for assessing and reducing risk.

"I think I'd go and see what it was like, I'd maybe explain to the person that I was a bit concerned cause I've eh, eh, explained the situation, that there's a germ in the air caused by hay. I don't know, see what they say and then maybe if they were concerned, they'd suggest something else."

Participant 7 - V4b

Placing responsibility for the final decision with another individual allowed the participants to agree to make decisions where they were aware of an increased risk to themselves or other people. This may have reduced any cognitive dissonance arising from such a decision.

Reduce impact to health. Where participants chose to engage in an activity that contained an identified element of risk to their health, they attempted to moderate the impact of this decision with strategies to reduce the degree of risk, outlined in these extracts. As can be seen in the extract from Participant 3, there is some awareness that the degree of proximity to another person with CF has an impact on the level of risk. Although the risk may be somewhat reduced by avoiding close contact, there is still a recognised risk of cross-infection in this situation.

"[...]I'd probably make it a, you know, more open environment, you know, kind of open air in a café or something, rather than a, somewhere where I'm gonna be in close proximity to them."

Participant 3 - V5a

"[...] But as I'd leave the room, I'd make sure that I washed my hands and I washed like, I washed my hands and made sure that I'd wear an apron in with her cause if she hasn't got MRSA it doesn't mean that it's not in her room. So and then as I make my way off the ward, I'd wash my hands again with that special gel."

Participant 5 - V6a

"I'd just go and see them and wouldn't speak to or try not to be near anyone else, or try and have a conversation with anyone else [...] I think I wouldn't want to go all the time if it wasn't necessary [...] I'd pick one day to go instead of going twice, cause obviously I'd put myself at less risk kind of thing (...)"

Participant 4 - V7

Again, this strategy may have been an attempt to reduce cognitive dissonance where participants were aware they were agreeing to engage in a potentially risky situation. This is evident in the extracts from Participants 5 and 4, who are aware there is some degree of risk involved in engaging in these activities, but feel able to do so by suggesting possible ways to reduce the level of risk. However, some of these strategies may not in fact reduce the level of risk to individuals with CF.

Hedonism . The extracts below demonstrate the hedonistic responses to some of the vignettes, with some neglecting to consider risk. This allowed participants to make decisions solely based on potential benefits, without considering any costs to the decision. Participant 7 explicitly states that she would not think about the situation in any detail, instead focussing on enjoyment and having fun.

“But yeah, I’d definitely want to go anyway, and just not think of anything and have fun.” *Participant 7 - V3a*

“Em, cause I’ve never been before and I think it’d be cool and the obviously if I did like someone, then I’d get to spend some time with them. Em, and just have a laugh, get to know them.” *Participant 1 - V4a*

“Yeah, I love camping, definitely. [...]I’ve been loads of times. I quite often go. [...] I like being outdoors.[...] I like being, I quite like, you know, it’s quite quiet. I can go off by myself or I can socialise. It’s away from here I suppose.” *Participant 8 - V3a*

Hedonism was an important factor for all participants when making lifestyle choices. As seen in the examples from Participants 1 and 8, a desire to engage in these particular activities negated the need to consider any possible risk to their health.

Medical Influences

This theme was shared by a number of participants when thinking about making decisions. This centred on the influence of rules imposed by healthcare professionals, as well as their suggestions to minimise infection risk. Participants 1 and 2 describe a desire to follow the advice of healthcare professionals when making a decision that presents risk. Where participants were aware of advice provided by healthcare professionals around infection risk, they considered this in reaching their decision.

"[...]Cause, cause I know, I know that the hospital don't quite like us all mixing up, because obviously one bug is more dangerous to one person than another."

Participant 1 - V5a

"Erm (...) do like they said, because it might (...) [...] I'd follow their instructions, and erm (...) cause it could make other people ill."

Participant 2 -V6b

"Um, well I know my doctors always tell me that Jacuzzis are very germy, there's lots of germs and things carried in the Jacuzzi [...] So when I go on holiday now, I never, I never use the Jacuzzi. I try my hardest not to use it [...] I'd rather get in the swimming pool than use the Jacuzzi [...] I don't think they're cleaned very much as far as I'm aware. I don't know exactly, but what they've led me to believe is that they carry a lot of germs in them and things."

Participant 4 - V2b

These extracts demonstrate the way in which participants were able to use information from healthcare professionals to inform their decision making for some of the decisions involving a higher level of risk. Where participants demonstrated a clearer understanding of the risk involved and the reason behind this, they were able to make a decision based on the level of risk. It would appear that where the level of understanding was less clear, decision making was based on other salient factors. However, it is noteworthy that even where there was some awareness of a healthcare message, participants' understanding of the reasons for this advice was limited and vague at times, as illustrated in the extract from Participant 4.

Social Influences

Social factors, including the influence of friends, the role of parents and family, and the emergence of independence appeared to have a significant influence on participants' decision making. Where infection risk was not considered, often social factors were cited as a reason for the decision. Moreover, social factors were at times considered more important than infection risk in choosing to act.

Influence of friends. In these extracts, participants emphasise the importance of social contact in making their decisions. Participant 3 provides an example of this, suggesting that if she was unable to meet another person with CF, she would try to find an alternative means of staying in contact with them.

"[...]I mean obviously, you still want to be a friend on Facebook, and you think they're gonna be a erm, a good contact and you know, someone you'd maybe like to get to know them. And I think it's quite important to get to know someone kind of face-to-face as well as over the internet [...]."

Participant 3 - V5a

It was also clear that the participants valued having fun with friends and feeling included in their friendship groups. The extract from Participant 5 demonstrates the importance of being with friends in lifestyle decision making.

"[...]it's just fun again, with your friends isn't it? You go on holiday to have fun with your friends, so it's all about having fun."

Participant 5 - V2b

Finally, a number of participants commented on the importance of being available to support friends, even if this would present a risk to themselves. Participant 4 described circumstances in which she would be prepared to take risks in order to support a friend. This scenario was raised by a number of participants, highlighting the value they place on friendships.

"In that case, I know this sounds horrible, but if I found out that, in the situation where, maybe my friend could be like, she could be dying [...] or it might, it might be the last time I'm gonna see her if it was a really close friend then I, I wouldn't let it stop me."

Participant 4 - V6b

It was clear that even where participants had identified a potential risk to themselves, some were prepared to take risks if it would benefit their friend or have a positive impact on their social life.

Parental and family influence. Participants also emphasised the importance of family as an influence on decision making. For a number of participants this meant a desire to visit a relative in hospital, even where there may be a risk to themselves. Participant 5 provides an example of this, acknowledging that even if she was made aware of a potential risk to her health she would be prepared to take the risk if it allowed her to spend time with a close family member.

“Erm, I don’t even think I would even be thinking about the risk or anything like that, it just wouldn’t even enter my head. If my mum said to me, look, your nana’s really ill, she’s got C Diff, she’s got MRSA, you can’t go in there, I am going in that room [...] to see her, I just wouldn’t care, I wouldn’t even think about it.”

Participant 5 - V7

Similar responses were found in interviews with other participants. In addition to this, participants recognised the supportive role parents and family members play in helping them make decisions that may affect their health. Participants 4 and 1 provide examples of family members offering support to make decisions regarding activities that may affect their health.

“[...]. Obviously I’m nearly nineteen now, I’m an adult. But as in if my friends were going somewhere and I’m, they [parents] know I’m not well, they’ll be like oh well why don’t you wait, why don’t you miss this time out and go when you’re feeling better because you’re only gonna go and you’re only gonna get iller [...] So they do try and they do have an influence when I’m, I’m not well kind of thing but when everything’s okay they just (...)”

Participant 4 - interview

“But the one who’s always stood by me is my sister, and she’s always helped me try and look after myself a lot more, and always been there when I needed someone to talk to, always told me if I’m going something stupid and it’s gonna make me ill (...)”

Participant 1 - interview

Emergence of independence. The emergence of independence was evident in the interviews with a number of the participants. This included

making decisions without parental involvement, and moving into employment.

“Erm, probably come to that point when it’s like, too much, and I’m like, just leave me alone sort of thing. My dad’s come round to it [...] But I think my mum is still a bit concerned. So it’s just a bit annoying really. Like all parents would be.”

Participant 7 -interview

The extract from Participant 7 is an example of the desire to move towards independently making decisions regarding career choices and the future. She acknowledges that the tensions between her and her parents are a normal part of this process. For other participants, becoming independent focussed on the move into employment, as illustrated by Participants 8 and 5.

“Yeah. I discovered I couldn’t work for people, it tended to irritate me, so it was best if I just work for myself.”

Participant 8 - interview

“And I went for it because I wanted to get my own independence, start my own life, be like, financially secure with the job [...] and have my own house and everything [...]”

Participant 5 - interview

These extracts demonstrate a growing focus on the self, as participants emerge into adulthood, making decisions for themselves and moving towards an independent way of life. This would be expected from people within this age group, as they begin to think about moving away from home, starting work or education.

Section IV: Interview with a Consultant Microbiologist

Microbiology Perspective

In order to explore the level of risk in each vignette and participant responses to this risk, an interview was conducted with Dr Miles Denton, Consultant Microbiologist specialising in Cystic Fibrosis. Dr Denton was provided with the anonymised transcripts from the participant interviews, and the interview focussed on the salient issues from a microbiology perspective, and an assessment of the risk involved in the decision making task. The themes that emerged from the participant interviews were not discussed in this interview.

Similar to results of the qualitative analysis, Dr Denton highlighted the lack of understanding of infection risk. He noted that it appeared difficult for participants to make an accurate assessment of risk, as they demonstrated limited knowledge and understanding of infections.

"[...] the most surprising thing for me was the lack of, um, understanding of infection risk. Largely based on the fact that they didn't really understand a lot about the potential infections that they were at risk from. So some of them were a bit vague about their own pseudomonas status, certainly most of them I think hadn't heard of cepacia, even though it's obviously a very significant infection for people with CF. Um, I think one or two of them had heard of aspergillus or fungi. But I, I didn't get a sense that the others really knew that [...] But certainly all of the answers that I was

reading from the transcripts did make me think that we've got a big problem educating our attendees at the clinic.”

In addition, it was noted that from a microbiology perspective it is difficult to precisely quantify the level of risk for an individual. This may consequently make it more difficult for individuals to make an accurate assessment of the potential risk of engaging in an activity.

“Um, well I think even if they have all of the information, about where you might find pseudomonas in the environment, say in a swimming pool, in a jacuzzi, or you know, in your back garden, we can't quantify the risk. I can't say as a microbiologist to anybody if they ask me a direct question, how, if I didn't have pseudomonas and I sat in that jacuzzi, what's the chances that I could get pseudomonas from that activity [...] we can only say we know that we can find pseudomonas in that jacuzzi water. We also know that because it's a relatively warm place, the pseudomonas grows very successfully in it, and the fact that it's bubbling, generates aerosols, which means within the sort of mist that comes out of a jacuzzi, you're sat there inhaling all this mist, you will be inhaling pseudomonas. So it, theoretically it's actually a very risky thing to do [okay], but we don't know how risky for a particular individual. So we can't advise them as such, other than we just issue a blanket statement that says don't go in jaccuzis.”

Exploring this further, Dr Denton identified a need within microbiology research to improve the understanding of infection risk to people with CF.

This would allow a clearer understanding of the risk present in particular situation.

“Yep, and I think from a, a research, from a microbiologist point of view we need much better research to understand how organisms are acquired, what the infected dose is. I mean, for, for example, we know the infected risk of salmonella from some contaminated food, what you need to cause the illness in most patients. It does vary from one person to another, but we’ve no idea of the infected dose of say pseudomonas in a person with CF, whether it’s one organism or a million organisms. We just don’t have that knowledge, because the research has never been done.”

In understanding why the participants may have a limited understanding of infections in CF, Dr Denton discussed the process of educating young people with the condition.

“[...] And why would that be? Well, I think, as we discussed, all of the ones that you interviewed were young adults, um, so many of them will have been in the paediatric setting in the recent past, and as we discussed, probably in that setting a lot of the information is given to parents rather than to, to the individuals themselves, and we’ve really got no idea how much information was then understood by the parents and then articulated to, to their children. So the parents may have got all the information and chosen not to give it for whatever reason, because they were scared of frightening them or something, or they didn’t understand it themselves, were unable to pass it on because, or it went in one ear and out the other, and maybe didn’t

think about passing it on, even when their children obviously grew up, became adolescents and now adults, they still never imparted that.”

It became clear that there is a lack of understanding surrounding how information about CF and infection is accessed by young people as they move from the paediatric service into the adult service. Moreover, Dr Denton suggested that the lack of awareness may be the result of very few people with CF contracting certain infections. This is similar to the results of the qualitative analysis, where participants' experience of an infection had a direct effect on their awareness in future.

“So there aren't that many people around now with Cenocepacia. Um, I mean to put it in context, here in Leeds we've got 2 out of 160 or so children with it, and in, in the adults I'd, I'd be surprised if it's more than 10 out of 350. So the proportion of people within the clinics who have it, you're talking 1 or 2%, which means that 98% plus don't have it. And I guess if you don't have something you kind of like, it doesn't register in the same way. And so whilst they would know about oh, you shouldn't meet other people with CF and segregation, and this that and the other, and what have you, they don't really understand the reasons why. And they will have heard of Cepacia, cause it's not like, well five of my friends in the last ten years have had it and died so I know a lot about it. We, we haven't had that many deaths from it in the last ten years. But I think that's probably the reason why. I think if you asked the older ones, they're more likely to know about it, but you're only interviewing the kind of 18 to 24 year olds. If you found some of them who were say in

their 30s, they're probably far more likely to have heard of it, they will have lost friends because of it."

It would therefore appear that from a microbiology perspective, the decisions made by the participants in this study did not appropriately consider infection risk. It also appears that this is due to a lack of awareness, possibly as a result of limited education.

4. DISCUSSION

Summary of Results

- All of the participants in this study were able to engage in the discussion around the vignettes presented, and articulate the reasons for their choices.
- All participants demonstrated a willingness to engage in behaviour considered to present infection risk by a microbiologist in at least some of the vignettes.
- In two of the vignettes, all participants chose to engage in activities that presented an increased risk of infection.
- In three instances, reasons other than infection risk were cited as the sole reason in deciding against engaging in an activity, and in other decisions, these reasons featured alongside risk.
- Participants tended to have a limited and at times confused understanding of bacteria, infection and risk.
- Participants tended to demonstrate a greater intention to follow rules about reducing infection risk when these rules were unambiguous.
- Participants often attempted to balance quality of life with risk to health when making choices in the vignette task and regarding their lifestyle.

The results of this study demonstrate a limited understanding of common bacteria and infections, and the situations in which these may present a risk to people with CF. Participants tended to demonstrate a better

understanding and greater intention to follow rules about risk when these were less ambiguous. However, a limited and ambiguous understanding of infection risk was more common in this sample. In addition, it was evident that participants considered quality of life to be an important factor in making lifestyle and career choices, often considering social and hedonistic aspects of the situation rather than their health or risk of infection.

Process of Decision Making

Ambiguity in decision making

Whilst participants did at times think about infection risk in reaching decisions, their limited knowledge of this area prevented them from making an informed choice. In the balancing process, it appeared that participants were unable to appropriately weight risk of infection on a number of occasions, as they did not fully understand this factor. Their understanding of the nature of bacteria and infections was often very ambiguous, so at times it was difficult for them to accurately assess the potential outcomes of the situations described in the vignettes. Where this was the case, a stronger weighting was given to other factors, of which the participants held a clearer understanding and could draw on previous experience. For instance, if the young person is unaware of the risk of MRSA when visiting a relative in a nursing home, the amount of weight given to infection risk will be less than that given to the benefits of seeing the relative. This fits with the ambiguity effect described by Ellsberg (1961). This states that decision making is affected by ambiguity and a lack of understanding of probable outcomes, with individuals more likely to select the situation for which the probability of the desired outcome is known. Where people are presented with two situations, both of which are equally likely to produce a positive outcome, but the probability of a positive outcome is only known for one situation, they are more inclined to choose the situation for which probability is known. For the participants in this study, choices frequently centred around personal and social benefits for which gains could be guaranteed. Einhorn and Hogarth

(1985) note that ambiguity affects an individual's perception of the degree of risk in a situation, as they are unaware of the potential outcome.

Theoretically, this should lead participants to be more cautious in decisions relating to risk. However, in the present study participants were often unaware of risk, instead making choices based on issues relating to potential benefits rather than potential costs.

Personal autonomy in lifestyle decision making

The results of the vignette decision making task indicate that the young people involved in this study were able to make clear choices regarding a range of lifestyle scenarios. This level of personal responsibility might be expected for this age group. Hamlett, Murphy, Hayes, and Doershuk (1996) studied the health behaviours, locus of control, and developmental tasks of adulthood in people with CF. They found that a number of tasks related to health had not yet been assumed by participants, including obtaining medical insurance and managing their diet to ensure nutritional requirements are met. Moreover, where they had assumed responsibility for aspects of treatment, participants reported adherence was poorer when they first assumed responsibility than at the present time. This indicates some initial difficulty in adherence for young people when they are beginning to take control of their health and locating control internally. Similar to the present study, Hamlett et al. (1996) found their participants were engaging in tasks related to age-appropriate developmental stages, including educational and career aspirations, marriage, and moving away from the parental home.

Personal responsibility was further emphasised in the present study by a desire to move away from parental and healthcare professional control, with some choosing to engage in an activity that they knew was discouraged. This move towards autonomous decision making has been explored in terms of a developmental model of emerging autonomy in middle to late adolescence. Wray-Lake et al. (2010) explored the decision making autonomy of children and young people in a longitudinal study. They used parental reports of who was involved in decision making in a number of areas, to explore the level of autonomy afforded to the child or young person. The authors found that decision making gradually becomes more autonomous in middle adolescence, between 13 and 15 years, before rapidly rising in late adolescence, over 15 years old. These findings may help to explain the actions of the young people in the present study, who were in late adolescence and early adulthood. It appeared that all the individuals in this sample were clearly able to assert their autonomy when making decisions in the vignette task. Wray-Lake et al. (2010) also found that autonomous decision making was demonstrated most often in decisions relating to personal factors, such as appearance, and least often for decisions relating to social conventions/rules and those which may impact on their health and safety. In the present study, it may be that participants do not perceive certain situations as having the potential to impact on their health and safety, instead focussing on the personal factors. This may enable them to assert a degree of personal autonomy in making the decision. Where participants were aware of a rule imposed by hospital staff, they were more likely to

behave according to said rule. This may highlight the lack of awareness of infection risks presented in certain environments.

Similarly, Myers and Myers (1999) found a relationship between self-reported adherence and an external locus of control with powerful others. They also found that personal factors, internal locus of control, and chance factors were not related to adherence. They suggest that it may be beneficial for healthcare professionals to enable an external locus of control for health-related behaviours. These findings fit with the results of this vignette task, where some participants chose to avoid infection risk when they were aware of unambiguous advice given by healthcare professionals. Locating control for healthcare or risk-related behaviours with healthcare professionals could therefore reduce risk-taking in this group. However, Williams and Koocher (1998) suggest that personal control is associated with improved psychological functioning in people with chronic illness. They acknowledge that a sense of external control may be beneficial for some individuals, but suggest that this should be treated with caution.

Balance

Participants in this study balanced the benefits to themselves with the potential risks to their health in some of the lifestyle decisions. Although they were not always clear on the extent or nature of the risks associated with particular activities, participants often attempted to find a balance between avoiding risk and engaging in enjoyable activities. It is important to note that this balancing process was not always evident, with some situations generating thoughts around social or personal benefits rather than infection

risk. This may fit within the Prototype-Willingness Model of risk-taking decision making proposed by Gerrard et al. (2008). It would appear that participants in the current study drew on previous experience and beliefs about infection risk where this was available to them, combined with their willingness to engage in the activity. This is similar to the reasoned action component of the Prototype-Willingness Model, which emphasises planning and reasoning. This balancing process can be seen in the results of this study, with participants trying to maintain a good quality of life and engage in enjoyable activities whilst holding an awareness of the potential impact on their health. However, where participants had no previous experience to draw upon, decisions were more reactionary and based on their willingness to participate in the behaviour. Gerrard et al. (2008) note that this type of decision making is associated with risk-taking behaviour, and this was demonstrated in the results of the current study. Where participants focussed on hedonism and the social benefits of engaging in an activity, they were less likely to consider infection risk. Moreover, participants often used both reasoned action and reactionary decision making when assessing the vignettes, in an attempt to find balance between maintaining their health and enjoying their life. Again, this is similar to the Prototype-Willingness Model, which suggests that these two thought processes are often engaged at the same time.

The process of balance has been emphasised by Abbott, Dodd, and Webb (1996), who explored the impact of health perceptions on treatment adherence in adults with CF. This study found that treatment adherence was

affected by a higher level of illness severity. The authors suggest certain behaviours are avoided as they serve to remind the individual of the severity of their illness. In addition, they note that external control was associated with greater treatment adherence, with the exception of exercise, which was related to internal control beliefs. They suggest that this indicates a belief that it is important to follow advice given by healthcare professionals. In the present study, where participants were aware of a clear message relating to infection risk, they were able to use this information to assess whether they would be prepared to engage in an activity and take the risk. For instance, where participants acknowledged healthcare advice on avoiding Jacuzzi baths, they chose to avoid this situation. This is similar to these results, suggesting a clear understanding of the view of healthcare professionals on infection risk has the potential to influence lifestyle decision making. However, Abbott et al. (1996) also acknowledge that lower levels of treatment adherence in those with an internal locus of control may be the product of a rational decision making process. They suggest these individuals may take into account how healthy they feel, and attempt to maintain a balance between following treatment advice and enjoying a good quality of life. This is also demonstrated in the present study, with participants emphasising the importance of balance, and the need to enjoy life.

Awareness of Risk

Ability to assess risk. The decision making vignettes revealed that participants drew on their previous experience in order to assess the level of

risk involved in each situation. It was clear that participants had difficulty identifying risk where they had no previous experience of a situation or of a particular infection. This was related to knowledge of CF and infections. Overall, participants had a limited understanding of the range of infections that are particularly harmful to people with CF, as well as the environments in which these can be found. It appeared that knowledge and understanding was limited where there was no direct experience, highlighting a lack of education or inability to recall relevant information in this area. In a study evaluating adherence to infection control recommendations in CF, Masterson, Wildman, Newberry, Omlor, Bryson, and Kukay (2008) found limited understanding of infection risk from other people with CF. They reported that 40% of patients and 41% of parents did not believe they could become ill following contact with another patient with CF. Similar to the present study, this highlights a significant gap in knowledge and understanding of the sources of infection and the nature of particular bacteria. Moreover, Masterson et al. (2008) suggest that compliance with segregation recommendations arise mainly from a lack of opportunity to interact with other people who have CF, rather than an assessment of the potential risks. Viewed alongside the results of the current study, it would appear that people with CF do not have sufficient knowledge and understanding of infections and infection risk to make informed lifestyle choices.

The current study indicates difficulties in accurately assessing infection risk. Similarly, people with CF have also demonstrated difficulties in

accurately assessing the severity of their condition. Abbott, Dodd, and Webb (1995) explored the difference in perception of disease severity between physicians and people with CF and their close companions. They found that generally patients and close companions rated CF as less severe than physicians. Moreover, they note that patients and close companions maintained their rating of disease severity over time, even where clinical indicators suggest the illness has become more severe. They propose that this may indicate a difference in the way patients and their close companions view disease severity, perhaps focussing on more than physical health, drawing on quality of life, social, and mental health factors when making their assessment. It may also relate to a form of psychological protection, with patients viewing their illness as less severe, reducing feelings of vulnerability. Taylor, Kemeny, Aspinwall, Schneider, Rodriguez, and Herbert (1992) studied the relationship between optimism, coping, and psychological distress and risk behaviour in people at risk of developing Acquired Immunodeficiency Syndrome (AIDS). They found that optimism was related to less distress and avoidant coping, fewer health concerns, and the use of positive attitudes as a means of coping. Moreover, optimism was unrelated to risk behaviour, and the authors suggest it may be a psychologically adaptive way of coping. In a similar way, it may be that people with CF choose to be more optimistic about their health status, reducing psychological distress related to illness experience.

The results of Abbott et al. (1995) are similar to those of the present study, relating to infection risk. The Consultant Microbiologist interviewed for

this study indicated the level of infection risk presented in each of the vignettes and his view on whether this should be avoided by someone with CF. However, it is clear that the participants thought about factors other than risk to their health when making their decisions, and were often swayed by those relating to quality of life.

Awareness of infection risk has also been explored in studies of Human Immunodeficiency Virus (HIV). As HIV can be contracted through unprotected sexual contact, a number of studies have explored the factors involved in condom use. In serodiscordant couples, where one partner is HIV positive and one is HIV negative, engaging in unprotected sex has been found to be related to stage of disease, use of drugs and alcohol, and psychological distress (Skurnick, Abrams, Kennedy, Valentine, & Cordell, 1998); CD4 count (a measure of disease severity), age, and length of relationship (Milam, Richardson, Espinoza, & Stoyanoff, 2006); and sensation-seeking and negative beliefs about condom use (Israel, Romeis, & Spitz, 2005). The findings of Skurnick et al. (1998) and Milam et al. (2006) indicate that an assessment of risk is made in deciding whether or not to have unprotected sex, with disease severity influencing the decision. This may be related to beliefs about the risk of infection transmission, as antiretroviral treatment for HIV can reduce an individual's plasma viral load. This reduces, but does not eliminate, the relative risk of viral transmission (Spire, de Zoysa, & Himmich, 2008). Where individuals believe they are healthier, it would seem that they are more likely to have unprotected sexual contact (Milam et al., 2006). A similar assessment may have been made by

the individuals with CF in this study. Where there was little experience of infections or limited understanding of the potential impact of infection, it appeared participants were less likely to consider infection risk or to give it significant weight when making lifestyle choices in the vignette task.

Role of Parents and Healthcare Professionals. Evident in the results of this study is a lack of awareness of the relative risk of infection in certain situations. Some participants in this sample considered the advice and support given by their parents in their decision making. If this is to be a useful strategy, parents must feel equipped with the knowledge and resources to ensure young people are given appropriate and accurate information. Ullrich, Wiedau, Schulz, and Steinkamp (2008) evaluated parental knowledge of PsA and the behaviours taken to prevent their child acquiring this infection. They found very few parents had a good level of knowledge of PsA, with misconceptions including over-estimating the virulence of the bacteria, and believing that home-based measures to improve hygiene could significantly affect the level of risk presented. It is also of note that almost one third of participants were dissatisfied with the information provided by healthcare professionals, suggesting more precise and elaborate information about PsA, actively offered by staff, would be beneficial. This study also found that infection risk prevention recommendations of CF physicians differed from the parental recall of these recommendations. The authors suggest that this may be related to parental bias and whether the recommendations are achievable. Finally, the study indicated some level of parental stress surrounding the acquisition of the

infection, though those who reported less stress were significantly more likely to have a good level of knowledge of the bacteria and to perform fewer home-based hygiene measures.

Similar to the present study, Ullrich et al. (2008) indicate a lack of knowledge and understanding about the bacteria and infection. They suggest that parents should be presented with accurate information, which explicitly states the physicians' recommendations. They also suggest that differences of opinion between physicians regarding the risk of infection in certain situations and the need for hygiene precautions should be explained to parents. Importantly, if parents are responsible for relaying this information to their children, it is crucial that they are well informed and do not pass on misconceptions. Moreover, the Consultant Microbiologist in this study acknowledged the difficulty in providing people with CF with an exact measure of the level of risk from infections, due to a lack of sufficient research in this area. If information from microbiology on relative risk was available, and if relayed clearly to patients and their families, it would enable a more accurate evaluation of risk when making lifestyle choices. Further exploration of the risk of infection in certain environments is required from a microbiology perspective.

Strengths and Limitations

Use of Vignettes

As noted in the introduction to this research, vignettes have frequently been used to assess decision making in healthcare professionals. However, this author has been unable to identify the use of this methodology with groups of patients. The vignette task offered an original and unique way in which to assess decision making in this group of young people. It was clear from the results that they were able to use the think-aloud technique to articulate their thoughts whilst making the decisions, and to treat these scenarios as if they were real. Whilst care was taken to ensure all thoughts surrounding the decision were articulated, it is possible that some factors were omitted by participants. The researcher also made efforts to ensure participants felt able to make decisions honestly, noting that interviews would be anonymised and treatment would be unaffected by participating. As the researcher was not part of the CF team from which the participants were recruited, some distance from healthcare professionals involved in patient care was achieved. Participants appeared to answer honestly, with some deciding to take risks even when they acknowledged that they knew these were present. It therefore seems unlikely that they were providing the researcher with answers that they thought the researcher would like to hear, perhaps reflecting social desirability, though this cannot be ruled out entirely.

Sample

Participants were recruited from one adult CF clinic. They therefore had similar experiences of clinic visits and inpatient admissions, as well as a

similar knowledge of infection risk. It may be that participants from another area would respond differently to these vignettes, if their experiences are markedly different. However, given the qualitative nature of this study and the common themes emerging from the group of participants, it may be possible to generalise the results to other people with CF attending this clinic. The nature of volunteer participants is often considered as potentially influencing the results. However, to avoid priming participants, the issue of infection risk was not raised when explaining the study prior to taking consent. It is therefore unlikely that individual factors affected the outcome of this study.

Recruitment Bias

It is important to note the difficulties recruiting participants for this study. The feedback received from patients indicated a high level of research had been conducted with this population in recent times. Many were therefore reluctant to engage in another research project. It would have been interesting to explore whether there were any differences between the small number of patients who chose to participate and those who did not wish to be involved in the project.

Other Variables

This study focussed on the impact of CF on lifestyle decision making. However, it would be interesting to explore the impact of other variables on this process. Gender, other co-morbid health problems, reduced lung function, transplantation, and having another family member with CF could all potentially impact on the decision making process. These factors were

not explicitly assessed in this study, given the size of the project. However, it would be interesting to explore whether these factors affect the weighting given to infection risk for young people. For instance, it may be that having a sibling with CF could alter the way in which individuals perceive the risk of cross-infection from other people with CF. Further research is required to explore this.

Telephone Interviews

The interviews for this study were all carried out via telephone. This reduced the risk of infection to the participants, as they were not required to have a face-to-face meeting with the researcher, or attend an additional hospital appointment. Moreover, it allowed the participants to arrange interviews at times convenient to them, in a setting in which they were comfortable. The researcher took care to verbally check that participants remained comfortable throughout the interviews, and participants were provided with the researcher's contact details, should they have any questions. This might be viewed as a particular strength of this study, as it gave appropriate consideration to the needs of the participants, whilst modelling an assessment of infection risk.

Assessment of Knowledge of Infections and Infection Risk

A limitation of this study is that it did not directly assess individuals' level of knowledge and understanding of infections and infection risk. This was not part of the methodology as it did not form part of the research question. However, the results indicate that this sample have limited understanding in this area, and an assessment of this would be valuable.

Moreover, further research is required to explore how young people access information on this topic. As noted in the interview with the Consultant Microbiologist, it is not clear whether young people are given information via their parents. If this were the case, it would be important to evaluate how this information is relayed, and whether parents choose to censor this in any way. This is particularly important in establishing clear, unambiguous advice and providing an accurate knowledge base of infections and risk, to support young people in the balancing process during lifestyle decision making.

Future Research

In the current study decision making involves a process of balancing any perceived risks to health with issues relating to quality of life. The young people in this sample appeared to lack the appropriate level of understanding of health risks to make an informed choice. It would be interesting to replicate this research with samples from other areas, or following a period of education. This would allow an evaluation of the process of lifestyle decision making where individuals may have a greater awareness of the health risks presented and are in a position to make an informed choice. It would be interesting to assess the process of balance and whether infection risk is weighted differently where there is greater understanding. Moreover, with a larger sample it would be useful to investigate the impact infection status has on decision making. This was not possible due to the sample size in the present study. However, this would allow an exploration of the relationship between decision making and disease severity.

Knowledge and Understanding

It would be useful for future research to explore the level of knowledge and understanding young people with CF have of their condition, infections, and infection risk. It would be important to consider how young people access this information, exploring whether this comes from parents/carers, healthcare professionals, or other sources. As there are guidelines available on CF and the common infections from the CF Trust, it might be interesting to evaluate how these are used by patients. These resources include brochures available on the Internet, offering guidance on avoiding infection,

as well as a helpline and online forums where people with CF, their partners, parents, and carers can share information. As noted earlier, Loeben et al. (1998) found a lack of consistency in the information presented in pamphlets about Cystic Fibrosis-screening. It is important to consider potential inconsistencies in the information accessed by people with CF, particularly the use of patient forums, and to assess any misconceptions or gaps in knowledge when they attend clinic appointments. This would allow healthcare professionals to provide accurate, relevant, clear information for people with CF and their families, reducing ambiguity and facilitating informed decision making.

Education and Support

It would also be valuable to explore the ways in which information on infections and risk could be conveyed to young people with CF. The results of the current study indicate some difficulty in following healthcare advice where the understanding of this was limited. It may be interesting to evaluate alternative means of providing information to this patient group, with specific reference to the impact this has on decision making. An example of this might be the use of Motivational Interviewing as a means of providing information and discussing behavioural change. Motivational Interviewing has been found to be 80% more successful than traditional advice-giving in improving adherence to treatment in a number of areas (Rollnick, Butler, Kinnersley, Gregory, & Mash, 2010). It would be interesting to explore this technique as a means of increasing knowledge and understanding with this

patient group, and evaluate the impact this has on decision making or adherence to infection prevention recommendations.

In addition to education, this study identified the need for support in lifestyle and career decision making. Young people are expected and encouraged to make lifestyle choices and plans for their future. However, it appears that the decision making process involves the need to balance quality of life with health. This is a difficult process, and it may be beneficial for young people to feel supported when making choices. Miller (2001) explored the factors paediatric nurses view as important in assisting young people to make decisions relating to their treatment and care. A focus group highlighted the importance of knowledge of the individual child and the context, the need to provide the young person with information that is suitable for their age and stage of development, and the need to consider ethical, professional, and legal factors. The author emphasises the need to provide young people with support when they are making decisions relating to treatment. Similar factors may prove useful in assisting young people with CF to make lifestyle and career choices. For instance, it is important to provide unambiguous information, in a way that is easy for the young person to understand. As previously discussed, this will allow them to appropriately weight risk factors when making decisions, and could help to develop an external locus of control for decisions involving infection risk. In line with the recommendations set out by Miller (2001), alongside this information-sharing, healthcare professionals could consider the individual support needs of the young person, and the context in which they are making

decisions. An example of this might be supporting a young person to use infection risk information when planning a holiday with friends or planning a career in a healthcare setting. Crucially, information should not be given in the absence of appropriate support, as it can be complex and difficult to interpret.

Quality of Life

The importance of a good quality of life was emphasised by participants in this study. As previously noted, it was important for participants to find a balance between fully living their life and looking after their health. It is recognised that quality of life outcomes are related to illness perceptions (Staab et al., 1998), disease severity (Gee, Abbott, Conway, Etherington, & Webb, 2003), coping style (Abbott, Dodd, Gee, & Webb, 2001), and to some extent survival (Abbott, Hart, Morton, Dey, Conway, & Webb, 2009). Although the present study did not assess quality of life directly, it would be interesting to assess the importance of quality of life in lifestyle decision making in higher risk situations.

Relationship with Coping

This study did not explore the relationship between risk-taking behaviours and the individuals' perception of the severity of their illness or style of coping. Abbott et al. (2001) examined the relationship between treatment adherence and coping style. This study found non-adherence in physiotherapy and enzyme therapy was related to an avoidant coping style, with partial adherence related to distraction strategies, and adherence related to optimistic acceptance and hopefulness. This is similar to the

findings of Abbott et al. (1996), suggesting people with CF may choose to avoid particular treatment behaviours as they are a reminder of their illness. In the present study, it appeared that avoidance and distraction strategies were employed as a means of achieving a good quality of life. Young people in this sample often commented on the importance of feeling part of their peer group. Where a situation might have presented more risk to someone with CF, participants often chose to engage in the activity, focussing on the personal or social benefits. In addition, participants often said they would not think about CF in making certain decisions. In the study by Abbott et al. (2001) these avoidant coping strategies were associated with non-adherence to certain aspects of treatment, although not with exercise. Indeed, avoidance was associated with adherence to exercise regimens. The authors suggest this may be because exercise is perceived as different to other aspects of treatment, as an activity in which young people without CF may engage in. It is possible that adherence to advice on avoiding infection risk would be related to optimistic coping, which focusses on the perceived benefits of treatment and following healthcare professional advice. However, further investigation is required.

Parental Understanding of CF and Infections

It is not clear from this study whether parents have held a central role in the provision of infection risk information. If parents are responsible for relaying information about risk to young people with CF, it is important to directly assess their understanding. This would allow identification of any gaps in knowledge or misconceptions held by parents, as well as how they

can be involved in supporting young people to make informed choices. The study by Ullrich et al. (2008) indicates limited knowledge and understanding of the PsA bacterium in parents of children with CF. This may prevent appropriate measures being taken to reduce risk, or place parents under undue stress in the efforts to try to prevent infection. Griffiths, Armstrong, Carzino, and Robinson (2004) highlight the support from patients and families for segregation measures to prevent cross-infection from PsA, suggesting a desire to follow advice and take measures to prevent contamination. It is important to explore this issue further to allow parents and carers to provide the appropriate support.

Clinical Implications

There are a number of clinical implications of this research. The research was carried out at the request of staff within a paediatric and adult CF service, with a view to supporting young people to make decisions about their lifestyle and career.

Knowledge and Understanding

The young people in this study indicated a substantial gap in knowledge and understanding of infection risk and their own infection status. None of the participants could provide a definition of Bcc, and many found it difficult to accurately describe their current Bcc or PsA infection status. The interview with the Consultant Microbiologist raised the issue of how information about infection risk is given to young people. As all participants in this sample were taken from the adult CF clinic, it would be interesting to know how or if their knowledge and understanding of CF and infections was assessed upon transfer from the paediatric service. It may be that a certain level of understanding is assumed on transfer from one service to another, and given the present findings this may be to the detriment of individual patients. It may therefore be useful to assess the level of understanding in young people in the paediatric service and those entering the adult service. This would allow healthcare professionals to counter any misconceptions, as well as providing clear information and advice of higher risk situations. Moreover, important risk information given to parents should also be articulated to the young people themselves, to ensure they are equipped to

make informed lifestyle choices and parents are not solely responsible for relaying this information.

It might also be beneficial to provide people with CF with up to date information about their health and infection status. Participants in this study were recruited from Leeds Teaching Hospitals NHS Trust. Within this Trust, other areas of physical health such as the adult congenital heart disease service, provide patient held records. These records contain up to date information about the patient's physical health in the form of clinic letters, as well as information leaflets. In an unpublished review of these records, this author surveyed patients who were given this folder. A total of 29 out of a possible 99 patients responded to a questionnaire assessing use of the folder. The information leaflets held within the folder were referred to by 78% of respondents for personal use, and 67% made use of their clinic letters. It was evident that patients valued the records, although they suggested that these should be tailored to meet the individual needs of the patient. If patient held records were considered for patients with CF, this could provide them with sufficient information about their condition and their current infection status, encouraging informed decision making.

Involvement of Microbiology

It was clear from the interview with the Consultant Microbiologist that further research is required to gain a greater understanding of the risk of contracting particular infections in specific environments. This interview revealed that there is limited understanding of the infective dose of specific micro-organisms required to cause illness in a person with CF. Further

research in this area could provide clinicians with a clearer understanding of the relative risk for people with CF, and allow them to give clear advice on particular lifestyle choices. It was evident from this study that participants were often unclear as to the risk of engaging in certain activities. More detailed research from a microbiology perspective might provide greater insight into the level of risk presented by bacteria such as PsA and Bcc.

In addition, it might be useful to involve microbiologists more directly in the care and education of people with CF and their families. Masterson et al. (2008) found that only 15% of patients in their sample reported an explicit recommendation to avoid other people with CF, from healthcare professionals. Whilst this result may be a product of the sample selected, in the present study participants' knowledge of infections and infection risk suggests a lack of education. Within a multidisciplinary team, microbiologists would be well placed to offer guidance on infection risk. They hold a detailed awareness of the subject and are aware of the current limitations of the research in the area. They would therefore be able to discuss potential risks with patients and their families with regard to best practice, whilst acknowledging any differing perspectives on infection risk.

Summary

This study indicates a significant difficulty in accurately assessing risk of infection in certain situations. Where participants attempted to make an assessment of risk to their health, they were often unable to do so as they lacked the information required to make an informed choice. However, it was clear that young people in this sample felt able to make lifestyle choices in an autonomous manner, unless they were aware of clear guidance from healthcare professionals. Where this was the case, external control beliefs were evident and appeared to influence decision-making. Moreover, the results indicate that young people with CF make lifestyle decisions in a similar manner to healthy young people, drawing on reasoned and reactionary processes of decision making. Finally, this study highlights the importance of quality of life in lifestyle choices, as participants emphasised the need for a balance between maintaining their health and living their life.

It is necessary to evaluate the level of illness knowledge and understanding of infections and infection risk within this population. This will allow an insight into the exact nature of the gaps in knowledge, as well as an assessment of the sources of information for this group. This would enable an intervention to ensure young people are equipped with available information on best practice guidelines and rationale for avoiding infection risk.

5. CONCLUSION

Through improvements in medical care, people with Cystic Fibrosis now live longer, healthier lives. Previously, career aspirations were not considered in CF research. However, young people are now encouraged to have careers, and engage in fulfilling lives. This study aimed to explore how young people make lifestyle and career choices, and whether their health or risk of infection affects the decisions they make. A vignette methodology was employed to access the process of decision making, and evaluate the factors that were important to young people when they made lifestyle decisions. The study found that young people with CF had a limited and ambiguous understanding of the risks of infection present in certain environments and of the bacteria that cause these infections. Importantly, they emphasised the role of the balancing process in making lifestyle decisions. Participants in this study often chose to engage in activities where there was a degree of risk, often referring to personal and social benefits to help them reach their decisions. It appears that a lack of understanding inhibits the ability to accurately weight infection risk in the process of decision making, when balancing this with factors that the young person has previously encountered and understands more clearly. It is therefore important that knowledge and understanding around infection and risk is addressed in this population. Whilst concise, unambiguous information about infections and infection risk should be made available to people with CF and their families in the CF clinic, they also need to be supported by healthcare professionals to use this information when making choices about their lifestyle and career. Clinically,

this could mean ensuring all patients are aware of their current infection status, and are supported to use this information in their decision making. It was evident that the young people in this sample were striving to lead a fulfilled life. It is important that they are supported in reaching informed choices about their future, so that it is as healthy and happy as possible.

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APPENDIX 1

Leeds (East) Research Ethics Committee

Room 5.2, Clinical Sciences Building
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Beckett Street
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LS9 7TF

Telephone: 0113 2065652
Facsimile: 0113 2066772

09 September 2009

Ms Lisa M Brash
Trainee Clinical Psychologist
Leeds Teaching Hospitals NHS Trust
Clinical Psychology Doctoral Program
University of Leeds
101 Clarendon Road
Woodhouse
Leeds
LS2 9LJ

Dear Ms Brash

Study Title: An exploration of the factors involved in lifestyle decisions in young people with Cystic Fibrosis using decision making vignettes, and the role of perceived risk of infection.

REC reference number: 09/H1306/67

Protocol number: 1

Thank you for your letter of 18 August 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
CV for Dr Gary Latchford		
Covering Letter		10 June 2009
Investigator CV		10 June 2009
REC application		10 June 2009
Protocol	1	10 June 2009
Interview Schedules/Topic Guides: Vignettes	1	10 June 2009
Compensation Arrangements		02 October 2008
Letter from Sponsor		11 June 2009
Peer Review: Research Panel Feedback		18 March 2009
Peer Review: Research Panel Constitution		10 June 2009
Information letter about the Trainee Clinical Psychology Research		
Participant Information Sheet	2	22 July 2009
Participant Consent Form	2	22 July 2009
Response to Request for Further Information		18 August 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H1306/67

**Please quote this number on all
correspondence**

Yours sincerely

Dr Carol Chu
Chair

Email: Amy.Beckitt@leedsth.nhs.uk

Enclosures: “After ethical review – guidance for researchers”
Copy to: Clare Skinner, University of Leeds

R&D Department, Leeds Teaching Hospitals NHS Trust

APPENDIX 2

The Leeds Teaching Hospitals 
NHS Trust



INFORMATION SHEET

22/07/09

Version 2

From: Lisa Brash
Psychologist in Clinical Training
Charles Thackrah Building
Clarendon Road
Leeds LS2 9LJ
07742075303

Study Title: An exploration of the decision-making process in young people with Cystic Fibrosis.

Names of Researcher: Lisa Brash, Psychologist in Clinical Training

The purpose of this information sheet is to invite you to take part in a study looking at the use of information about the risk of infection in making decisions about your lifestyle. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?

A number of studies have suggested that living with Cystic Fibrosis can significantly impact on an individual's daily life, leading to a variety of difficulties. However, there has been little research into the ways in which people with Cystic Fibrosis make decisions about their lifestyle. The aim of this study is to investigate the use of information about risk of infection in lifestyle decisions, such as leisure activities and hobbies.

Why have I been chosen?

As you have Cystic Fibrosis and attend St. James's University Hospital, you have been invited to participate in this study. We value your opinions on your Cystic fibrosis and the service you receive. A total of 30 participants are required for this study.

Do I have to take part?

You are completely free not to participate in this study and you are free to withdraw from the study at any time, without any explanation. If you do not wish to participate, your treatment will not be affected.

What will happen to me if I decide to take part?

If you agree to take part in this study, by **signing the consent form**, you will be asked to leave your contact details. A researcher will contact you at a later date to answer any questions you may have and ask if you would like to participate in an interview that will last approximately 30 minutes at a time that is convenient to you. *In order to avoid any additional infection risk, the interview will be conducted over the telephone. There will be an opportunity to discuss this with the researcher, and a face to face interview can be arranged if you wish.* The interview will be with the same researcher and will involve discussing the decisions you might make regarding a number of lifestyle choices. This will be followed by a small number of questions regarding your Cystic Fibrosis and the impact this has had on your decision making. *You may choose not to answer all of the questions. If you feel distressed following the interview, the researcher has the contact details of clinical psychologists who work with people who have Cystic Fibrosis, and can arrange for them to contact you if you wish.* Although the interview will be audio-recorded and transcribed, your name or any means of identifying you will not be recorded. *These audio recordings will be destroyed following transcription.* If you consent to be interviewed, the researcher will obtain information about your current respiratory health and pseudomonas infection status from your consultant. However, this information and the answers you give in the interview will be anonymised. *You may choose to have a family member or a friend with you during the interview.*

What are the possible benefits of taking part?

It is hoped that the information gained from this study will allow psychology to support staff in helping patients think about lifestyle and career choices.

Will my taking part be kept confidential?

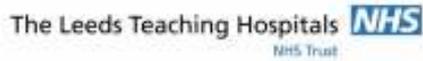
All information that is collected about you during the course of the research will be kept strictly confidential, *unless deemed important for your continuing care in which case it will be shared with your Cystic Fibrosis Consultant. An example would be sharing information about serious risk to yourself or someone else.* Any information about you, which leaves the hospital, will have your name and address removed so that you cannot be recognised from it. The information you give will not be passed on to the staff working in the clinic until all identifiable information has been removed.

What will happen to the results of the research study?

It is hoped that the results of this study will be published in a medical journal, as well presented as a thesis to the University of Leeds. Although extracts from interviews may be used in future publications, these will be anonymised and unidentifiable.

Thank you for taking the time to read this information sheet. If you would like additional information regarding this study, please contact me at the address above.

APPENDIX 3



Consent Form

From: Lisa Brash
Psychologist in Clinical Training
Charles Thackrah Building
Clarendon Road
Leeds LS2 9LJ
07742075303

22/07/2009

Version 2

Title of Project: An exploration of the decision-making process in young people with Cystic Fibrosis.

Name of Researchers: Lisa Brash, Psychologist in Clinical Training

Please initial

I confirm that I have read and understand the information sheet dated 01/05/09 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that any information, disclosed during the course of the research, will remain confidential unless deemed important for my continuing care in which case it will be shared with my Cystic Fibrosis Consultant.

I understand that relevant sections of my medical notes and data collected from the study may be looked at by the researcher or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I understand that the interview will be audio recorded and verbatim extracts from this interview may be used in future publications of the research. *Any extracts used would be anonymised.*

I agree to take part in the above study.

Name of Patient

Date

Signature

Name of Person taking Consent

Date

Signature

APPENDIX 4

Interview Script

Vignettes

- *Neutral.* Imagine that you are invited to a close relative's wedding at a hotel in town. Do you decide to go? What factors do you consider important in making this decision?
 - You find out there will be over 100 people at the reception. Does this affect your decision?
- *Holidays.* Imagine you are on holiday with friends. You are staying in a complex with a large swimming pool. Your friends want to go swimming. Do you go with them? What factors are important in making this decision?
 - Your friends decide they want to use the Jacuzzi next to the swimming pool. Would you join them in the Jacuzzi? What factors would be important to you in making this decision?
- *Camping.* Imagine your friends want you to go with them for a weekend camping at a big camp site. Would you go along with them? What factors would be important to you in making this decision?
 - You find out that the camp site has communal toilet and showering facilities. Would this affect your decision? What would you think about in this situation?
- *Horse Riding.* Imagine that you are single and someone you are really attracted to works on a farm with horses. They invite you to go horse riding with them. Would you go? What would be important to you in making this decision?
 - They then ask if you would like to spend time with them on the farm, where they feed and clean the animals. What would you do? What would be important to you in making this decision?

- *Meeting someone with CF.* Imagine that you meet someone on Facebook who has CF, and you really hit it off. After a few weeks they ask you if you would like to meet for a coffee. What would you do? What factors would you think about in making this decision?
 - [If they decide to meet the person] Imagine that before you go to meet them, they send you a message telling you that they have chronic pseudomonas [if the participant is free from infection] / are free from pseudomonas infection [if the patient has intermittent / chronic pseudomonas.] What would you do? Does this information alter your previous decision? If so, what factors were important to the decision?
 - [If they still decide to meet the person] Imagine that you go to meet the person for a coffee and you get on really well. You arrange to meet again, and on your way out of the coffee shop it starts to rain. As it is raining and you both travelled by train, your new friend offers to share a taxi with you to the train station. What would you do? What would be important to you in making this decision?
- *Visiting a friend in hospital.* Imagine that you decide to go to the hospital to visit your best friend, who doesn't have CF. When you arrive at the hospital, you are told that some of the patients on the ward have MRSA, but that your friend does not. What would you do? What factors are important in making this decision?
 - The next week, you decide to visit your friend again. This time, when you arrive, you are told to wash your hands and put on an apron and gloves as your friend has MRSA. What would you do? What did you think about in making this decision?
 - Have you heard of MRSA? Could you tell me what you know about it?

- *Visiting a relative in a nursing home.* Imagine that you have an elderly relative that you have always been close to, who has recently been moved to a nursing home. Would you go to visit them? What factors were important in making this decision?

Questions

- I wonder if you could tell me about about career choices you have made or your plans for the future?
 - Are you in employment at the moment, or have you been in the past? What factors were important for you in deciding what to do as a career?
 - What are you currently studying or planning to study? What was important for you in deciding to do this?
- I wondered if you could tell me how important you think it is to consider infection risk when you make lifestyle and career choices?
- I was also wondering to what extent your parents might have influenced past and present lifestyle or career choices?
- Could you describe your current psuedomonas and cepacia infection status?
- Have you always been aware of segregation in clinics for these infections?