

THE UNIVERSITY OF HULL

**The Psychosocial Impact of Segregation
in Cystic Fibrosis:
A Phenomenological Study**

This thesis is submitted to the University of Hull in fulfilment of the
requirements for the degree of Psy D

by

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Abstract

Background. Segregation, a procedure where people with Cystic Fibrosis (CF) are restricted or discouraged from social mixing, is used increasingly to prevent cross-infection in CF Centres. However, research is sparse about the impact of segregation, particularly the potential negative psychosocial impact, on young people with CF.

Objectives. To gain an in-depth understanding about the experience of hospitalisation under segregation and its impact from the perspective of the young person with CF.

Method. In-depth interviews were conducted with 14 young people with CF aged 7 to 17 years at the end of their two-week admission for IV antibiotics. Interpretative Phenomenological Analysis (IPA) was used to analyse transcribed interviews.

Results. The young people could be categorised into two groups in terms of their experiential history of hospitalisation. Segregation was *‘protective, and better than expected’* for relatively ‘inexperienced’ participants; whereas it was deemed to be *‘restrictive, and led to a difficult stay’* by ‘experienced’ participants. Three common themes appeared to characterise the views of all participants regarding the issue of cross-infection: *‘wanting to reduce the risk’*, *‘the importance of contact with similar others’* and *‘difficult choices’*. A range of coping strategies were discernible from the data with the main connecting theme regarding coping as *‘being resilient’*.

Discussion. The themes emanating from the data are discussed in terms of Lazarus and Folkman’s Transactional Model of Stress and Coping and the concept of peer support. The results suggest that there may be four ways in which segregation impacts negatively upon young people with CF in terms of: (1) anxiety about bacterial infection, (2) loss of CF peers, (3) learning to cope with limited social contact during hospitalisation, and (4) fragmentation of the CF community. The findings are discussed in relation to existing research and in terms of their clinical implications.

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CHAPTER 1

Cystic fibrosis is the most common genetically inherited disease in the UK, with approximately 8000 children and adolescents being affected (Cystic Fibrosis Trust UK [CF Trust], Standards of Care Working Group, in press). As infection with specific bacteria can reduce the life expectancy of people with CF, preventing bacterial infection has become increasingly important. One method of doing this is by using segregation to discourage young people with CF from mixing. However, there are concerns about the psychosocial impact of segregation. Ensuring young people with CF cope well with their disease and treatment is important, as poor psychosocial functioning has been associated with deterioration in health and poorer outcome (Thompson, Gustafson, George & Spock, 1994). Furthermore, segregation relies upon patient adherence in order to prevent the spread of bacteria. As young children may be unable to consider the long term implications of early bacterial colonisation, it is important that their health is protected during hospital admissions. This thesis aims to describe the practice of segregation as experienced by young people with CF during a period of hospitalisation in a Specialist Paediatric CF Centre.

This chapter presents an overview of the disease of CF and the role that bacterial infection plays in the disease. Current issues and controversies regarding the use of segregation are outlined, together with expert and patient views about segregation. Next, an overview of coping with CF and hospitalisation is presented, including a systematically conducted review of research about the paediatric patient experience of hospitalisation in isolation. Finally, relevant theoretical models and concepts are presented with the aim of providing a framework to guide our

understanding of the psychosocial impact of cross-infection measures in young people with CF.

1. CYSTIC FIBROSIS – AN OVERVIEW

What is CF?

Cystic Fibrosis (CF) is a life-limiting genetic condition, with a carrier rate of 1 in 25, and an incidence of 1 in 2500 births in the UK (Dodge et al., 1997). Difficulties with salt and water transfer within cell membranes result in the production of excessively thick mucous in the gastrointestinal, respiratory, hepatic, and reproductive systems (Hodson, Bush, & Geddes, 2007). The increased mucous or secretions in the lungs lead to the growth of bacteria, and in turn, to chronic inflammation. In addition, secretions in the pancreas block the release of digestive enzymes, contributing to malabsorption and nutritional compromise. As a result, people with CF have recurrent lung infections, are underweight, are usually smaller than their healthy peers and often experience delayed puberty. Many people have CF-related complications, such as diabetes, liver disease, and arthritis which require additional care (Stark, Mackner, Patton, Acton & Roberts, 2003).

One of the defining features of CF is recurrent bacterial infections of the lungs, leading to ‘exacerbations’, or periods of excess mucous production, cough, and tiredness. Each exacerbation results in damage to the lung tissue. Premature death is caused by respiratory failure as a result of this repeated damage (Emerson, Rosenfeld, McNamara, Ramsey & Gibson, 2002).

There is currently no cure for CF - treatment is palliative and aimed at relieving symptoms and enhancing patient quality of life. In the UK in the early nineties, 50% of those with CF survived to age 20, and 25% of those with CF

survived to the age of 30 (Coyne, 1997). The availability of CF Specialist Centres with multidisciplinary CF teams, and increasing awareness of transmissibility of bacteria have ensured that survival is increasing (Mahadeva et al., 1998; Taylor, Gaya & Hodson, 1993). Infants born with CF today can now expect to live into their 30s and beyond (Davis, 2006).

Treatments for People With CF

People with CF require a complex daily program of treatment which aims to address the many symptoms of the disease. Following the treatment protocol is time consuming, often without immediate gain, and difficult for young people and carers to undertake (Sanders, Gravestock, Wanstall & Dunne, 1991). Pancreatic enzymes are taken with all meals and snacks in order to facilitate the digestion of food from a high fat, high calorie diet. Vitamins and additional nutritional supplements are required, and in more severe cases, nasogastric (NG)¹ or peri-epigastric (PEG) feeding² is used. Chest physiotherapy³ is required several times per day to remove the sticky mucous which coats the lungs. Inhaled nebulisers⁴ facilitate this by reducing the viscosity of the mucous. Inhaled and oral antibiotics are used to minimise the growth of bacteria and to prevent exacerbations. During acute exacerbations, intravenous (IV) antibiotics are used over a period of two weeks to target the bacteria in the lungs in a concentrated manner (Kerem, Conway, Elborn & Heijerman, 2005).

Lung transplantation offers some hope for those with severe disease, although sadly the number of donors is low in the UK, particularly for children. Consequently many people with severe disease die waiting for transplantation (Keller, 1998).

¹ a reusable plastic tube that is inserted via the nose into the stomach in order to deliver liquid nutrition

² a permanent tube inserted directly into the stomach which is used to provide liquid nutrition

³ percussions on the chest in order to loosen and remove sticky mucous

⁴ treatments that are delivered directly to the lung tissue in order to loosen mucous or fight infection

However, with the discovery of the CF gene in 1989 (Davis, 2006), there are hopes that a cure for CF will be found.

Bacteria Associated With CF

A range of bacteria are found in the lungs of people with CF. The most common bacteria affecting people with CF is *Pseudomonas aeruginosa* (Banerjee & Stableforth, 2000), which is estimated to affect 80% of the UK adult CF population (CF Trust Infection Control Group, 2004a). *Pseudomonas* is acquired through environmental sources such as water and soil, by intimate contact with others with *pseudomonas*, or through lack of routine infection control or contaminated equipment (Geddes, 2001). Once *pseudomonas* appears in the lungs, usually in adolescence, it quickly colonises and becomes almost impossible to eradicate (Banerjee & Stableforth, 2000).

Other commonly occurring bacteria include *Staphylococcus aureus*, and a more virulent strain of these bacteria called *Methicillin-resistant staphylococcus aureus* (MRSA). One less frequent but dangerous bacteria is *Burkholderia cepacia complex* (*cepacia*), an organism that is naturally occurring in onion rot and soil. *Cepacia* is of particular concern as this organism can spread rapidly through airborne particles, and survives on surfaces longer than other bacteria.

The Importance of Infection Control

In the past, young people with CF mixed freely together and were encouraged to attend camps and group educational activities. This changed with the rapid spread of *cepacia* across America and Europe in the eighties, leading to the death of many patients (Festini et al., 2006). This highlighted the importance of a long term strategy

to minimise ‘cross-infection’, that is, the spread of bacteria from person to person. Colonisation with *cepacia* is known to reduce survival by up to 50% (Govan, 1999).

In a similar vein, the damage done by repeated exacerbations from *pseudomonas* is the major cause of mortality in CF (Emerson, Rosenfeld, McNamara, Ramsey & Gibson, 2002). The age of onset of chronic infection with *pseudomonas* has been negatively associated with life expectancy (Koch, 2002). People with CF who are *pseudomonas-free* require significantly fewer treatment sessions and hospital days, have better lung function, and a higher quality of life (Lebecque et al., 2006). Consequently, increasing emphasis is being placed upon the prevention of *pseudomonas* colonisation, to ensure that people with CF maintain a good quality of life and can benefit from interventions in the future (Hoiby, 2000). To achieve this, increasingly restrictive infection control measures are being adopted in CF Centres (Kerem, Conway, Elborn & Heijerman, 2005; Saiman et al., 2000).

Section Summary

Along with the challenges of living with a life-limiting condition and time consuming daily preventive treatment regimes, people with CF face the new challenge of the need to prevent bacterial infection from the environment and cross-infection from other people with CF. The next section will explore the use of segregation in specialist CF Centres.

2. THE USE OF SEGREGATION TO PREVENT CROSS INFECTION

What is Segregation?

Segregation refers to the practice of grouping patients according to infection status. Different types of segregation are used (see Table 1), although the term ‘segregation’

is not clearly defined in the literature despite it now being commonly used. The most common form of segregation is referred to as ‘cohort segregation’ (Davies, McShane, Davies & Bush, 2003) and describes the practice where those with one type of bacteria can mix together, but only with others who share the same bacteria. Another variation of segregation describes the practice of patients being treated in individual rooms in a CF ward and unable to mix with other patients with CF. It is this type of segregation that is the focus of this study and, hereafter, referred to as ‘segregation’. Finally, a much stricter form of segregation is used to manage those with *cepacia* and *MRSA*, and involve patients with these infections being treated in their own room away from the CF ward (referred to as ‘isolation’).

Table 1. Types of Segregation Used in CF Centres

‘Cohort segregation’	Patients use single room accommodation within the CF ward, and can mix in communal areas only with other CF patients who share the same bacteria. Used now in most CF Centres in the UK
‘Segregation’	Patients use single room accommodation within the CF ward, but cannot use communal areas and are not able to mix with any other CF patient. As introduced to the study CF Centre
‘Isolation’	Patients use single room accommodation away from the CF ward, and are unable to mix with any other CF patient regardless of bacteria. Used for those with <i>MRSA</i> or <i>cepacia</i> .

Note: These terms are not used universally in the literature, although there is consensus on the use of the term ‘cohort segregation’

Patients with CF who experience segregation may receive unrestricted visiting from their families, friends, teachers and hospital staff. Thus, the segregation experience is not one of isolation per se. Patients are able to receive visitors from others including their school friends and teachers. This is because the bacteria that people with CF

harbour in their lungs do not cause harm to others without CF as they cannot colonise in healthy lungs. However, all visitors are required to wash their hands upon entering and leaving a patients' room in order to minimise the transmission of bacteria in the hospital environment.

Evidence of Cross Infection and the Need for Segregation

There is overwhelming evidence of cross-infection of *cepacia* (Govan et al., 1993) and the isolation of patients with these bacteria has been recommended by the UK CF Trust since the early 90s (CF Trust Infection Control Group, 1994b). This reduced the prevalence of these bacteria within the CF population to a current low prevalence of 3% within the UK (Jones, Dodd & Webb, 2001; Muhdi, et al., 1996; Zuckerman & Seder, 2007).

The evidence regarding cross-infection of *pseudomonas* has been more mixed, with some earlier studies reporting little evidence of cross-infection of *pseudomonas* within their UK CF Centres (Tubbs et al., 2001). This research, in addition to reluctance to prevent people with CF from mixing, resulted in variations in practice across much of the UK. However, with more up-to-date methods for identifying strains of bacteria there is now overwhelming evidence that cross-infection of *pseudomonas* has been occurring in many CF Centres (Edenborough et al., 2004; Zuckerman & Seder, 2007). Furthermore, the effectiveness of 30 years of cohort segregation has been shown in Denmark, where the prevalence of *pseudomonas* is low and life expectancy is higher than in the UK (Frederiksen, Koch & Hoiby, 1999).

There is now general agreement that reducing the onset of *pseudomonas* colonisation is one of the main challenges of CF care, and segregation is now

recommended by the UK CF Trust as one of the key strategies that should be adopted by all specialist CF Centres in order to meet this challenge (CF Trust Standards of Care Working Group, in press).

Problems Associated With Cohort Segregation

Cohort segregation has now been introduced to most CF Centres within the UK in an attempt to minimise the risk of cross-infection, with fewer CF Centres introducing segregation (as outlined in Table 1). Although cohort segregation allows young people with the same bacteria to mix thereby minimising the psychosocial impact, there are ethical and practical problems related to this practice. For example, there is the need for up-to-date accurate bacteriological surveillance⁵ of all patients and rapid detection and re-organisation of cohorts according to latest infection status – many CF Centres simply do not have the resources and funding to undertake this (Saiman & Siegel, 2004). Furthermore, children may become confused at changing cohorts which often disrupt friendships and can lead to low adherence to segregation (Russo, 2003). Cohort segregation also raises privacy concerns as people have to be aware of the infection status of others. This may increase the potential for those in some cohorts to become ‘microbial lepers’ (Duff, 2002). Finally, although most people with CF who colonise *pseudomonas* harbour their own unique strain, there is increasing concern about the development of ‘super-strains’ that are resistant to antibiotics, and are associated with increased treatment requirements and poorer outcome (Edenborough et al., 2004). For all these reasons, patients at some CF Centres are now advised not to mix with others even of the same ‘cohort’ (e.g. see Appendix 1 for details of the segregation policy at the study CF Centre). As the

⁵ microbiological technique of examining sputum cultures in order to determine bacterial growth

future population of young people with CF will grow up without the contact and support of other people with CF, it is important that professionals attempt to identify the likely impact of this practice.

How Does Segregation Impact Upon Young People With CF?

Research on the psychosocial impact of segregation and cross-infection measures has not received sufficient attention. The practical and ethical difficulties as outlined in the previous section have led some professionals to argue that the ‘costs’ of segregation may outweigh any benefit from minimizing cross-infection (Govan et al., 1993; Geddes, 2001). Many professionals believe that it is likely that segregation will have a negative psychosocial impact upon young people, families, and the CF community. However, the nature and extent of any impact is unclear (Saiman & Siegel, 2004). Existing literature on this topic is reviewed below.

Psychosocial Impact of Segregation

Despite isolation being used for people with CF with *cepacia* and *MRSA* for over ten years, little empirical research has been published on the psychosocial impact of these infections. Duff (2002) used existing literature on adults who are isolated within the hospital setting to highlight the possible psychosocial impact of segregation upon CF patients with *cepacia*, including feelings of isolation, loneliness, and stigma. More recently, Waine, Wighthouse and Honeybourne (2007) used a questionnaire survey to find that 35% of adults with CF reported mixing with other CF patients during admissions to hospital, and 21% mixed in the community despite medical advice to minimise contact. They also reported this sample of adults had poor knowledge of the risks and consequences of cross-infection with *pseudomonas*,

cepacia and *MRSA*, with many incorrectly reporting *MRSA* as the bacteria they most wished to avoid. Participants also reported that minimising contact with others with CF would not significantly impact upon their quality of life. The authors conclude that more education on the risks of cross-infection was required. Lowton and Gabe (2006) undertook interviews with 31 adults with CF to determine the impact of the risk of *cepacia* upon the CF community. The authors concluded that fear of contracting *cepacia* had resulted in individuals avoiding the hospital setting, and had dispersed the central CF community into smaller groups of individuals. Perceived membership of the CF community depended upon an individuals' health state and contact with the hospital.

Only two studies have explored the psychosocial impact of segregation and cross-infection in paediatric populations, and both studies focus upon the carer perspective. A survey of parents and young patients in an Australian CF Centre one year following the introduction of segregation found that families were concerned about the loss of social contact with others with CF and expressed feelings of alienation (Griffiths, Armstrong, Carzino, & Robinson, 2004). In Germany, the introduction of segregation approximately ten years ago raised awareness of *pseudomonas* amongst young people and families, which then led to high levels of anxiety about contracting *pseudomonas* from the environment. Ullrich, Wiedau-Gors, Steinkamp, Bartig, Schulz, and Freihorst. (2002) found that this high anxiety led carers to engage in preventive and restrictive behaviours in order to prevent the acquisition of *pseudomonas*. Carer's anxiety was identified on a continuum of 'bacterium focused', where carers were concerned about the high risk of bacteria in the environment; 'child focused' where parents would balance their fears of infection with expectations of quality of life; and an interactional focus, where carers engaged

in balancing between these two opposing viewpoints. To date, no research has been published on the impact of segregation upon young people with CF.

The User Perspective of Segregation

Research on the views of young people with CF and their families regarding segregated treatment and care is also sparse. Only two published studies to date have explored patient and parent satisfaction with in-patient segregated care. Firstly, Griffiths, Armstrong, Carzino and Robinson (2004) surveyed parents and young patients two years following the introduction of cohort segregation to their Australian clinic and found that the majority of parents (84%) and children over 12 years (64%) reported support for the new policy. However, parents expressed concerns about the emotional impact of their child not socialising with others with CF, feelings of alienation, and confusion regarding the inconclusive evidence of cross-infection. This study was conducted some time after the implementation of segregation, and the focus of concern was on 'satisfaction with' rather than involvement or any attempts to understand the impact of segregation or how young people and carers attempted to manage the changes.

Secondly, a user involvement initiative was undertaken prior to the introduction of segregation in a UK Paediatric CF Centre in order to determine level of support for segregation (Russo, Donnelly & Reid, 2006). Questionnaires were sent to all carers and young people with CF aged over 10 years to obtain their views of the proposed policy, to determine the level of support and to identify potential difficulties and solutions. This study identified overwhelming support (91%) from carers to introduce segregation and strong support (92%) from young people aged over 10 years. As in the Ullrich et al. (2002) study, carers highlighted the balancing act

required between recognising the pros (reduction in risk) versus cons (social isolation) of segregation, but all ultimately felt that the physical health of their child was paramount. Young people were mostly concerned about boredom during their hospital stay. However, the response rate was low (43% and 23% from carers and young people respectively), and there was a response bias towards families of younger children, that is, those without *pseudomonas* who are not regularly admitted to hospital.

Several published abstracts from conference proceedings have also highlighted that carers support and indeed welcome segregation (e.g. Dawson, Prasad, Sheehan, Bryon & Dinwiddie, 2004; McDonald, Belessis, Dixon & Morton, 2005), although miss contact with other families with CF (Dawson et al., 2004). In one large unpublished study by Walters and Warren (2001), a cross-sectional postal survey was undertaken of all adults with CF registered with the UK CF Trust regarding views about cross-infection. A response rate of 55% (n = 1245) was achieved. This survey showed that 53% of adults who responded were worried or very worried about cross-infection. Adults with CF wished for more information about cross-infection, and also were less worried about cross-infection if segregation and enforcement of hygiene practices were implemented at their local clinic.

Section Summary

In summary, there is now clear evidence that cross-infection occurs within CF clinics. Segregation has been shown to reduce these risks. Research to date shows that adults with CF are not well educated about the risk of cross-infection, and many ignore advice to minimise contact with others with CF. Carers of young people with CF are very concerned about cross-infection and show strong support for segregation. Young

people appear to wish to reduce the risks of cross-infection, although are concerned about boredom during admissions to hospital. However, there are issues regarding the representativeness of those who have participated in research on this topic. The views of young people with CF who spend comparatively more time in hospital than other CF patients and, therefore, are likely to be affected to a greater degree by segregation, have not been reported.

The next section will present the research relating to how young people with CF cope with their disease and hospitalisation.

3. COPING WITH CYSTIC FIBROSIS AND HOSPITALISATION

Coping can be defined as “the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 283). The literature on children coping with chronic illness and hospitalisation is conceptually confusing as researchers use different approaches to categorise coping, such as categorising individual strategies (e.g. distraction or social support), global dimensions (e.g. approach/avoidance) or coping styles (e.g. problem- or emotion-focused coping). In recent years attempts have been made to make sense of the existing literature and to develop consistent ways of conceptualising coping in children and adolescents (e.g. Skinner, Edge, Altman & Sherwood, 2003; Skinner & Zimmer-Gembeck, 2007).

Although much has been published on young people coping with chronic illness and hospitalisation, fewer studies have been undertaken exploring how young people with CF specifically cope with their disease and hospitalisation.

Coping With CF

Early research on young people coping with CF tended to focus upon searching for psychopathology, or comparing those with CF to other clinical populations. Mador and Smith (1989) reviewed the early literature and summarised that young people with CF generally coped well with their disease, despite the low life expectancy of less than 20 years at that time. However, as outlined in the previous section, young people living with CF today have a more optimistic outlook with more effective treatments, longer life expectancy, and hopes for a cure. It is not clear whether the findings from early research about coping with CF can be applied to young people growing up with CF today. For this reason, only research on young people coping with CF published after 1990 will be reviewed.

How Young People Cope With CF

Recent studies (i.e. post-1990) examining the psychological adjustment of young people with CF suggest that they are similar to their healthy peers (Blair, Cull & Freeman, 1994), though they are at increased risk of psychological, attachment and behavioural problems (Berge & Patterson, 2004; Thompson, Gustafson, Hamlett & Spock, 1992). Research on young people's adjustment to CF is based upon the assumption that positive adjustment reflects effective ways of coping (Abbott, 2003). The literature on young people coping with CF is fragmented, uses different methods and tools to evaluate coping, and at times uses health professionals or parents as proxies. More recently it has been suggested that the patient is the most effective person to evaluate the effectiveness of their coping strategies (Abbott, Dodd, Gee & Webb, 2001; Christian, 2003), and more research should explore the patient perspective of coping.

Several questionnaire measures have been used to assess the coping strategies of young people with CF. In a German study, Staab et al. (1998) used the Freiburg Questionnaire of Coping with Disease (FQCD) with 39 adolescents and adults with CF (age 12 - 49 years). They reported that social comparison (e.g. *'I told myself that others were worse off'*) was associated with a higher quality of life; whereas depressive coping (e.g. *'I asked myself again and again, why me?'*) was related to poorer quality of life. In a UK study, Abbott et al. (2001) developed a disease specific measure of coping based upon interviews with 60 people with CF (age 16 - 44 years). Four distinct ways of coping were identified: *optimistic acceptance* (reflecting an optimistic, determined and positive way of coping with CF); *hopefulness* (reflecting a hope that everything will turn out for the better); *distraction* (reflecting an attempt to try and forget CF); and *avoidance* (reflecting an avoidant and passive way of dealing with CF). This questionnaire was then used to explore the relationship between coping and adherence. The authors found that those using optimistic acceptance and hopefulness had higher rates of adherence to treatment. The previous two studies using questionnaires have provided important information on coping with CF; however the samples used combined adolescents with adults, ignoring specific developmental challenges faced by those during the adolescent period. Therefore, few conclusions can be drawn from this study regarding the ways in which young people specifically cope with their disease.

In an American study, Pendleton, Cavalli, Pargament and Nasr (2002) explored the use of spirituality in coping with CF using interviews and drawings with 23 children with CF (age 5 - 12 years). The authors concluded that almost all children used some form of religious or spiritual coping strategy which was associated with

adaptive health outcomes, with 72% relying on spiritual social support (e.g. *'it feels good to have others praying for you'*).

A program of research was undertaken by American nurse researchers exploring the views of children, adolescents and adults growing up with CF. In the first of these studies, 20 children with CF (age 6 - 12 years) were interviewed by D'Auria, Christian and Richardson (1997) in a grounded theory study of perceptions of living with CF. The central theme for children was *'discovering a sense of difference'*, with four further themes of *'puzzling out the diagnosis'*; *'being teased and picked on'*; *'telling others'*; and *'keeping up'*. Participants appeared to cope by concealing or hiding aspects related to CF from their healthy peers in order to minimise differences. The authors suggested that interventions should focus upon helping children with CF feel normal with their healthy peers. In a further study of the next developmental age group, the same researchers used grounded theory to describe how 20 adolescents (age 12 - 18 years) experienced growing up with CF (Christian & D'Auria, 1997). One central phenomenon was identified – that of *'reducing a sense of difference'* which captured the struggle of adolescents with CF to regard themselves as 'normal'. Participants stressed the importance of meeting others with CF to help them feel normal. In addition, several protective strategies were identified that helped participants manage the deterioration in their health – *'keeping secrets'*, *'hiding visible differences'*, and *'discovering a new baseline'*. Following on from this, D'Auria, Christian, Henderson and Haynes (2000) interviewed 15 adolescents with CF (age 17 - 22 years) in another grounded theory study aiming to explore the impact of increased symptoms experienced during adolescence. These participants reported their experiences as *'fighting a never ending battle'*. They

reported that they coped by seeking support from their CF peers, comparing illness severity to others, having CF role models, and having hope and a positive attitude.

Similarly, Admi (1996) used a life history approach which aimed to identify the adolescent and adult (age 16 - 25 years) longitudinal view of living with CF. Participants reported that as young children they felt similar to their healthy peers, with treatments differentiating themselves from their healthy peers. Those diagnosed at infancy recalled not knowing any different to having CF in their lives. There was a growing awareness of the meaning of the disease during early adolescence. The dominant viewpoint of participants was continuation of life, rather than preoccupation with disease and death (Admi, 1996). The methodological approach of obtaining retrospective accounts from an adult perspective can be considered problematic in terms of attempting to understand the experiences of young people with CF. However, these studies have highlighted the challenges faced by those with CF across various developmental stages, with the consistent theme of being aware of being different effectively capturing the essence of life for young people with CF.

The Role of Peer Support in CF

Peers have a significant influence upon emotional and social functioning in children (Spirito, DeLawyer, & Stark, 1991). Several studies have shown that young people with a chronic illness have difficulties with developing social competence with their healthy peers (e.g. Breitmayer, Gallo, Knafl, Zoeller, 1992; La Greca, 1990), and that these difficulties are more pronounced in certain illnesses such as CF where there are visible differences, particularly during the teenage years (Spirito, DeLawyer & Stark, 1991). Furthermore, it is during adolescence that CF increases in severity and intrusiveness (Admi, 1996; D'Auria et al, 2000), suggesting that the struggle to feel

normal is particularly difficult during adolescence. Unfortunately, this also occurs at a time when developmentally adolescents are attempting to determine how they ‘fit in’ with others and the world around them (Christie & Viner, 2005).

Very few studies have explicitly explored the role that healthy peers play in the lives of young people with CF. Patton, Ventura and Savedra (1986) found that adolescents with CF rated close friendship support with healthy peers as minimally helpful, with many identifying difficulties in forming close friendships with healthy peers. D’Auria, Christian and Richardson (1997), in their study of 20 children with CF (age 6 – 12 years), reported that only ‘special friends’ were trusted with the knowledge of CF in order to reduce the sense of stigma and difference that young people with CF felt. Finding friends who could be trusted played a critical role in their adjustment to CF, although this came at the cost of concealing symptoms and CF related tasks. “By focusing on the similarities [with healthy peers] they achieved a sense of solidarity with friends, which protected them when they decided to disclose the diagnosis” (D’Auria et al, 1997, p. 109).

More recently, Graetz, Shute and Sawyer (2000) identified that family members provided adolescents with CF with tangible and informational support, whereas healthy peers provided adolescents with emotional support and companionship. However, these researchers identified that adolescents with CF were reluctant to fully share details of their disease with their healthy peers, potentially limiting the support they received. D’Auria et al. (2000) used a grounded theory approach in interviews with 15 adolescents with CF (age 17 - 22 years) in order to explore the impact of CF upon peer relationships. This study clearly showed the difficulties that face adolescents with CF, and themes of ‘*losing ground*’ and ‘*being*

out of the loop' characterised their contact with healthy peers as fatigue and other symptoms made it increasingly difficult to keep up.

Even fewer studies have explored the role that CF peers play in the lives of young people with CF, and those studies that have suggest that friendships between young people with CF are essential in helping to develop an acceptance of their disease. In an earlier study, Harboard, Cross, Botica, and Martin, (1987) found that young people with CF aged over 12 years valued their friendships with CF peers and attendance at camps together as there were fewer difficulties in relating to similar others. Similarly, D'Auria et al. (2000) also reported that adolescents with CF reported '*finding a new company of friends*' that they could relate to - those with CF – was particularly helpful during the time when they became aware of increasing symptoms. Having CF peers allowed for close friendships to develop due to shared experiences and allowed adolescents with CF to focus upon similarities rather than differences. Older peers with CF became role models for managing CF in their lives, and allowed for hope and optimism about the future. Participants acknowledged however that it was difficult to see the deterioration of their CF peers. Overall, D'Auria et al. (2000) summarised the perspectives of the adolescents with CF regarding contact with CF peers:

Their message was very clear – meeting others who share their same disease is essential for incorporating CF into their developing ideas of who they are and who they will become. Interactions with this new company of friends gave them a greater perspective of the illness, its consequences, coping, and the importance of believing in a positive future. (p. 182).

From these few studies, it is clear that segregation has the potential to significantly impact upon the development of important friendships with similar others at a time when they are most needed, that is, during adolescence.

Coping With Hospitalisation

There is extensive research on various aspects of the hospitalisation of children and adolescents, and the topic is one that is regularly reviewed (e.g. Bonn, 1994; Cornsweet, 1990; Coyne, 2006; Denholm, 1985; King & Ziegler, 1981; Shields & King, 2001; Vessey, 2003). There is recognition that young people hospitalised for an acute medical problem have different experiences and cope differently to those who are admitted for a chronic illness (e.g. Boyd & Hunsberger, 1998; Spirito, Stark & Tyc, 1994). The admission experience of young people with CF can be seen to be different to those with other chronic illnesses in several ways. Young people with CF with *pseudomonas* are usually admitted every three months, for a period of two weeks (Kerem et al., 2005), and therefore spend a considerable amount of time in the hospital setting. Specialist CF Centres have developed resources, infrastructure, and multidisciplinary teams to ensure that the frequent two week admissions are as pleasant as possible. Furthermore, treatment demands for CF are time consuming, requiring a hospital routine that takes up a lot of the day with physiotherapy, nebulisers, IVs, and gym activities that are structured around school. For all these reasons, CF hospitalisations are uniquely different. Research on the CF hospital experience is presented below.

Young People With CF in the Hospital Setting

Very few studies have explicitly explored the experience of hospital admission for a young person or adult with CF, or from a CF carer perspective. Nuttall and Nicholes (1992) undertook semi-structured interviews with 20 adolescents with CF (age 12 – 22 years) to identify concerns about hospital and home care. Adolescents reported that they needed more information regarding issues relating to their future

and wanted to be more involved in their treatment and care. Most of the concerns identified about the hospital setting related to comfort, frequent interruptions of therapies and activities, a desire to be separated from younger children, and poor food choice and variety. Forty percent of participants commented on boredom during their hospital stays. One major concern for the adolescents was being informed of the death of their peers, whom they formed close friendships with during hospitalisations. Similarly, D'Auria et al., (2000) in their study of 15 adolescents with CF (age 17 - 22 years) described how hospitalisations allowed for the development of friendships with CF peers, which helped participants assimilate their CF-related experiences with their personal identities. In another study of young people with CF in the hospital setting, Weiland, Schoettker, Byczkowski, Britto, Pandzik, and Kotagal (2003) evaluated a new program of personalised hospital schedules for adolescents with CF that had been introduced following a quality improvement exercise. Daily routine activities such as time of wake up, medications, physiotherapy, school, meals, and ward rounds were included, in addition to less frequent activities such as time out of the hospital and other assessments. The authors reported that older males in particular were more likely to use the personalised schedules, and perceived benefits were increased control and independence over treatments and activities, which increased patient satisfaction and reduced boredom.

Two other studies have used young people with CF along with other clinical populations in the hospital setting. For example, one qualitative study elicited the views of a mixed group of children with chronic illness and highlighted that one patient with CF reported feeling less lonely in hospital compared to home and also received reassurance from CF peers (Sartain, Clarke & Heyman, 2000). Another young participant with CF in this study reported that the only positive thing about

hospitalisation was '*going home*'. Spirito, Stark and Tuc (1994) used the KIDCOPE (Spirito, Stark & Williams, 1988) with 125 hospitalised children (age 7 – 17 years) to explore how children cope with hospitalisation. The aim was to compare those with a chronic illness (defined as having previous admissions to hospital, $n = 54$ and including 6 with CF) with those who were hospitalised for the first time with an acute admission ($n = 71$). They found that those with acute illnesses were more likely to use less adaptive strategies such as distraction, wishful thinking, and self-criticism. Adolescents used more cognitive strategies than younger children, and no sex differences were found in the type of coping strategies used. This study used a heterogeneous sample of children with a range of illnesses, so it is difficult to determine the specific experiences of the children with CF.

To summarise the above studies, hospital admission for young people with CF can be boring given the frequency and length of time spent in the hospital setting. Things that appear to help are having control and being included in the structuring of daily activities and treatments, and having contact with CF peers – these activities have both reportedly relieved boredom. Studies that include CF populations with other young people with chronic conditions provide little information about the CF hospital experience specifically. Furthermore, studies of young people in the hospital setting rarely provide a detailed description of the individual, hospital or family context (e.g. if admitted to a shared room or on their own, frequency of family visits, etc) making it difficult to compare experiences within and across studies. More research on homogeneous groups of young people in the hospital setting is needed in order to tease out some of these variables.

Gaps in the Literature

The studies reviewed on young people coping with CF generally and coping with CF hospitalisations make no mention of cross-infection. This could be a reflection that cross-infection is a relatively new concern amongst young people with CF today; and also may reflect variations in country standards of care and research priorities. For example, some CF Centres in the USA continue to arrange social activities and groups for young people with CF, and therefore American-led research continues to reflect patient experiences. More virulent strains of multi-resistant *pseudomonas* have occurred in Australia, leading to the unexpected death of many young children with CF and high rates of cross-infection (Griffiths et al., 2005), therefore the experience of living with CF is different. With recent moves towards segregation in the UK (CF Trust Standards of Care Working Group, in press), young people with CF are now more likely to experience hospitalisation with little contact with other CF patients, and indeed if treated in a CF ward, limited contact with any other patient. However, research funding by the CF Trust is prioritised towards the search for a cure, with little psychosocial research funded. Research is needed on segregation in order to determine the impact of decisions made to improve the life expectancy of people with CF, and to plan services accordingly.

The literature reviewed in the previous section suggests that limiting contact with CF peers may lead to difficulties in adjustment, but also may reduce the positive experiences of hospitalisation by removing opportunities for social contact. The topic of children in isolation in the hospital setting has received some attention in the literature, and is perhaps of relevance to the topic of segregation. The research on young people in the hospital setting who experience care in similar conditions to segregation is reviewed in the next section.

Coping With Hospitalisation Under Conditions Similar to Segregation

Early research by Bowlby (1960) and Roberston (1958) with children in hospital and foster care highlighted the negative effects of social isolation on childhood development. Indeed, this early research contributed to significant changes in the management of children in the hospital setting (Shields, Pratt & Hunter, 2006). Today, most children are hospitalised under arrangements that encourage open visiting and family-centred care. However, a small number of children are treated in isolation in the hospital setting. 'Protective isolation' is the practice where patients who are infection-free but vulnerable to infection are kept isolated in order to reduce the risk of infection. Protective isolation is used in the treatment phase of Bone Marrow Transplantation⁶ (BMT). Here, carers are able to spend time with their child, usually after changing or wearing gloves or masks during the most intensive phases of treatment. Protective isolation is also used for patients with Severe Congenital Immune Disorder Disease⁷ (SCID) (van Rijn, Kuijper & Kreis, 1997). Children with SCID are more limited in their contact with others, with carers usually unable to have direct contact and instead are restricted to visiting behind a glass screen in order to minimise the risk of infection which could be life threatening.

'Source isolation' is the practice where patients with a bacteria or virus are isolated in order to prevent the spread to other hospital patients. Source isolation is used for reducing the spread of virulent bacteria or viruses, such as Human Immunovirus (HIV), Tuberculosis (TB), Severe Acute Respiratory Syndrome (SARS), and *MRSA*. Under these conditions, most patients with these infections are

⁶ Treatment where white blood cells are replaced which lowers the immune response of children, making them susceptible to all infections during the treatment phase

⁷ A disease where infants are born with an underdeveloped immune system, making them susceptible to all infections

able to spend time with their families who usually wear protective clothing such as masks, gowns, and gloves during activities or for close contact.

Although segregation as used with young people with CF differs from these forms of isolation, there are some parallels in experience – the length of the typical CF admission for IV antibiotics (14 days) is similar to the period of isolation for patients undergoing BMT; and people with CF are now unable to mix with other patients. However, there are important differences – people visiting a child with CF are required to wash hands to reduce the spread of bacteria however do not require protective clothing or restricted visiting as bacteria are not harmful to those without CF. By examining the literature on the experiences of young people who are isolated in the hospital setting, it is hoped that some light may be shed upon the experience of admission under segregation.

A Review of Hospitalisation Under Isolation

A systematic search was undertaken in order to identify relevant studies about the views and experiences of young people who receive hospital treatment in conditions characterised by protective or source isolation. Most early research on children in isolation in the hospital setting related to those in protective isolation, whereas more recent studies include the experiences of those under source isolation. Empirical research relied mostly upon the carer or health professional perspective, usually employing behavioural observations and staff- or carer-rated questionnaires to determine the child's psychological functioning during and after periods of isolation. Only five studies were identified that focused upon the experience of isolation from the young person's perspective – these are outlined in Table 2 overleaf and will now be critically reviewed.

Table 2. Summary Table of Studies Exploring the Young Patient Perspective of Isolation

Author	Type of study	Client group	Length of isolation	Sampling	No.	Age	Data collection	Analysis
Broeder 1985	Qualitative	Meningitis, Cellulitis	5.3 days (range 3 – 11)	Consecutive	6	6-9	Interviews; drawings	Phenomenology
Günter, et al 1999	Prospective longitudinal	Cancer, BMT	3 weeks	Consecutive	15	8-12	Self report measures; drawings; interviews	Psychoanalytic interpretation
Gunter 2000	Case study	Cancer; BMT	3 weeks	Case study	1	8	Drawings	Psychoanalytic interpretation
Koller et al 2006(a)	Ethno-graphic	Probable SARS	2 weeks	All fulfilling criteria	5	6-18	Interviews	‘Qualitative coding’
Koller et al 2006(b)	Ethno-graphic	Probable SARS	2 weeks	All fulfilling criteria	5	6-18	Interviews	‘Qualitative coding’

The young patient perspective. In the first study, Broeder (1985) undertook a qualitative study of six children (age 6 – 9 years) who were admitted to a large acute-care children's hospital in America to explore their perceptions of the reasons for isolation. Participants were selected if their treatment required them to be isolated from other patients at any point during their stay. The average length of admission for all patients was 11 days, with an average of 5.3 days spent in isolation. Observational data was gathered daily during hospitalisation by the researcher, and interviews and a drawing activity were conducted at an unspecified time following the child's discharge from hospital. The author concluded that children over the age of 7 years were able to understand medical reasons for isolation; whereas younger children reported isolation as a result of punishment: *"because I was bad and got sick, I was supposed to stay in my room"*. Children described feelings of loneliness during isolation, and a fear of nurses in their isolation attire: *"She [the nurse in gown and mask] needs to do something to you; you don't know what, you just wait and see"*. Fear was also related to carers wearing protective clothing. Children reported that IVs were the most distressing part of their hospitalisation; and they expressed wishes for play, food, and companionship. The author highlighted the importance of nurses engaging with children when not doing procedures to reduce distress. This study allowed the child to speak directly about his or her experiences; however the children's accounts were retrospective. Drawings were described and included in the study, but were not interpreted. Indeed, the nature of data collection (i.e. the participants received daily observational visits by the author in order to 'develop a relationship') may have affected the children's experiences of isolation.

The next was a German study undertaken by Gunter Karle, Werning, and Klingebiel (1999). These authors argued that children appear to adapt well to isolation

through a process of ‘over normalising’, which they aimed to assess using self-report questionnaires on anxiety, depression, body image, personality, intelligence tests, in addition to projective tests, psychoanalytic interview and a drawing game. Eighteen consecutive patients (age 8 – 12 years) admitted to isolation following BMT were approached, and 15 agreed to participate. Data collection occurred before, during and after the period of isolation which occurred for a period of three weeks. Gunter et al. (1999) concluded that self-report questionnaires did not identify excessive worry or low mood in the children who were isolated. However, psychoanalytic interpretative tests and interpretation of drawings identified the use of ‘protective denial’, that is, the avoidance of direct discussion of feelings about isolation. They argued that participants were aware of the seriousness of their situation, particularly following the BMT where they were more able to express their emotions on a subconscious level through drawings. These authors suggested that questionnaire measures were not appropriate for exploring the impact of isolation on children, and instead suggested alternatives to talking therapy for children who experience isolation. This study used a prospective longitudinal approach to select participants, and a psychoanalytic approach to inform the research. However, clinical judgement or opinion was used to represent the child views. Little information was reported from the participant’s interviews, and some of the large range of assessment tools selected were of questionable relationship to the stated aims of the study.

To further expand upon the above study, Gunter (2000) reported a more in-depth analysis of drawings undertaken by the participants in the previous study and a detailed case analysis. He reported that the nature of anxiety experienced by participants was consistently related to the themes of poisoning, escape, and ‘oral-aggressive fantasies’, a term which was not clearly defined or described. He

concluded that defences were there to protect patients during isolation, and clinical intervention should aim to strengthen these defences prior to the period of isolation. The use of the children's drawings and the inclusion of a detailed case example was a strength of this study. However, including children's verbal accounts of their experiences would have made the conclusions drawn by the author more transparent.

Next, Koller, Nicholas, Goldie, Gearing, and Selkirk (2006a) used an ethnographic approach to explore the impact of treatment in isolation upon children with suspected SARS during the Toronto outbreak. All children aged between 6 – 18 years hospitalised for probable SARS ($n = 5$) participated in the study, along with eight health care workers, and ten carers. Interviews were conducted one month following the discharge of the children from hospital, and medical chart reviews were also undertaken to obtain detailed information about the child's hospitalisation. All interviews were then analysed together using 'qualitative coding methods' leading to three main themes: (a) *the emotional impact of SARS*, (b) *communication challenges*, and (c) *role changes*. The only child results reported related to the first theme of the emotional impact. Here, children reported being sad due to being alone, missing family members, worry about others in the family, and feeling alone. Several also had family members isolated in other hospital centres, which contributed to worry. The authors concluded that hospitalisation during the SARS crisis resulted in frustration, difficulties in communication and significant distress for paediatric patients. The resultant distress pointed to the need to enhance patient participation, to provide information, to make use of the phone and other technologies for keeping in contact with others, and to work collaboratively in order to overcome some of these challenges. The authors highlight that during infection control outbreaks, "the individual rights of parents and children appear to subordinate to those of larger

societal needs” (p. 58), which made the delivery of family-centred care challenging. Despite in-depth interviews, minimal detail of the child experience was reported, and combining with the carer and health carer worker did not lead to an in-depth understanding of the context of the SARS experience from the child perspective. Furthermore, the ‘themes’ identified appeared to reflect categories of questioning, rather than provide an in-depth understanding of the three perspectives obtained.

In the final study, Koller, Nicholas, Goldie, Gearing, and Selkirk (2006b) used the same study as published above to further explore the impact of SARS, this time relating the child’s experiences to the work of Bowlby (1960) and Robertson (1958) on attachment and separation. More detail was provided in this paper regarding the quality of data collection methods used (i.e. children were interviewed by staff experienced at working with children; drawings were used to facilitate the interview process; and many interviews with health care workers and carers were undertaken over the phone). In this paper, Koller et al. (2006b) reported on three main themes: (a) *the emotional impact of isolation on children hospitalized because of SARS*, (b) *changes in parental and professional roles*, and (c) *familial experiences following discharge*. The same comments from Koller et al. (2006a) were used to describe the experiences of children, again relating only to the first theme. The authors added that some children described feeling punished – ‘*like being in jail*’; and highlighted the importance of play to reduce boredom. Parents and staff reported changes in their child that appeared to follow stages of protest, withdrawal, and despair as outlined in Bowlby’s (1960) earlier work on attachment. Despite aiming to use an inductive approach, data from the child experience was not reported in-depth, and the authors appeared to impose existing theories when reporting the results. Also, no ages were reported making it difficult to determine the experiences of younger and older

children, although the authors commented that younger children appeared to be the most impacted by the experience.

Summary of the young patient perspective of treatment in isolation. It is important to note that the studies of the young person's perspective of isolation reviewed here have some methodological flaws. The small number of mainly qualitative studies had poorly specified methodologies. Participant interviews were often based upon retrospective accounts some months following the period of isolation. The voice of the young person in some studies were not heard, despite stated aims of obtaining the child perspective. Furthermore, there were differences in the experience of isolation with regards to visits from family, length of time, and presence of protective clothing. For example, Broeder formed relationships with her participants during their period of 'isolation', whereas those in Koller's et al. study were isolated even from family members. This makes it difficult to make conclusions regarding the impact of treatment in isolation. Descriptive findings appear to support earlier research that children are sad, lonely and anxious in the hospital setting; however little new knowledge is learned from the patient's themselves about what is uniquely different about admission under isolation. Larger scale studies are impractical due to low numbers of children experiencing isolation.

Despite these shortcomings, it is important that the young person's perspective is heard regarding the experience of isolation. Research exploring the child's experience of treatment in isolation in the hospital setting needs to take into account the child view of hospitalisation generally in addition to the experience of isolation, and ideally accounts should be obtained during the experience to ensure credibility and minimise memory bias.

Section Summary

Recent research has shown that young people with CF use a range of strategies to cope with their disease. Young people with CF find it difficult to relate to healthy peers, and are reluctant to share their diagnosis with others. They do however gain enormous benefit from contact with similar peers. Where CF peer support and contact might have been highly valued in the past, there are now concerns that these same peers are a source of risk. These new challenges faced by adolescents with CF are little researched. There is also limited research on the experience of and coping with hospitalisation for young people with CF, and there are few insights from the literature covering child perspective of hospitalisation under conditions similar to segregation. There is a need for further research on how young people with CF learn to cope in light of the new challenge of cross-infection.

In the following section, an exploration of theoretical and conceptual models of coping and peer support is outlined in terms of the ways in which these models may be helpful when investigating the issue of segregation.

4. THEORETICAL CONSIDERATIONS

In the early 90s, Bluebond-Langner used an ethnographic study to develop a model of how carers and families of children with CF cope over the disease trajectory (Bluebond-Langner, 2000). This is the pre-dominant model used in clinical practice today in CF teams. However, the focus of the model is on carers and unaffected siblings, rather than the young person with CF. Furthermore, the model is based upon interviews of families living with CF over 15 years ago, when life expectancy was lower and there were few concerns about cross-infection. Therefore the model per se is insufficient to develop a thorough understanding of the impact of segregation.

Several models have been used to guide research about the ways that young people cope with illness, including the Stress-Coping Model (Moos & Schaefer, 1993); Transactional Model of Stress and Coping (Lazarus & Folkman, 1984); and the Disability-Stress-Coping Model of Adjustment (Wallander & Varni, 1992). One of the most common frameworks of coping used in clinical and health psychology is Lazarus and Folkman's Transactional Model of Stress and Coping (1984). Although devised with adults, it has been applied to many studies of coping in healthy and chronically ill children (e.g. Caty, Ellerton & Ritchie, 1984; Hanton, 1998; Walker, Smith, Garber & Claar, 2007). The Transactional Model is useful in researching coping with chronic illness, as it allows for a systematic way of exploring coping that takes into account the illness context (Kelso, French & Fernandez, 2005). The model also allows for a framework for identifying and discussing participant-identified coping strategies. Finally, the model is particularly suited to qualitative research, which allows for an in-depth exploration of individuals' subjective perceptions and exploration of the meanings of stressful events assigned by participants. The model is described in the next section and then applied to stress and coping with cystic fibrosis.

Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)

General Overview of the Model

The Transactional Model provides a framework for evaluating the process of coping with stressful events, by looking at the interaction (or transaction) that occurs between the individual and the stressor. The model considers the *appraisal* of an event, rather than assuming stress is automatic as a result of a difficult situation. Cognitive appraisal can be defined as the "conscious or unconscious process of

categorizing an encounter, and its various facets, with respect to its significance for well-being” (Lazarus & Folkman, 1984, p. 31).

In response to a stressor, a primary appraisal is made, which involves a decision as to whether an event should be considered a threat, challenge or harm-loss, based upon meanings and beliefs attached to the event (Wallander & Varni, 1995). Next, a secondary appraisal is made, which involves decisions about what can be done, the consequences of such actions, and a judgment about whether those consequences will be effective in reducing the threat. The central idea of the model is that coping efforts (or strategies used) mediates the effects of stress on an individuals’ wellbeing. That is, individuals cope by perceiving that they have the resources to meet the individual demands of stress. The model is outlined further in Figure 1 below.

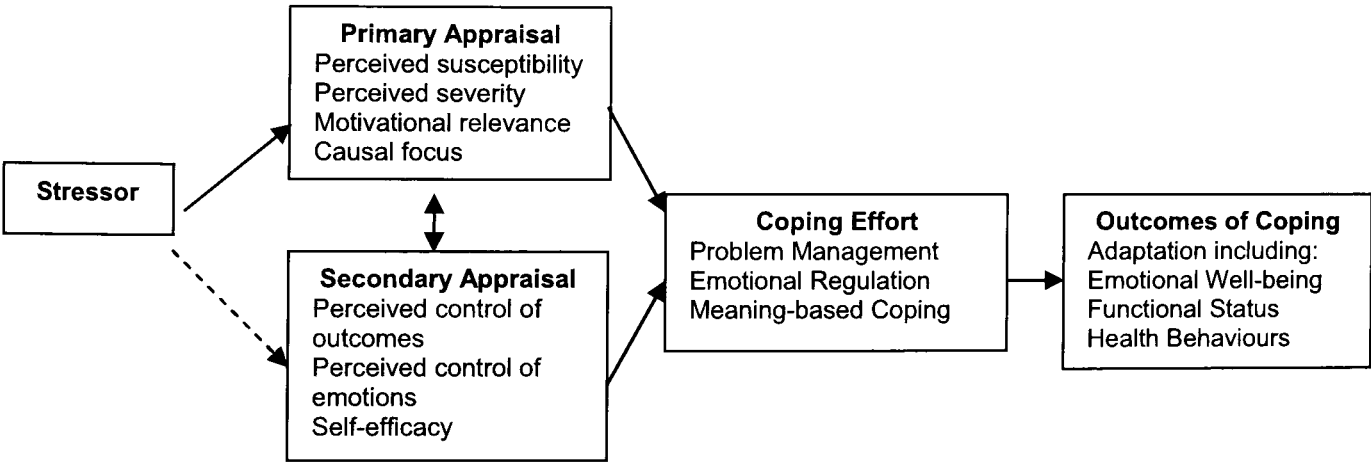


Figure 1. The Transactional Model of Stress and Coping

According to the model, coping is achieved by either managing the problem that causes the distress or regulating the emotions associated with the stressor. Problem-focused coping focuses attention upon the stressor, and include strategies such as monitoring, vigilance, seeking information, and positive thinking. These strategies are aimed at overcoming the challenges or stressors. In contrast, emotion-focused

coping is a style of coping that diverts attention away from the negative stressor, and include strategies such as avoidance, minimizing, denial, and distraction. These strategies are aimed at regulating the emotional impact of a given stressor. Examples of problem- and emotion-focused strategies that have been used by young people with CF are outlined in Table 3. Coping strategies and styles are believed to be a mediating variable between stressors and adjustment (Abbott, 2003). Individuals who are having few difficulties with adjustment are seen to be using effective coping strategies, whereas those who are struggling with managing stress are seen to be using maladaptive strategies.

Table 3. Examples of Problem- and Emotion-Focused Coping Strategies Used by Adolescents and Adults with CF

Problem focused coping (focuses attention on CF)	Emotion focused coping (diverts attention away from CF)
Active	Passive
Approach	Avoidance
Direct	Palliative
Monitoring	Blunting
Optimistic	Pessimistic
Sensitization	Repression
Vigilant	Distraction
Positive	Negative
Fighting spirit	Denial
Information seeking	Distracting

Note: Taken from Abbott, 2003, p. 42

Using the Transactional Model to Understand Segregation

The many challenges associated with living with CF place enormous demands upon young people, their carers, and their families (see Table 4). Stressors that are unique to those with CF include *disease related stressors*, such as symptoms; *social interactional stressors*, such as feeling different; *psychological stressors*, such as anxiety; and *situational stressors*, such as hospitalisation. Coping with CF is a

dynamic process that is ever changing according to changes in disease, function and individual variables. These stressors are in addition to the normal everyday stressors of daily life, and therefore make young people with CF more vulnerable to difficulties in adjustment due to the additional demands placed upon them (Abbott, 2003). Stressors specifically related to environmental acquisition of bacteria and cross-infection have rarely been mentioned in the literature, however appear to impact upon all aspects of life (e.g. Ullrich et al., 2002). Using the Transactional Model as a framework for understanding coping in CF can account for the additional threat of fear of cross-infection that existing CF models, such as the Bluebond-Langner model, do not address.

Table 4. Illness Related Stressors Experienced by Young People With CF

Disease- related stressors	Social / interactional stressors	Psychological stressors	Situational stressors
Progressive nature Increase symptoms Exacerbation Treatment regime	Impact upon family Feeling different Isolation Missed schooling	Body image Motivation Low mood Health anxiety Existential anxiety	Medical procedures Hospitalisation Overnight stays alone Difficult decisions

Other Relevant Theoretical Constructs

This section explores the potential for other relevant concepts and theories to guide the study of segregation.

Peer Support in Coping With Illness

Seeking support from those who experience similar difficulties is an important coping resource. Research on informal peer support in young people with CF, and

indeed in children in general, is in its infancy. There is evidence that formalised peer support programs are of benefit to young people with chronic illness, and has been extensively studied in adults, particularly with cancer (e.g. Steginga & Dunn, 2001). There are two different but somewhat complementary concepts that are used to explain the effectiveness of peer support as a method of helping individuals cope with illness – that of ‘social support’ and ‘social comparison’.

‘Social Support’ (Schaefer, Coyne & Lazarus, 1981). Linking in with the Transactional Model, the concept of ‘Social Support’ suggests that individuals benefit from contact with peers as they receive the resources that are required to engage in active coping strategies or problem solving (Lazarus & Folkman, 1984). These resources are made up of emotional, informational, and tangible support (Schaefer et al., 1981). Emotional support involves intimacy and the feeling of being cared for; whereas informational support involves information and advice about the stressor experienced and suggestions on how to overcome difficulties. Finally, tangible support involves practical assistance. Individuals who share an illness experience such as CF are uniquely placed to provide such support. Mastrovito, Moynihan and Parsonnet (1990) found that this concept of social support was useful in explaining the benefits derived from contact with other patients with cancer. Furthermore, Dunn and Steginga (2000) found that women with breast cancer who had limited incidence of cancer within their social network identified peer support as their preferred source of support. Such support allowed them to normalize their feelings of distress and to help develop resilience (Stanton, Danoff-Burg, Cameron, Snider & Kirk, 1999).

‘Social Comparison’ (Festinger). First described by Festinger (1954), the concept of ‘Social Comparison’ involves people making an evaluative comparison to similar others of their emotional and physical responses to a stressful event, and is

used at times of uncertainty in an attempt to decrease uncertainty. In the health context, social comparison is also considered to be a useful method of coping (Kulik & Mahler, 1997; Wills, 1997). Disease-specific social support groups are considered useful in not only providing social support (as above) but also in providing people with access to an appropriate reference group, thus facilitating coping (Davison, Pennebaker & Dickerson, 2000).

Taylor and Lobel (1989) identified that upward comparisons occur when there is an opportunity for self-improvement and the situation is controllable, and is a form of problem-focused coping. Downward comparison, on the other hand, allows individuals to engage in emotion-focused coping (Kelly & Ratner, 2005; Taylor & Lobel, 1989). Bennenbroek, Buunk, van der Zee, and Grol (2002) found that their adult participants with cancer were keen for social comparisons, and particularly wanted information from those who were better off than them. They also wanted contact with others who were coping well, information about disease progression and normalisation of treatments in the future.

Few studies have explicitly researched the concept of social comparison with young people, and is limited to young people with cancer (Eiser & Eiser, 2000; Meltzer & Rourke, 2005), eating disorders (Krones, Stice, Batres & Orjada, 2005), self concept (Brown & Lohr, 1987), and cardiac implant (Sears, Burns, Handberg, Sotile & Conti, 2001). The use of social comparison in young people with CF has been highlighted by Christian and D'Auria in their program of research on growing up with CF (see previous section). Social comparisons were one method used to determine 'normality', which was a central struggle for young people with CF. The desire to feel normal is a basic human need - "his deepest feelings about what he is

may be his sense of being a ‘normal person’, a human being like anyone else, a person” (Goffman, 1963, p. 17).

The process of learning to adjust to difficult circumstances in order to feel normal is referred to as ‘normalisation’, and was first outlined by Strauss, Corbin and Fagerhaug (1984). Knafl and Deatrick (1986) further described normalisation in families with chronic illness, where families go through a process that is aimed to convince others – and themselves – that life is the same as healthy others despite treatments and hospitalisations. The concept of normalization also features strongly in the model of Family Coping with CF by Bluebond-Langner (2000).

Section Summary

The Transactional Model appears to offer an appropriate framework to explore how young people with CF cope during hospitalization under segregation. Furthermore, by clearly defining and drawing upon two different concepts of peer support, it is hoped that they can be used to explore the psychosocial impact of segregation upon young people with CF, and point to ways in which clinical practice can be improved to meet the challenges associated with segregation.

5. CHAPTER SUMMARY

Research suggests that segregation should lead to an increased life expectancy by reducing the age of acquisition of *pseudomonas*, and preventing multi-resistant bacteria from being passed between people with CF. Unfortunately, young people with CF will no longer be able to mix with their CF peers during their frequent lengthy hospitalisations, and therefore will spend most of their time in hospital on

their own. Contact between CF peers in the community is also now being discouraged. There is evidence to suggest that young people with CF and their carers support these segregation measures. However, the few studies are biased towards reporting the views of young people and carers who are anxious about cross-infection and under-representing the views of young people with CF and their families who are severely affected, and therefore, experience segregated care more frequently. To date, no research has been undertaken on the psychosocial impact of segregation upon children.

Coping with CF is a dynamic process that is ever changing according to changes in disease, function, and individual variables. Studies of children and adolescents coping with CF have identified the importance of contact with CF peers. However, it is this contact between CF peers that is now being discouraged in order to minimise the risk of cross-infection. Existing research on the young person's perspective of isolation in the hospital setting does not contribute to the understanding of the potential impact of segregation on young people with CF. More research is needed to explore the psychosocial impact, both in the short term during hospitalisations and in the long term on coping with CF. In particular, research on the impact of segregation, as experienced by young people with CF is needed.

CHAPTER 2: AIMS OF THE CURRENT STUDY

The current study aims to produce an account of the lived experience of hospitalisation under segregation from the perspective of the young person with CF. This may help to address the identified gaps in knowledge and the literature as outlined in Chapter One and will hopefully shed light on the nature and extent of the psychosocial impact of segregation upon this clinical group. This information may then be used to inform clinical practice by suggesting ways in which we may reduce this impact.

Epistemological Statement

The topic of research was initiated by a change to the organisation of care and treatment in hospital for young people with CF. The need for research was identified by the author in her role as the Clinical Psychologist in the Paediatric CF team. Thompson (2000) refers to this practice-led framework as ‘reflective practice’, where the research is meaningful in the real world and beneficial to the service and service users (Suarez-Balcazar & Harper, 2003). A phenomenological approach was used to ensure that the experience of segregation could be understood and explored in-depth. A coping framework was used to guide the research and to discuss the main findings, with the main themes arising from the analysis of interview data.

Rationale for the use of a Phenomenological Approach

Controversy surrounding the use of segregation, as outlined in Chapter One, reflects concern about the potential negative impact upon young people with CF. However, the few studies available exploring this topic with young people with CF do not illuminate or describe the nature of any potential negative impact. Furthermore, the existing literature on children experiencing admission under conditions similar to

segregation is mostly based upon retrospective accounts, with few reporting the views of the young people themselves. Therefore, a qualitative approach was undertaken in order to obtain an in-depth understanding of the lived experience of segregation during the period of hospitalisation.

Qualitative approaches in psychology are generally engaged with exploring, describing and interpreting the personal and social experiences of participants. An attempt is usually made to understand a small number of participants' own frames of reference or view of the world rather than trying to test a preconceived hypothesis on a larger sample. (Smith, 2003a, p. 2)

There are several well established qualitative approaches, including phenomenology, grounded theory, narrative and discourse analysis, and co-operative inquiry (see Smith & Dunworth, 2003 for brief explanations of each). This current study uses a phenomenological approach, as this approach lends itself well to the aims of the study and to patient involvement. The phenomenological approach originated with Husserl (1962) who developed a theory of consciousness and philosophy behind science, which was further expanded by Heidegger (1962). Within the broad philosophical approach of phenomenology, several different frameworks have been devised (e.g. Colaizzi, 1978; Giorgi, 1985; 1995; Smith, 1996). One phenomenological approach that is used increasingly in health, clinical, and social psychology fields is Interpretative Phenomenological Analysis (IPA) (Smith, 1996). IPA was of particular interest as it was developed within the field of psychology and offered consistency between the clinical and research role of the author.

Overview of Interpretative Phenomenological Analysis (IPA)

As with all phenomenological approaches, IPA aims to explore the experience, perceptions and meaning of a particular event. The approach draws upon Heidegger's

hermeneutic (i.e. interpretation) of empathy, and embraces the subjective experiences of participants: “the important reality is what people perceive it to be” (Kvale, 1996, p. 52). The researcher attempts to gain insight into the participants’ experience through immersion with their accounts (Willig, 2004). A two-stage interpretation process is involved, which Smith & Osborn refer to as double hermeneutics: “the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2003, p. 51). The approach utilises the social cognition paradigm, which acknowledges the complicated relationship between an individual’s comments and their emotional and cognitive state. The researcher is required to interpret meanings through what the interviewee is saying. IPA requires the researcher to have a good understanding of the area under investigation, along with the culture in which it is set in order to provide meaningful interpretations (Solomon, 1997). Semi-structured interviews, which are recorded and transcribed verbatim, are the pre-dominant method of obtaining the data from a small homogeneous group of participants. The aim of analysis is to arrive at several main themes that ‘capture the essence’ of the experience of the topic under investigation (Smith, 1996).

There are several strengths of IPA. There is an explicit understanding that the researcher is interpreting the words to reflect the lived experience. In addition, there is a unified approach to interpretation and analysis of the individual and group perspectives, with examples of the process of analysis published to facilitate researchers (e.g. Smith & Osborne 2003; Smith & Dunworth, 2003; Willig, 2004).

IPA relies upon the analysis of verbal accounts, and this ignores the non-verbal communication from the participants, which some researchers have highlighted is especially important with younger children (Miller, 2003). The interviewer needs

to be flexible to encourage participants to provide rich descriptions of their experiences (Smith & Dunworth, 2003). Several groups, including children and those with learning difficulties, and indeed individuals who find it difficult to express their thoughts, feelings and experiences, will provide more limited accounts, with danger of analysis being descriptive rather than interpretative (Brocki & Wearden, 2006). Despite these shortcomings, IPA was considered to be the most appropriate approach to explore the lived experience of segregation.

Research Questions

IPA does not aim to test a hypothesis, rather, the aim is to obtain a detailed account of the lived experience of an event. Smith and Osborne (2003) argue that “the aim of the study is to say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims” (p. 54). To facilitate this, research questions are usually stated broadly and openly. For the current study, the following three broad research questions are posed:

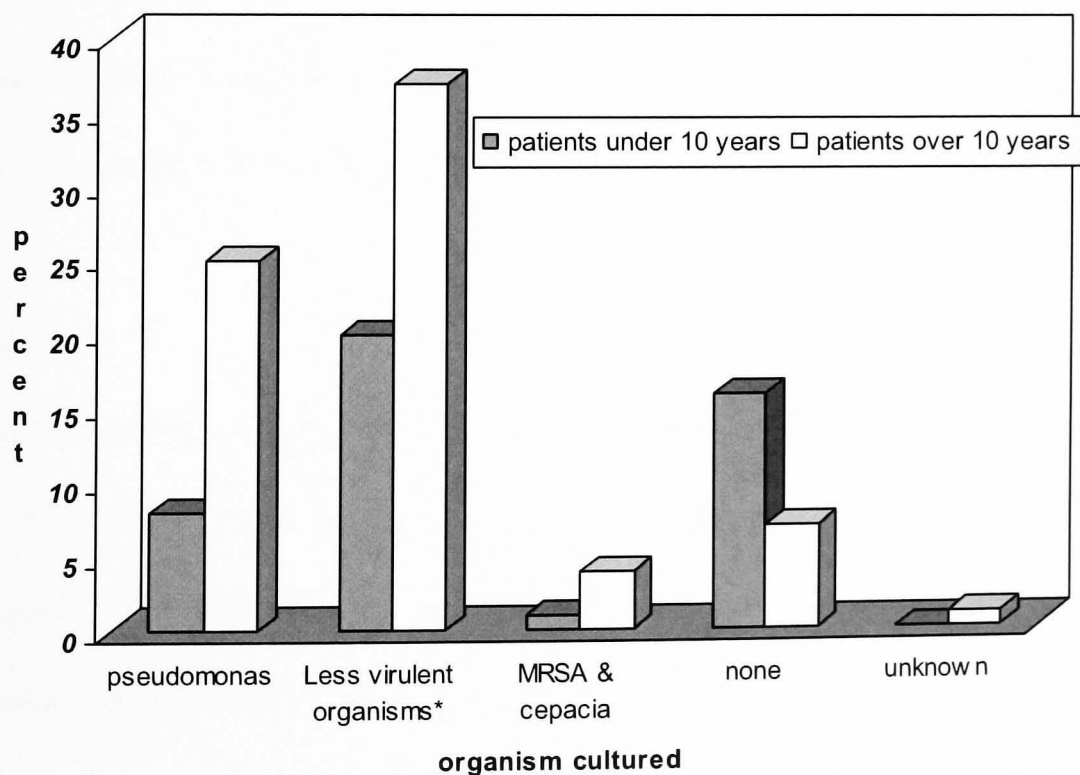
1. What is the experience of hospitalisation under segregation from the perspective of the young person with CF?
2. How do young people with CF ‘make sense’ of the use of segregation to minimise the risk of cross-infection?
3. What coping strategies are used by young people with CF during hospitalisation under segregation?

Finally, a more general research question is posed: What is the psychosocial impact of segregation upon young people with CF?

CHAPTER 3: METHODOLOGY

Setting

This study took place in a large paediatric CF Centre, which provides a service to young people with CF (age 0 – 17 years) in Northern Ireland. Full details of the clinical population were collated in June 2004, and are represented in Figure 2. The mean age of all patients attending the Centre at this time was 10 years (n = 192; median age = 10 years; age range = 3 months to 17 years). The male to female ratio was 1:1. Over half (63%) of the patient population had experienced one or more overnight stays in hospital during the previous two years, with 44 (23%) of these being for IV antibiotics. The average number of hospital days for these patients across the previous two year period was 34 (range 1 – 265 days).



^a contains the bacteria of *staphylococcus aureus*, *haemophilis influenzae*, *stenotrophomonas maltophilia*, and *alcaligenes xylosoxidans*

Figure 2. Bacterial Status of Patients Attending the Study CF Centre (June 2004)

Data on the bacteriological status for all patients was also collated in June 2004. A total of 45 patients (23%) did not have an infection, and the infection status of two patients was not known. Of the remaining 145 patients with bacterial infection, 83 (43%) cultured one organism; 52 (27%) cultured two organisms; and 10 (5%) cultured three or more organisms (see Figure 2). According to the UK CF Registry Database, the study CF Centre has a similar profile of patients to other specialist Paediatric CF Centres in the UK.

Design

An in-depth exploration of the young person's experience of segregation was the focus of this study to increase awareness and understanding of this specific infection control practice. The research questions were designed to explore areas of concern regarding the unknown psychosocial impact upon young people with CF. Interpretative Phenomenological Analysis (IPA) was the methodological approach used for the analysis and interpretation of interview data.

Participants

All patients aged between 7 and 17 years who were admitted to hospital for a two-week course of IV antibiotic treatment between June and November 2005 ($n = 44$) were eligible for participation in the study. Sampling was purposive on the basis that participants had experience of segregation and could articulate their experiences. Exclusion criteria for the study were: (a) patients who stayed less than 10 days of the standard 14 day typical admission, (b) those who had communication (language or hearing) difficulties, and (c) those judged by the team Social Worker to be

experiencing significant stress at the time of the study (e.g. due to bereavement or family separation).

A consecutive series of eligible patients were approached in order of admission and within the time constraints of the researcher who was present two days each week. Following the completion of nine interviews, it emerged that the experiences of segregation described by participants who were new to admission differed to those who had experienced prior admissions. Therefore, interviews continued with the final few participants selected based upon prior hospital experience to ensure homogeneity within two groups, that of ‘Experienced’ and ‘Inexperienced’ participants. In total, 15 patients were approached and 14 were interviewed, with one adolescent male refusing to participate.

Measures

Semi-structured interviews were used as the main data collection method (Kvale, 1996). The framework for the interview questions was based upon the phenomenological perspective and other sources of ‘pre-understanding’ (van Manen, 1990). These were feedback from parents and young people from an earlier study conducted by the researcher (Russo, Donnelly & Reid, 2006); identified gaps in the literature (as outlined in previous chapters); and the researchers’ own clinical experience of the difficulties faced by patients and their families during hospitalisation. The interview guide included open-ended questions to elicit participant descriptions of experiences on the following three main areas of focus: (a) *the experience of the current hospital admission* (eliciting the context of hospitalisation under segregation and the treatment experience), (b) *knowledge and experience of segregation* (eliciting knowledge and views about bacteria, cross-

infection, and segregation), and (c) *methods of coping with hospitalisation under segregation*.

The interview guide was compiled to ensure that novel and personally meaningful information from participants could be introduced without feeling constrained by the questions (see Appendix 2). A pilot exercise was undertaken with two young people which led to the addition of standardised prompts to facilitate discussion of experiences. All interviews were conducted by the researcher, were tape-recorded and later transcribed verbatim by the researcher and an assistant.

Procedure

Ethical approval to conduct interviews with young people with CF and their families was obtained through the University Research Ethics Committee and the Hospital Research Office, following research governance procedures (see Appendix 3). Written information was provided to children and carers about the nature of the study (see Appendix 4). Verbal and written consent was obtained prior to the commencement of the interviews (see Appendix 5), and again following the interviews to ensure that participants agreed to the content being used for the purposes outlined. Participants were informed from the outset that identifying information would be removed, with anonymous quotes used to communicate the main themes that would then be disseminated. Upon completion of the analysis, pseudonyms were allocated to anonymise the participants, and interview tapes were deleted. Lengthy and detailed quotes used within presentation and published material were discussed with individual participants to ensure they were comfortable with the use of their comments – all participants approached were positive about the use of their anonymised comments in such material.

Data collection commenced six months following the introduction of segregation. Eligible participants who were admitted to the CF Centre during the period of data collection were approached by the researcher on day 10 of their 14 day admission, to enable them the opportunity to reflect upon the experiences of their current admission under segregation.

The study was explained to each potential participant (and to the carer, if present) and written information was provided and discussed (refer Appendix 4). Carers who were not present when the researcher met the young person were left written information and consent forms in an envelope which were collected the following day. An interview time was arranged once verbal consent was obtained from the young person and written consent from their carer (refer Appendix 5). All participant interviews were conducted in the hospital room. Information regarding confidentiality and the use of the interview material was explained to participants. Consent was again obtained from participants following the interview to ensure they were comfortable with the experiences discussed. A flowchart of the process of data collection can be seen in Figure 3.

Analysis

Transcribed interviews were checked for accuracy by comparing the original recordings with the typed transcripts. This helped the researcher gain familiarity with the data at an early stage. Next, interview transcripts were imported into NVivo 2.0, a qualitative software used to facilitate analysis, and printed out with line numbers to facilitate the stages of analysis. Once all interviews were completed, the interview transcripts were then analysed separately by the researcher following guidelines outlined in Smith and Dunworth (2003).

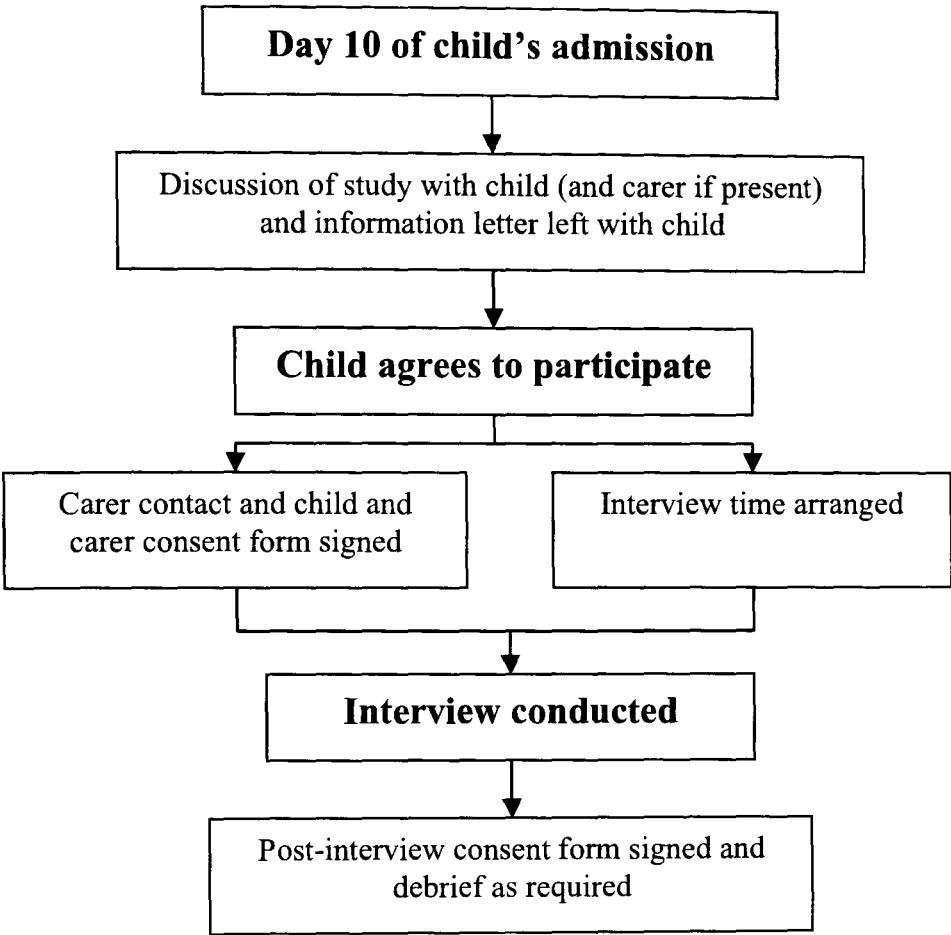


Figure 3. Flow Chart of the Process of Recruitment, Consent, and Data Collection

Stage One. Relevant notes and comments were made in the left margin of the transcript. The researcher commented on ideas, concepts, and words that arose from the participant, keeping close to original accounts. Stage One of the analysis for five interviews was also undertaken by a second researcher and then compared and discussed in order to clarify the general approach and increase rigour and consistency.

Stage Two. Interviews were read again with the aim of interpreting and translating stage one comments into ‘conceptual categories’ that captured the essence of a participant’s recorded experience, which were then written in the right margin of the interview transcript. Once again, a second researcher completed this stage for five interview transcripts, and results were compared and discussed in order to gain consensus of the main themes emerging from the transcript.

Stage Three. All conceptual categories that were recorded for each interview transcript were listed in a Word Document in order of their appearance, together with examples from the text highlighting the meaning of each conceptual category. This practice was used to ensure that the meanings of each of the conceptual categories were clearly defined and to prevent ‘contextual drift’.

Stage Four. Connections and similarities between the emerging themes were identified, and a master list of initial themes for each interview was created using ‘cut-and-paste’ in Word. These major themes were then reorganised and reduced down to capture the key experiences for each participant.

Stage Five. The main themes for each participant were listed, and again reorganised, resulting in identification of major themes across all participants. Illustrative quotes from each theme were discussed with a second researcher to ensure the conceptual clarity and consistency of the list of themes. Following discussion, a final list of the master themes was produced. This master list of themes was then applied to all interviews using NVivo 2.0, which helped to organise the data. A worked example of this process is provided in Appendix 6.

Criteria for Quality

In recent years, several researchers have offered guidelines to ensure rigour in qualitative research (e.g. Elliot, Fischer & Rennie, 1999; Mays & Pope, 2000; Yardley, 2000). Smith (2003b) highlighted the flexibility of Yardley’s (2000) guidelines for assessing the quality of qualitative research, and the usefulness of having criteria that can be applied to different theoretical orientations. Yardley’s criteria were therefore considered to be appropriate for the current study.

Yardley's Criteria for Quality

Yardley (2000) outlined three criteria that can be used to determine the quality of qualitative research. Attempts were made at all stages of the research process to ensure rigour and quality, which are summarised in Table 5 and outlined further.

Sensitivity to Context. The researcher has provided a clinical psychology service as part of the CF team to patients, families, and staff for a period of seven years. This prolonged engagement has allowed for familiarity with the context and events of the CF service and community (Krefting, 1991). Additionally, detailed notes were collated on important contextual information such as family relations, non-verbal communication, situational stressors, and other important information and impressions before, during and after interviews. This allowed for a better understanding of the similarities and differences between individual participants and more accurate interpretation of the verbal accounts. Also, this allowed the researcher to make explicit pre-existing views and perceptions, a process described as 'bracketing' (Ashworth, 1999; Smith & Dunworth, 2003).

Commitment, Rigour, Transparency and Coherence. Commitment to the topic was shown in several ways. The researcher was engaged in day to day clinical practice with the client group. The researcher was involved in raising issues about the potential psychosocial impact of segregation at local meetings with members of the CF team, and at regional meetings with medical and psychosocial professionals working in other Specialist CF Centres. In addition, the researcher guided the process of change when the segregation policy was introduced, and continued this process by ongoing evaluation and feedback of the impact of the policy upon patients, carers, and staff. This information has been presented at several national meetings and international conferences (see Appendix 7 for details of dissemination activities

during the study period). Ongoing research, reading, discussion, and dissemination of the process was undertaken during the period of study which highlighted the level of immersion in the data. Rigour was shown by the use of a process diary which highlighted the development of thoughts and ideas relating to interviews and analysis, a systematic method of organising paper and computer files which formed an audit trail to allow for independent observation of the process of data analysis (Rodgers & Cowles, 1993); and frequent discussions with a research supervisor regarding boundaries, roles, and objectivity. Extensive use of participant quotes are used to ground the analysis in the patient experience (Elliot et al., 1999). In addition, a worked example of the methodology has been provided to enable transparency of the process (refer Appendix 6).

Table 5. Summary of how Yardley's (2000) Criteria for Quality Were Met

Sensitivity to context	Commitment, rigour, transparency, coherence	Impact and Importance
Prolonged engagement in the research context	Engaged in program of research on and wide dissemination of topic	Topic of real life relevance to participants which meets gap in knowledge
Aware of recent CF community significant events	Use of process diary and audit trail	Wide dissemination of findings and highlighting clinical implications
Contextual information recorded for before, during and after interviews	Extensive use of quotes to keep grounded in participant's accounts	Advising other CF Centres on the implementation of segregation
'bracketing' of pre-conceptions	Worked example of analysis provided	Incorporating research findings into national Standards of Care
	Respondent and expert validation	

Respondent validation was undertaken by discussing the main themes with several participants prior to presentation at an international conference. Expert validation was undertaken by the process of discussion, clarification, and agreement of the main themes with a research supervisor (Krefting, 1991). Additionally, the main themes were presented, discussed, and clarified with expert CF psychosocial professionals at international conferences (Russo, 2006b; 2007a).

Impact and Importance. This research was clinically driven by the need to obtain information from young people with CF on the psychosocial impact of segregation to help professionals plan for and address potential difficulties when implementing segregation in CF Centres across the UK. Information obtained from young people and carers from a previous study by the researcher (Russo, Donnelly & Reid, 2006) contributed to the segregation policy and implementation plan, and this information was then disseminated at local, national, and international meetings (refer Appendix 7). The researcher is on the National Committee involved in updating the Standards of Care for UK CF Centres, and has advised other CF Centres in the UK and further afield on the practical issues of introducing segregation and involving service users in the process.

Reflexivity

Central to the IPA approach is the concept of reflexivity, that is, being aware of the influences of beliefs, culture, past experiences, and perceptions that shape the development of a study and subsequent analysis and interpretation (Burns & Grove, 1999). It is therefore important to note that the researcher was a female clinical psychologist with a belief prior to commencement of the research that segregation would be an additional burden upon young people with CF that may lead to

difficulties in managing hospitalisation, and further difficulties with coping with CF. In line with Bourdieu (1992), who suggested that ‘critical reflexivity’ is reflection about one’s whole approach to research, further details and reflections are provided in Appendix 8.

Ethical Considerations

As the researcher was an existing member of the CF team and was known to some of the families attending the CF Centre, consideration was given to the issue of power and compliance during the recruitment process. The pool of eligible participants was relatively large, which minimised pressure to recruit and the potential exploitation of vulnerable individuals or individuals previously known in a clinical capacity.

Prior to the research interview, the role of the researcher was explained to participants and their carers in order to clarify roles and boundaries during the interview. Participants were then provided with an opportunity at the end of the interview to discuss further any issues that were of concern. Two child participants subsequently raised concerns of a psychological nature unrelated to the content of the research following their interview, which were then addressed within the usual clinical remit of the researcher. One adolescent participant raised issues related to personal circumstances in the middle of the research interview. This was managed by stopping the interview and audio recording, and then following discussion and resolution of concerns and with the young person’s consent, continuing with the interview. Interviewing technique was facilitated with basic listening and reflecting skills, with no interventions being undertaken during the interview process. Further reflection of the issues involved in being a clinician–researcher are raised in the Appendix 8.

CHAPTER 4: RESULTS

Profile of Participants

A total of 14 young people with CF were interviewed. All participants were diagnosed with CF by neonatal screening⁸ during infancy. The average age of participants was 13.6 years, (range 7 – 17 years). The male to female ratio was 6:8 (male to female ratio of all patients was 49:52). Two participants had *pseudomonas* which had been eradicated some time ago; and five participants had been admitted previously to a different ward when they had *cepacia* or *MRSA* which had cleared since then. Table 6 below presents the summary profile of participants in terms of disease severity, infection status, hospital experience, and family background. A detailed profile of each participant is provided in Appendix 9.

Table 6. Disease and Demographic Characteristics of Participants

Disease characteristics	n	Socio-demographic characteristics	n
<i>Disease severity^a</i>		<i>Family background^b</i>	
Mild CF	5	Intact family	10
Moderate	5	Single parent family	4
Severe	4	<i>Siblings</i>	
<i>Infection status</i>		Healthy siblings	12
<i>Pseudomonas</i> +ve	8	CF siblings	3
<i>Pseudomonas</i> –ve	6	<i>Age group</i>	
Past <i>cepacia</i> or <i>MRSA</i>	5	7-10 years	2
<i>Hospital experience</i>		11-14 years	5
First admission	3	15-17 years	7
Admissions yearly	4		
3 monthly admissions	7		

^a Severity was rated by the CF Doctor according to the participant's most recent Shwachman scare, which is a method of classification according to scores on chest X-ray and other disease markers; ^b An 'intact' family was a family in which both parents and their child(ren) were living in the same home

⁸ All infants in Northern Ireland have been screened for CF since 1985

The high average age of the group of participants reflects the fact that most patients admitted to hospital for two week antibiotic treatments tend to have *pseudomonas*, with the average age of onset of *pseudomonas* at the Centre at the time of the study being 13 years.

Experience of Hospital Inpatient Care

The participants were homogeneous in that all had experienced a two week admission for IV antibiotics under the new segregated care arrangements. However, it became clear early on in the analysis that participant accounts differed according to prior hospital experience. Therefore, participants were grouped according to experience. ‘Inexperienced’ participants were those with limited or no previous admission or had remained in their rooms during past admissions (mostly *pseudomonas*-free). ‘Experienced’ participants were those that had had repeated admissions and in particular had formed friendships with other CF peers (mostly with *pseudomonas*). The average age of Inexperienced participants was 13.5 years (range 7 to 16 years), and the average age of Experienced participants was 13.7 years (range 10 to 17 years).

Organisation of the Results

This chapter is organised according to the first three research questions, (i.e. the experience of segregation; making sense of segregation; and coping with segregation) which are answered in turn by reporting on the main themes (referred to as ‘superordinate’ and ‘subordinate’ themes) identified using IPA. Illustrative quotes are used to highlight the main points and to remain close to participant accounts. All names are pseudonyms. The organisation of the chapter and the main superordinate themes for each research question is outlined in summary form in Table 7.

Table 7. Main Superordinate Themes for Each Research Question

Research Questions	SUPERORDINATE THEMES	
1. What is the experience of segregation?	<i>Inexperienced Participants</i> Segregation is protective, and better than expected	<i>Experienced Participants</i> Segregation is restrictive, and leads to a difficult stay
2. How do participants make sense of segregation?	Wanting to reduce the risk Importance of contact with similar others Difficult choices	
3. How do participants cope with hospitalisation under segregation?	Being resilient	

1. WHAT IS THE PATIENT EXPERIENCE OF SEGREGATION?

The first research question aimed to ‘capture the essence’ of the experience of segregation for young people with CF admitted to hospital for two week IV antibiotic treatment. Whilst Inexperienced participants did not perceive anything negative as a direct result of segregation per se, Experienced participants perceived segregation as restrictive and very different to their past experiences of hospitalisation (see Table 8).

Table 8. Superordinate and Subordinate Themes of the Experience of Segregation

INEXPERIENCED PARTICIPANTS MAIN THEME <i>Protective - Better than expected</i>	EXPERIENCED PARTICIPANTS MAIN THEME <i>Restrictive – Leads to a difficult stay</i>
Not feeling so alone Boring but manageable	Normality of admission No one to be with Range of negative emotions

Inexperienced Participants’ – Segregation is Protective, and better than expected

Inexperienced participants described the circumstances surrounding deterioration in their health leading up to their hospitalisation. For these participants, admission to hospital was a significant event. Main concerns and fears focused on procedures and being separated from family members.

Not Feeling so Alone

Participants with limited experience of admission perceived their hospitalisation as easier than expected. Several Inexperienced participants described how coming into hospital had helped them realise that there were others with CF who shared similar life experiences. For example, Belinda described how she felt reassured by this discovery despite not being able to mix with others:

You see it’s really strange, because you don’t think (*pause*) cause you don’t really normally walk about the street and think (*pause*) because people always ask you what it [CF] is and stuff. But there is loads of people that have it. I didn’t think there was that many.

So how does that make you feel?

That you are not the only one, not the only (*pause*), there’s other people that have it and they are worse than you. Stuff like that. (Belinda, age 13)

Inexperienced participants perceived that they received a lot of contact with staff during their admission, with one participant describing his contact with a physiotherapist ‘like a big brother’. Others appreciated when staff and medical students would come and chat with them, or join in on activities and tasks such as homework, crafts or play:

Yeah, it’s been really nice because at least you have someone else to talk to during the day. They come and check that you are ok, and help you with your schoolwork and have a laugh with you. (Belinda, age 13)

Boring but Manageable

Inexperienced participants reported that being in hospital was boring, but resources helped pass the time:

But what normally happens is that your days are marked in sections, and you know how the way you have breakfast early, and you have your treatment, physio, then treatment, then physio, then you are on your own for a wee while. So for the first half of the day up until about two-ish, I wouldn't be staring at the [TV or computer] screens or whatever, I would just be occupied with other stuff. (Bradley, age 16)

Most Inexperienced participants were, however, able to manage their boredom by engaging in activities such as reading, watching TV and videos, playing computer games, doing school work or other art activities with the play specialist. The words used by participants who had little or no previous experience of hospital admission included 'no worry', 'holiday' and 'a lot easier than expected'. Overall, Inexperienced participants reported that they did not feel segregation per se impacted negatively upon them.

Experienced Participants – Segregation is Restrictive, and Leads to a Difficult Stay

Experienced participants, in contrast, reported that their experience of hospital admission under segregation was difficult. They made repeated comparisons to past admissions which were perceived to be more positive. Table 9 highlights the change in language when Experienced participants spoke about admissions pre- and post-segregation.

The Normality of Admission

Experienced participants described admission to hospital as a 'normal' part of life for a person with CF and that they had been 'doing it for years'. Admissions

afforded a chance to see old friends and for this reason were associated with positive emotions. Experienced participants did not appear to be concerned about hospital procedures such as the insertion of the long line⁹, or blood tests. Instead, the focus of concern appeared to be on the new segregation arrangements:

Now it's like a real hospital, earlier it wasn't.
If it wasn't a real hospital, what was it like?
It would be a hospital, but I wouldn't have called it that, I would just say
(pause) I don't know, a home from hospital it was fun then cos you used to go out there and play games and all, and paint, and eat dinner together and all that there together, so you did. (Isaac, age 12)

Table 9. Descriptions of the Hospitalisation Experience Pre- and Post-Segregation

Before introduction of segregation		After introduction of segregation		
Fun	Have a laugh	Lonely	Different	
Happy	A second home	Miserable	Repetitive	
Relaxed	Liked coming in	Annoyed	Harder	Time goes slow
Brilliant	Good times	Grumpy	Thinking	Not fun
Excited	Good friends	Cheeky	Waiting	Need air
Chill out	Time went quickly	Bored	Prison	Didn't want to come
Chat	Memories	Homesick	Strict	
		Bad form	Stuck	

Note: Descriptions provided by Experienced Participants

The new care arrangements were perceived to be an additional burden resulting in a sense of loss and negative experiences and emotions:

But you see when we came in here before segregation, it wasn't like hospital. It was like you were going away, just, chill out for two weeks. But now it's

⁹ a thin tube inserted directly into the vein for a period of two weeks to facilitate the delivery of IV antibiotics

like, it's like (*pause*) a prison. I mean, like everybody is nice, it's not that, but it still feels like you are going to prison. (Fiona, age 15)

Experienced participants reported that they were reluctant to come into hospital since the introduction of segregation, and whilst in hospital they were eager to get home:

Before segregation I used to be like 'awwh I'm going home in so many days', and they [CF peers] were like 'awwh no I don't want you to go', 'No neither do I'. And now you're like, 'God I can't wait to get out of here'. You're literally counting down the hours. (Pam, age 17)

No one to be With

Experienced participants reported feeling more boredom since segregation, as they were not able to spend their spare time with others as they had done in the past. Participants reported that it was boring and time passed slowly on your own, so they preferred the company of others.

Participants had positive memories from past admissions, and many described their fondness of 'the Saturday night routine' of ordering in a meal and eating together. This kind of social get-together stopped when segregation was introduced and participants felt that they lost something special: "just that the way we were all, you know, so close and you know now we just, it's all gone" (Betty, age 12).

Experienced participants felt that they had lost the support of their CF peers due to segregation. One participant was concerned that restrictions in social contact with her CF peers would jeopardise the friendships that she had formed prior to segregation. Although she left her room several times during her admission to talk to other patients with CF, she noted with disappointment that other patients did not leave their rooms to reciprocate visits.

During past admissions, Experienced participants appeared to obtain social interaction from nursing staff when they were in communal areas and from other patients, in addition to their family members during visits. With segregation, participants appeared to rely solely on their families for social interaction. Several participants felt that the new policy did not impact upon the frequency of visits from their families, or on their desire for more frequent visits. Some perceived themselves to be lonely, even though they appeared to have the fairly constant company of family members and staff. One participant reported having difficulties being alone and separating from her mother – this appeared to be exacerbated by the new care arrangements. She described feeling guilty when her mother was trying to arrange a ‘day off’ from visiting:

She’s like ‘are you sure you’re ok, and we’ll see, we’ll talk about it in the morning over the phone’, and all that stuff, see how it goes. And I was like ‘I don’t really want to’. I didn’t say that, but in my head I was thinking ‘I don’t really want to do give you the day off, but it’s only fair’. (Betty, age 12)

Others perceived that they were never on their own as family members visited often. One older participant appeared to enjoy time alone on the ward, and felt “there are some times when you feel like you are being bombarded and you would rather be by yourself for while. (Bradley, age 16). One participant described the kind of conflict that characterised family visits when siblings come along now under segregated care arrangements:

It’s annoying, because they keep nagging ‘mummy can we go home?’ And I’m like, ‘no mum please don’t go home’. And she’s like, ‘would all of you just shut up?’ (*laughs*) You know, cause we’re all nagging at her. (Betty, age 12)

Participants described their attempts to seek interaction from members of staff in order to reduce boredom by breaking the rules of segregation, which resulted in negative attention; or by asking for something:

What would you ask for?

Just something stupid like a glass of water or something. (laughs)

(laughs) Would you ever say to them 'hey I'm just bored, I'd like some company?'

Eh no not really, because they wouldn't have time.

And have.. how do you know that they don't have time?

I just notice, they just kinda do what they have to do and then go, they don't really want to sit and talk with you. (Ian, age 15)

Participants reported that staff used to interact with patients in the past, and often got 'into mischief' along with patients:

Like, I can remember us sitting down there in the nurse's station absolutely having a ball. *(Getting excited)* It was brilliant, and during the summer and everything, the nurses used to have water fights with us and the ward used to be drenched - it was just brilliant! *(smiling)*. (Pam, age 17)

With segregation, however, participants reported a change in the quality of relationship with staff, with the focus of interactions now almost solely on treatments:

"No one just comes in and has a chat you know, they are always giving you something" (Donna, age 10). There were several participants who felt staff tried hard to spend more time with patients, with one showing awareness of the impact of segregation upon staff:

But I think it's harder now for the nurses because there's more of us. Whereas before the nurse could have talked to us together but now *(pause)* I don't expect nurses to come around all the time and sit because they have the rest of the ward. (Fiona, age 15).

Range of Negative Emotions

All participants explained that being in hospital was boring. However, Experienced female participants expressed the most dissatisfaction with boredom, seeing it as a direct result of no longer having anyone to talk with. Those who did comment about being bored felt that they perceived time ‘slowing down’ when they were on their own. To manage feelings of boredom, female participants appeared to seek social contact, whereas male participants enjoyed the computer games and equipment, and appeared to be less bothered about boredom.

Some participants felt that each admission was more difficult than the previous one partly because the hospital environment was a reminder of the nature and severity of their disease. For some participants, segregation intensified this worry because they experienced more time on their own to think and ponder about their illness and their life: “I think it gets harder, because you just... you get.. I suppose, you get older and you realise, and it gets harder” (Betty, age 12).

Some participants reported that segregation resulted in frustration and annoyance at restrictions imposed upon them, and also due to the mixed messages given by staff. For example, one participant was chastised for ringing for a nurse to get a drink, despite not being allowed to get it herself:

I felt like shouting back at her, but I knew that’s not the solution. Cause I felt like saying ‘why are you saying that when I’m not allowed out of my room, and I’m trying to be good and stick to the rules, but I could go out and get it but yet somebody would come round the corner and catch me and I’d get shouted at’, you know. (Betty, age 12)

Participants with *pseudomonas* were reluctant to get *cepacia*, although no participant reported excessive anxiety about this. Few participants reported feeling stigmatised with *pseudomonas*, as this was perceived to be common amongst other patients. One

participant was embarrassed at the use of gloves and aprons by physiotherapists during admissions: “They make you feel like you’ve got some really bad disease that’s going to kill everybody you know, sometimes that feels a bit horrible” (Betty, age 12). One participant who had *MRSA* in the past reported feeling stigmatised by other patients and the general public:

You were treated like a leper a wee bit. If someone was coming down the corridor they would go ‘here’s Ian, get into your room’. [*and later*] You don’t want to mention it to people in case they think you’re going to give it to them and they’ll die, so you don’t want to mention it. (Ian, age 15)

This participant felt less stigmatised in the CF ward under segregation than being treated in a different ward, despite not having contact with other CF patients:

You feel a wee bit more normal down here. So at least down here if you do run into somebody by mistake it wouldn’t be the end of the world, like cause we all have the same thing anyway, most of us, so you just feel a wee bit more normal. (Ian, age 15)

Section Summary

It is clear that Experienced participants had more and greater difficulties than Inexperienced participants with the new segregated care arrangements. The process of comparing past and present hospital experiences made segregation more difficult to manage and appeared to be associated with a feeling or sense of loss among Experienced participants.

2. HOW DO PATIENTS ‘MAKE SENSE’ OF SEGREGATION?

The second research question investigated how participants made sense of segregation. Participants were able to identify the positive aspects of segregation (i.e.

reducing the risks) in addition to identifying the main loss associated with segregation (i.e. reduced contact with CF peers). These two conflicting aspects of segregation were discussed in-depth by participants, as outlined in Table 10.

Table 10. Superordinate and Subordinate Themes of the Meaning of Segregation

THEME 1 <i>Wanting to reduce the risk</i>	THEME 2 <i>The importance of contact with similar others</i>	THEME 3 <i>Difficult choices</i>
Being aware of cross-infection	Trying to be normal	Balancing between risk and normality
Managing this awareness	Only CF patients really understand	Incorporating our needs whilst reducing risks

Superordinate Theme 1 - Reducing the Risks

The first superordinate theme revolves around how participants appear to be ‘experts’ in terms of having knowledge and insight about their health, overall, and about CF and its treatment. Having this ‘expert’ information subsequently helps young people with CF form their own views about segregation and cross-infection, although this is hampered by the awareness of the negative aspects of segregation.

Being Aware of Cross Infection

Participants appeared to understand how CF impacts upon their health as well as the underlying rationale for various treatments. Younger children, such as Stephen, age seven years, sometimes struggled to find the right words but were able to describe the main symptoms and aspects of treatment:

I know I could get fungus, and I could get (*pause*) what is it? I can get this type of cough (*pause*); I forget what it is called. It's a bit like (*pause*) it sounds a bit like cancer but it's not. I don't know I forgot. Yeah, but I think it's going away. (Stephen, age 7)

Older participants were able to recall their bacterial history in detail, and this knowledge appeared to play an important role in their discourse with doctors regarding symptoms and illness experiences:

I've been saying the whole time that I thought I had Aspergillus¹⁰ but nobody really thought I did and then it showed up in my spit this morning that I did so (*pause*). And the antibiotics make the Aspergillus worse so that's why I have it now. (Ian, age 15)

All participants were aware that bacteria could be found in the environment and could be passed between people with CF, and most were aware that segregation was a method used to reduce the risk of cross-infection. Participants reported that their knowledge of bacteria had increased as a result of the introduction of segregation. However, awareness about different strains of bacteria was lacking.

Managing This Awareness

Several of those who had been isolated in the past (with *MRSA* and *cepacia*) reported that the segregation policy reduced their concerns about cross-infection. One Experienced participant who was used to mixing with other young people with CF reported that the policy removed the potential for 'awkward' social interactions:

Yeah, I sort of would be worried [about cross-infection during past admissions]. Because say if somebody had a really bad bug and we were allowed to mix at that time, it would be sort of hard to try and stay away from them because they would be keep coming over to you and passing it on. I'd just be nervous with anyone in case they had a different bug than I had. Like, I wouldn't have really told anyone I'd just have been like 'here you go', really nervous like then. After a while I got kind of used to it. And now since

¹⁰ a type of fungus that grows in the lungs, particularly after 2 week antibiotics, that causes the feeling of tightness in the chest

segregation started it's got a lot easier, because you can't touch anything that they've touched. Or the nurses and all have to wash their hands before they come in and stuff. (Katie, age 14)

Participants without *pseudomonas* appeared to be motivated to remain free of *pseudomonas*, and believed that the risk of infection would be reduced if they stayed away from others with CF. One participant who had *pseudomonas* in the past although was currently clear described the importance of not getting it again:

I don't want it, simple as that, I just don't want it cause all of the extra treatment and my spit would have been a lot stickier and harder to get up, and I would have been more short of breath, stuff like that. (Betty, age 12)

The youngest participant Stephen, aged seven years, described that he did not want to mix with CF patients with other bacteria and appeared to judge the level of risk based upon perceived similarities between each patient and his own profile: "Oh, well I think it would be OK if I had the same, and they are going home with the same, and they looked the same, same age" (Stephen, age 7).

Some participants appeared to be observing staff to ensure they were complying with infection control guidelines, with several participants commenting that staff had not washed their hands upon entering their rooms. Others commented that some staff were not enforcing the policy:

But nearer the night, some of the other nurses would like ignore the fact that there is segregation. It's like when they see two people talking they would just walk past and not say anything. (Bradley, age 16)

In contrast, participants who had *pseudomonas* perceived colonisation to be 'inevitable' and appeared less concerned about the risk of cross-infection: "I think that if you are going to get it you are going to get it" (Fiona, age 15). Experienced participants highlighted 'gaps' or risks of cross-infection that they believed were not addressed by the segregation policy. For example, participants noted that staff in the

hospital shop did not clean surfaces after each CF patient visit; and cleaning staff did not clean dials on music equipment or door handles. One Experienced participant felt it was the responsibility of the staff, not patients, to prevent cross-infection:

I think if they [CF staff] don't want us to catch the bugs they should be looking out for these small things themselves. We are put in our rooms for the segregation and it's not as if we all want the segregation. (Pam, age 17)

Finally, participants who had siblings with CF were aware of the increased risk of cross-infection due to prolonged close contact. One participant shared a room (and identical strain of bacteria¹¹) with her CF sibling, and was not concerned about cross-infection. However, other participants with CF siblings reported difficulties with everyday tasks such as mealtimes and travelling in the same car due to trying to minimise risks of cross-infection. The disruption to family life was evident. One participant described the difficulties of staying away from younger CF siblings when she had *pseudomonas* in the past, and her thoughts on cross-infection: “I would feel really bad [if they got *pseudomonas* from me], because they werebecause they are younger they would have had more chance of them... you know, having to come in” (Belinda, age 13).

Superordinate Theme 2 - The Importance of Contact With Similar Others

The second superordinate theme related to the social world of young people with CF. Subordinate themes related to perceiving themselves as ‘normal, but different’ to healthy others, including peers and family members. These differences made relating to healthy others on a personal level challenging, highlighting the importance of having contact with others with CF who share their experiences.

¹¹ bacteria have different strains. An identical strain suggests the same environmental source or cross-infection.

Trying to be Normal

All participants were diagnosed with CF during infancy. Most stated that they did not feel any different to their healthy peers, though they engaged in treatment-related tasks where their friends did not: “No, I feel like normal still, the only thing that is different is that I take tablets to eat and everyone else can just eat” (Isaac, age 12). Despite explicitly stating that they were ‘normal’, participants appeared to be acutely aware that they were indeed different from others: “I’m the only one in my school who has CF. There used to be [another] one but now I’m the only one” (Stephen, age 7).

Most participants reported that their school friends were aware that they had an illness called CF, but did not know much about it. Participants differed with regards to how much they shared CF with their healthy peers. Whilst many older participants were open with their friends about their disease and admissions to hospital, not all were open about the severity of their disease. For example, one participant described how she did not want her friends to visit in hospital, preferring to keep her life of CF treatment separate to her everyday life to avoid feeling different: “I just would want like, to get it done and then (*pause*) get back to normal and carry on again” (*laughs*) (Brenda, age 15).

Older female participants described how their ‘best friend’ would attempt to learn about CF and would try to offer support. However, participants stated that their healthy peers did not share their knowledge or experience and that this difference made it difficult for them to relate to and confide in their friends: “She wouldn’t understand as much, but she tries to, she tries to make it easy” (Fiona, age 15). One participant with severe CF who spent a lot of time in hospital described the difficulties in ‘reconnecting’ with healthy peers after discharge home from hospital:

[you feel] a bit left out, sorta thing. And then you don't wanna talk about what happened in the hospital because you don't really want their sympathy or whatever. So you just try and sit until something else more exciting that's happened. (Pam, age 17)

Although this same participant was open regarding frequent admissions, she described a reluctance to share too much information with her healthy peers as it appeared to affect how others related to her:

I'll not say anything, cause in case it like, like not annoys them but, in case they start feeling weird or anything, in case they're not comfortable talking about it or something. Even though it's my illness, and in case they just don't like it or something. (Pam, age 17)

Many participants described relying on their mother for emotional support, due to shared experiences of coping with CF and hospital admission. However, participants also reported difficulties in confiding fully in their carer. For example, Betty spoke about holding back from her mother as a way of protecting her from additional worries: “she gets really stressed out and I worry is it ok for her” (Betty, age 12).

Most participants with healthy siblings reported feeling different within the family and at times resentful about ‘having to do treatments’ when their siblings were ‘having fun’:

If I had one brother and sister and they didn't have it, it would be alright. But I've got [several] brothers and sisters, and they are all running around, and I'm like ‘no I don't want to be in here doing this [physio]’ (*pause*). I know they wouldn't say nothing or anything, but I just like doing it myself. I don't like to create a big show. (Brenda, age 15)

Participants reported that their healthy siblings did not understand the difficulties associated with CF. Several participants reported their annoyance at healthy siblings, who would comment about how fun it would be to stay in hospital.

Only CF Peers can Understand

Experienced participants described that prior to the changes they helped one another cope with hospital admission by spending time together. Furthermore, they sought advice from their CF peers about invasive interventions such as nasogastric tube feeding and Portacaths¹². Participants noted also that they learned about the way that CF progressed and varied between patients by having contact with others:

Sometimes it would have been, yeah about our treatments. You know you'd maybe say 'awwh this morning I nearly choked on my whatever tablet, my vitamins this morning', and they'd be like, 'what are they?' Like maybe not them like maybe 'I'm on that' and other people wouldn't be because it's more of an asthmatic one, and they'd be like, 'what's that, what does that do' and stuff like that. (Betty, age 12)

CF peers were also an important source of information, particularly regarding managing treatments in every day life. Participants described how talking and listening to other CF patients particularly about treatments helped them to prepare ahead for changes that they might experience:

And they'd say 'I have to go and get my feeds'¹³ and you'd be like, 'what do they really do for you? Do they make you eat or do they make you put on weight, or are they nice, do you taste them?' Things like that.
And would you ask those sort of questions to [name of consultant]?
 Not really because I don't really have to go on them so I don't really need to know. (Betty, age 12)

Older participants and those with more severe disease appeared to express the strongest desire to talk with others who shared similar experiences. They believed that only those with CF could understand which made their friendships with CF peers unique. "Talking to people like CF patients in here, it's really easy because they know what you are going through, but nobody else seems to know" (Fiona, age 15). The

¹² A device implanted under the chest wall giving direct venous access, used for those who require regular IV antibiotics who have veins that are difficult to access with a long line

¹³ NG or peg feeds administered by the stomach in order to increase caloric intake

opportunity to talk with CF peers was particularly important to them as their healthy peers did not have the knowledge or vocabulary of CF and this ‘mismatch’ limited discussion. Having contact with CF peers allowed discussions to occur on topics that could not be discussed with healthy peers: “Well, I’d speak to Fiona more like (*pause*) because she has CF, and she knows what it’s like” (Roisin, age 15).

Participants also explained how they would turn to their CF peers for emotional support, because they could relate to them in a way in which healthy peers were unable to do. One older participant reflected on the amount of support she used to provide for others: “you knew how to just talk to her and what to say because you knew about the illness and everything. And it’s just gonna be hard on people, growing up now” (Pam, age 17).

Despite good relationships with staff, Experienced participants explained that it was difficult to talk to staff about certain issues, such as feelings about having CF:

We should still be able to talk to our friends. The people you want to talk to are the others with CF, not them’uns, the staff.

Sometimes you don’t want to talk to adults about things?

No, (*pause*) like, I can talk to you because I can always talk to you. But I couldn’t just sit [names Consultant] down and start talking to him about whatever.

Why not?

I don’t know I just couldn’t.

What about others, like the physios or nurses?

I couldn’t tell them everything. But the others [other patients with CF], you want to chat. (Fiona, age 15)

Participants were annoyed by staff comments that ‘two weeks out would be relaxing’, feeling that others did not understand how difficult it was to remain on their own during admissions. Several participants joked that the CF staff should experience an admission under segregated care arrangements and claimed that they would not be

able to cope: “I just think they’d start cracking up. It would let them know how we feel - like taking them away from their families and their friends and everything, they would really hate it” (Pam, age 17).

Superordinate Theme 3 – Difficult Choices

Balancing Risk and Normality

All participants understood the importance of minimising cross-infection amongst patients. Those without *pseudomonas* reported that ‘it was better to stay away’ from others with this bacteria. Those who had not established strong friendships with their CF peers appeared to be more accepting of the new care arrangements, and appeared to ‘weight’ the health benefits of segregation over social contact. This view was held even by those who recognised that not mixing would result in boredom: “Well, just that you have no one to talk to, you are all on your all day and everything. But I think it’s good because then nobody else catches anything else so you get better quicker” (Belinda, age 13).

Participants without any established CF peer friendships were curious about other people with CF during their hospital stay as they recognised that others were similar to them. Inexperienced participants recognised benefits of contact with CF peers and expressed a desire to do so, although accepted the restriction that came with segregation:

Well I don’t really know anyone, so if I have questions I ask the nurses. It would be nice to chat to someone but we can’t really, we are not allowed. I think it’s OK if it helps us not to get anything. (Belinda, age 13).

However, one older Inexperienced participant described that he would seek contact with similar others in the future, although would remain mindful of the risks:

[if I saw another person with CF] I would probably go up and talk to them about it, without thinking about it. I don't think 'I don't want to go near you; I don't want your disease'. Like, it would come up in conversation, like what kind of stuff you had. And like, if they didn't have *pseudomonas*, or if I didn't have it at the time and they did, I would be like 'sorry, I can't do this with you, just in case I get this'. (Bradley, age 16)

Participants who had *pseudomonas*, *MRSA*, or *cepacia* in the past and were clear now appeared to be the most concerned about re-infection. These participants were motivated to remain *pseudomonas*-free and thus prioritised their health over social contact: "As long as I don't get anything, as long as I stay well and healthy, so it doesn't really matter what (*pause*) what I would have to do for it, I don't think" (Ian, age 15). However, Experienced participants with *pseudomonas* seemed to prioritise their friendships and social contact over strict adherence to the rules of segregation. Experienced female participants in particular expressed negative comments regarding the reduced opportunity for social contact during admission:

It's been hard coming in here and knowing they [names two friends] were both in it's kind of (*pause*). It's hard, you just kind a (*pause*) feel bad that you can't talk to them. And they are just there. (Fiona, age 15)

Those with *pseudomonas* did not recognise any additional advantage to be derived from not mixing and they felt that they had 'nothing to lose' by maintaining contact with others.

Incorporating Needs Whilst Reducing Risks

Several Experienced participants felt that patients should be able to mix during admissions:

It's hard enough (*pause*) it's hard to explain but (*pause*). It's hard to come in here knowing that you have nobody. You have nobody in here until somebody visits here, that's the only time you get to talk. (Fiona, age 15)

Experienced participants identified alternatives to the segregation policy with many suggestions well thought out and logical in relation to the known evidence regarding risk. In particular, they felt that patients with the same bacteria should be able to mix, essentially describing cohort segregation:

Apparently there's different strains, but (*pause*). My view is well, that if you're taking the treatment for that bug anyway, it's not really going to make any difference [if you mix with others with *pseudomonas*] like. But (*pause*) I'm not a professional or anything, I don't know. (Brenda, age 15)

One participant felt that swabbing each patient as they came in for admissions would facilitate this 'cohort' segregation: "I would nearly say people would prefer something sticking in the back of their throat and up their nose¹⁴ if they are allowed out to have a decent conversation with somebody" (Pam, age 17).

Two participants argued that patients with CF should be able to mix if they were in the open air outside. One suggested that wearing masks when mixing would reduce risks, although she was aware of the stigma associated with protective equipment: "Well I don't want to look like a SARS victim or anything (*laughs*)" (Brenda, age 15). Suggestions were also made to allow those with different bacteria or strains to communicate, such as using walkie talkies or email. A few Inexperienced participants felt that having IV treatment at home (home IVs)¹⁵ would minimise the risks of cross-infection, whilst also preventing spending time alone during admissions. One had discussed this arrangement already with their carer as an alternative to future admissions.

Several Experienced participants reported that they did not participate in consultation or involvement exercises such as surveys about the introduction of

¹⁴ referring to the giving of sputum in order to be cultured to identify bacteria

¹⁵ IV treatment given in the home setting by parents/ carers after intensive training

segregation because they did not feel that any patient would want segregation. Therefore they were surprised when they learned that the majority of young people with CF wanted segregation to be introduced.

Section Summary

It is clear that the dilemmas raised by the issue of cross-infection are difficult for young people with CF. Huge importance was placed upon the role of CF peers in managing and feeling normal with their disease, and those with established friendships felt this would be a big loss to them and future cohorts coming through. Again, Experienced participants appeared to feel the loss of segregation more, which then influenced how they made sense of it and their support for the policy.

3. HOW DO PATIENTS COPE WITH SEGREGATION?

The third research question explored how participants coped with segregation during hospitalisation. One main superordinate theme of ‘*Being resilient*’ was evident (see Table 11), which highlighted the strengths of participants managing their disease, the treatments, hospitalisation, and the new threat of cross-infection.

Table 11. Superordinate and Subordinate Themes of Coping With Segregation

THEME 1 <i>Being resilient</i>
Striving to be normal
Feeling at home in hospital
Managing on my own

Superordinate Theme 1 – Being Resilient

This main superordinate theme of *‘being resilient’* consisted of three subordinate themes, which each described how participants managed aspects of their hospitalisation.

Striving to be Normal

Participants were acutely aware that healthy peers had better health, did not do complex daily treatments, and did not experience hospitalisation. These comparisons were associated with negative emotions such as frustration, isolation, and worry:

Like you have to go in early to do your physio and you have to take your tablets and all. Usually you feel on your own, thinking that no one understands what you have to do. (Belinda, age 13)

Inexperienced participants appeared to find reassurance upon admission knowing that there were others with whom they could compare their experiences, and “that you are not the only one, not the only (*pause*) there’s other people that have it and they are worse than you” (Belinda, age 13).

Participants perceived themselves to be more resilient than their non-CF peers which appeared to give them a positive feeling of strength regarding life in general. “Like, I always felt older than I actually was when I was younger. I feel my age now, but I used to think I was so much more mature, just mentally” (Bradley, age 16).

Experienced participants were able to compare themselves to their CF peers and this comparison seemed to reduce feelings of being different. In this way, they were able to feel a sense of being ‘normal’ when they were experiencing their treatments, admissions to hospital, and generally about life with CF. “Talking to people like, CF patients in here, it’s really easy because they know what you are going through, but nobody else seems to know” (Fiona, age 15).

Social comparison was used as a strategy to cope with living with CF, in addition to admission to hospital. Comparisons were made on topics which included coping skills, visitors, illness severity, and general health. Comparing to CF peers appeared to result in positive emotions, and served the need for information, reassurance, and belonging. Participants who had no previous contact with other CF peers were only able to compare their experiences to their healthy peers. Comparing to healthy peers appeared to enhance participant's sense of resilience, however was also most likely to lead to a negative emotions such as isolation.

Learning to Feel at Home in Hospital

For Inexperienced participants, generally, hospitalisation was considered to be a stressful event as it was a new experience. The most difficult part for Inexperienced participants were procedures, particularly the insertion of the long line used for IVs. In contrast, most of the Experienced participants reported that they no longer had difficulties with procedures, and did not find hospitalisation per se too challenging. Participants minimised the role that hospital played upon their lives, stating that they had 'always' come into hospital. "When you've been doing it for fifteen years like, you just sort of get used to it" (Brenda, age 15).

Prior to segregation, Experienced participants used their CF peers in many ways to help them adapt to being in the hospital setting. In addition, informal contact with staff (such as having fun; short but frequent contact) was helpful. Family members were not required as often due to the availability of CF peers and staff. In addition, there were many organisational resources, such as the pool table, dance mat, communal lounge, shared kitchen, frequent takeaways, and arranged group activities such as cinema outings and art therapy that were available to reduce boredom.

A range of coping resources were available to participants pre- and post-segregation to help them manage their hospitalisation. The most commonly mentioned resource used during past admissions was the company of CF peers, which was perceived to be beneficial in helping pass the time and reducing boredom. CF peers were the source of information, reassurance, distraction, and support for Experienced participants. Following the introduction of segregation many of the coping resources used during previous admissions were no longer available (see Table 12). This resulted in participants having to learn new ways of managing within the hospital setting. For Inexperienced participants, this was less of an issue as they had not used contact with CF peers and other available resources during admissions, and so did not have any experiences to compare to.

Managing on our own

A range of strategies were used by participants in order to cope with life with CF, hospital admissions, admission under segregation, and managing the risks of bacterial infection. The biggest challenge for Inexperienced but especially Experienced participants related to having to spend their time on their own in hospital under the new care arrangements.

Table 12. Coping Resources Used by Participants Pre- and Post-Segregation

Prior to segregation	Following segregation
CF Peers	
Healthy peers	Healthy peers
Family members	Family
Staff	Staff
Organisational resources	Individual entertainment resources
Group activities	
Individual entertainment resources	

Coping with segregated care arrangements appeared to be less difficult for participants who had none or only a few admissions to hospital. These Inexperienced participants appeared to manage segregation by keeping themselves busy with activities, games or reading, spending time with frequent visitors, and leaving the ward for short periods of time with family members. One male participant was able to compare his past experiences of hospitalisation for surgery to his CF admission. “It could be a lot worse. What you have here is good. A lot of my stuff I would compare to being over in [the surgical] ward” (Bradley, age 16). Most Experienced participants, in contrast, appeared to find the new care arrangements more difficult to manage due to the change in the hospital experience. “There’s so much (*pause*) there’s so many memories down here, so many good times you had, even just going to school it was just (*pause, sighs*)” (Fiona, age 15).

Despite differences in the experience of segregation all participants used a range of strategies to manage being on their own in hospital. Many appeared to use positive coping strategies, such as having something to look forward to at the end of the admission, and providing self-reassurance: “I’ll be saying to myself ‘aww, you’ve only a few more days to go, its ok’, stuff like that” (Betty, age 12).

Most participants reported bringing in personal objects from home in order to make their hospital room look more like home. Several enjoyed engaging in hobbies such as playing the guitar or reading up on magazines, that they enjoyed doing at home on their own. All participants reported that they enjoyed ‘getting out of their room’ during their hospital stay – sometimes visiting home for short periods, or going shopping or out for meals locally, and even simply visiting the hospital shop.

Whilst boys appeared to engage in activities within their rooms, many of the female participants found this difficult to do and attempted to seek social interaction.

Some participants used alternative ways of communicating with their CF peers in different rooms such as leaning out windows to talk, using walkie talkies, texting, and using the Patient Line phone to call direct. Several participants developed strategies that appeared to initiate or increase social contact with members of staff, either by keeping the door open and calling out to individuals passing, asking for food, or directly arranging with specific members of staff to visit when family members were not present. “I asked the play specialist as she was walking out, so she’s going to try and be with me a bit more tomorrow” (Betty, age 12).

Experienced participants reported that adaptation to segregation took place over time, “cause in a way then, that whenever you keep coming in you kind of get used to it, all the times are just going to be like the last time, really boring” (Katie, age 14). Some participants engaged in coping behaviours that led to difficulties in managing time on their own during hospitalisation. Those who dwelt on the fun of past admissions appeared to feel sad about the things that had changed. Those who dwelled on the ‘unfairness’ of segregation, or whom engaged in wishful thinking appeared to have the most difficulty.

Similarly, those that focused on challenging the rules of the policy experienced more negative emotions. Using the communication resources (i.e. walkie talkies) to arrange face to face contact without staff knowledge also led to difficulties in adjusting to segregation, and appeared to interfere with acceptance of the new care arrangements. One participant continued to leave her room to speak with her CF peers in their rooms, leading to being chastised by staff resulting in feelings of anger and loneliness. This same participant had delayed her admission by not informing her mother of the severity of her symptoms.

Section Summary

Young people with CF appear to cope with many challenges associated with feeling different, in addition to the demands placed upon them by their disease and treatments. Most saw themselves as resilient, and described several strategies that they found helped them manage their lives with CF and to cope in hospital under segregation.

4. CHAPTER SUMMARY

The process of IPA revealed that for Inexperienced participants, admission under segregation was boring but acceptable as it reduced the risk of cross-infection. In contrast, those who had experienced admissions prior to segregation found the new segregation policy resulted in a significant loss and a yearning for a return to the way that admissions had been managed in the past.

Young people with CF reported that they had the knowledge and experience to contribute to decisions about their care. Participants recognised that they shared a special bond with other young people with CF and this bond appeared to be invaluable in helping them adjust to their lives with CF. There was a dilemma between maintaining a sense of normality by ‘keeping in touch’ with CF peers or minimising the risk of cross-infection. Despite this difficult dilemma, there was a sense of resilience and acceptance of segregation and the new challenge of cross-infection.

CHAPTER 5 - DISCUSSION

This final chapter discusses the findings of the current study in relation to the aims of the study and existing literature and theoretical constructs outlined in Chapter One. Focused additional attention is being given to the final research question regarding the potential psychosocial impact of segregation upon young people with CF with a view to discerning implications and lessons for clinical practice. The methodological strengths and limitations of the current study are discussed, followed by suggestions for further research.

1. WHAT IS THE PSYCHOSOCIAL IMPACT OF SEGREGATION?

Previous research has identified that carers and young people with CF support the introduction and use measures such as segregation because they reduce the risk of infection (e.g. Griffiths et al, 2004; Russo et al, 2006). The results of this current study provide an in-depth account of the experience of segregation and the meanings that young people place upon bacterial infection, segregation, and hospitalisation. The findings indicate that there are four ways in which segregation appears to impact upon young people with CF: (a) increased awareness-related anxiety about bacterial infection, (b) loss of contact with CF peers, (c) coping with hospitalisation under segregation, and (d) potential fragmentation of the CF community. Each of these four issues are discussed, in turn, including their relationship to existing research and to possible implications for clinical practice.

Anxiety about Bacterial Infection

The first way in which segregation has impacted upon young people with CF is in terms of heightening their awareness about bacterial colonisation and prevention or

control measures. Infection control does not appear to be a major or frequently reported concern in existing research about young people with CF and their families, suggesting that this is a relatively new concern.

Risk Information

Knowledge. The participants of the current study appeared to have good understanding about treatments, bacteria, and infection status. This finding contrasts with other research such as Chapman and Bilton (2004), and Pizzignacco and de Lima (2006), who found that young people with CF did not have a good understanding about their disease. This higher-than-expected level of knowledge may be due to the process of implementing the new care arrangements when patients and families received written information about cross-infection and its control (refer Appendix 1 for information leaflet). In addition, ongoing discussions were undertaken with patients and their families to encourage their involvement in the process of change. However, the rationale for continuing to segregate patients who had *pseudomonas* (i.e. in order to prevent multi-resistance) did not appear to be as well understood, particularly by those with *pseudomonas*. Participants with *pseudomonas* appeared to be frustrated by segregation because they did not perceive that there was any additional benefit: “we are already being treated for this bacteria anyway”. There is evidence of poorer outcomes for those with multi-resistant epidemic strains of *pseudomonas*, such as the Liverpool strain (Al-Aloul et al., 2004), the Manchester strain (Jones et al., 2005), and the Melbourne strain (Griffiths et al., 2005). Therefore preventing the development of multi-resistance is important and needs to be appreciated and understood by young people with CF.

The introduction of segregation in specialist CF Centres has raised the level of awareness of bacteria amongst the CF community. For most of the participants in the current study, this awareness did not appear to lead to generalised fear or anxiety about contact with other young people with CF. A few participants reported situational anxiety at times of heightened risk. In comparison, there is some evidence to indicate that anxiety among carers about contact between their son or daughter and other people with CF appears to be high (Ullrich et al., 2002; Russo, in preparation), perhaps reflecting the responsibility that carers feel to keep their child infection-free.

Awareness has also increased regarding the presence of bacteria in the general environment. Participants in the current study were aware of these risks, and again did not appear to experience generalised fear or anxiety about specific 'high risk' environments. Again, preliminary findings from research interviews with carers that were conducted in parallel with the study reported here suggest that carers are concerned about these risks and that they manage anxieties by engaging in preventative behaviours. Ullrich et al. (2002) reported increasing anxiety about environmental acquisition in carers following the introduction of segregation in Germany. CF families there reported engaging in strong avoidance behaviours and preventative actions in order to minimise the risk of environmental contamination, which for many families impacted negatively upon their quality of life. It is clearly important to ensure that the information given to families about the risk of infection does not over-burden and impact negatively upon family life.

Developmental Understanding. From a developmental perspective, it is believed that even young children can understand issues related to cross-infection and risk. By the age of six years, children can think logically and systematically, however may lack the knowledge base to solve real life problems (Sroufe, Cooper & DeHart,

1996). Broeder (1985) highlighted that children's experience of isolation was influenced by their age-related understanding of the reasons for their isolation. Harboard, Cross, Botica and Martin (1987) showed that children's knowledge and understanding of CF increased with age though even children under 7 years appeared to understand causation which was in contrast to previously published research. Eiser (1989) highlighted that it was the experience of events that shaped understanding in children, rather than understanding being purely dependent upon cognitive development. This current study indicates that young participants appeared to understand the rationale for segregated care and to adhere to the procedures and restrictions emanating from this. The youngest participant Stephen, age 7 years, clearly described his desire to reduce the risk of getting bacteria from other patients, and he remained in his room for his stay. However, he perceived patients who were similar to him as being 'safe', that is, that they had the same bacteria. This suggests that younger people with CF look for differences in appearance in order to identify bacteria – an ineffective strategy to use to determine whether or not another patient has the same bacteria. In turn, this strengthens the argument for discouraging contact between all people with CF in order to minimise opportunities for young people like Stephen inadvertently mixing when perceiving others as 'safe'.

In Adult CF Centres, segregation is advised in order to reduce the risk of cross-infection during hospitalisations, although professionals acknowledge that adults can make informed decisions on whether they adhere to recommendations. Waine, Whitehouse and Honeybourne (2006) reported that 35% of adults with CF responding to a questionnaire still chose to continue to mix despite being discouraged from mixing. In a paediatric setting, professionals have a duty of care to ensure that young people with CF who are hospitalised for treatment are not placed at an

increased risk of cross-infection. This implies that the wishes of a minority of young people with CF to mix needs to be placed second to the need to reduce risks for all young people with CF. Two important issues arise from this. Firstly, it remains unclear as to when young people with CF are able to give ‘informed consent’ to mix with their peers. Secondly, there are challenges to delivering quality care when the service users disagree with how the care is delivered. Chan et al. (2006) and Koller et al. (2006b) highlighted this issue during the SARS crisis, when the need for infection control was prioritised over family-centred care.

The Appraisal and Management of Risk Information

Information per se does not necessarily lead to increased knowledge and understanding about personal risk (e.g. Gerrard, Gibbons & Bushman, 1996; Sheeran, Abraham & Orbell, 1999). Furthermore, salient individual beliefs may be incongruent with knowledge, and the ways in which events are *perceived* have been shown to be important regarding health behaviours (Janz & Becker, 1984). In the current study, the provision of information helped individuals to become aware of the risks of cross infection. However, as with existing research, the perception of risk of *pseudomonas* infection appears to be important in terms of understanding the differences in levels of support for segregation, and the extent to which young people cope with segregation. The concept of primary and secondary appraisals from the Transactional Model of Stress and Coping offers a useful framework for describing how participants make sense of the risk of bacterial infection. Table 13 shows that the primary and secondary appraisals made by participants without *pseudomonas* (i.e. Inexperienced participants) differ to those with *pseudomonas* in several ways.

Furthermore, the differing appraisals appeared to result in the use of different strategies in order to reduce anxiety about bacterial infection and risk.

Table 13. Appraisals Made by Inexperienced and Experienced Participants

	Inexperienced participants	Experienced participants
Primary appraisals	• High risk of cross-infection from peers • PA infection is dangerous and results in ↑ treatments & symptoms • Getting PA can be prevented	• Low risk of cross-infection from peers • PA infection is manageable • Getting further strain of PA would make little difference • Getting PA cannot be prevented
Secondary appraisals	• Segregation is protective • Avoidance of infection is within my control • Taking action to prevent infection reduces anxiety • I am responsible for my own health	• Segregation is restrictive • PA is ‘inevitable’ • Frustration at restriction for no personal benefit • Others are responsible for preventing infection

Note: pseudomonas is abbreviated to PA

Inexperienced Participants – Protective Behaviours to Manage Risk. Those participants who had no prior experience of *pseudomonas* perceived that there was a high risk of obtaining this bacteria from contact with others with CF. *Pseudomonas* was perceived as having a negative impact upon health, resulting in increased treatment demands and hospital admissions, which is consistent with medical evidence (e.g. Lebecque et al., 2006). Inexperienced participants appeared to perceive that they could control their exposure to this bacteria by staying away from others, and for this reason segregation was perceived to be protective and helpful in reducing exposure during hospital admissions. These perceived benefits of segregation

appeared to make any restriction acceptable and non-threatening, and participants appeared motivated to adhere to the segregation guidelines.

Segregation was a method of ‘protection’ that appeared to help avoid anxiety about coming into contact with bacteria during hospital admission. According to Lazarus and Folkman (1984), these protective behaviours would be a form of problem-focused coping. Here, behaviours are targeted towards gaining control over the perceived risks, that is, by reducing contact with others with CF who potentially could be a source of cross-infection. This form of coping has been found in other studies exploring how individuals live with risk. For example, in a study on worry in adults about medical errors, Peters, Slovic, Hibbard and Tusler (2006) highlighted that increased worry about risk is adaptive in that it enables individuals to take preventive actions to minimise risk.

In this study, Inexperienced participants who appraised high risk of obtaining *pseudomonas* and high threat appeared to cope the most effectively with the implementation of segregation. These findings are similar to those of Zerbe, Parkerson and Spitzer (1994), who found those in protective isolation were judged to be less anxious than those in source isolation.

It was interesting to note that the few individuals who had *pseudomonas* in the past which had since cleared had appraisals similar to that of Inexperienced participants. This is possibly because they have experienced the additional symptoms and treatments and possible stigma and were adapting to these changes by altering the meaning of infection in order to cope. This may suggest that having cleared *pseudomonas* increases the feeling of control over the bacteria, which in turn allows individuals to feel motivated to engage in protective behaviours.

Experienced Participants – Cognitive Adaptation to Risk. In contrast to these Inexperienced views, participants with *pseudomonas* did not appear to be anxious about having *pseudomonas*, although were threatened by the introduction of segregation. Those with *pseudomonas* perceived the risk of cross-infection from their peers to be low, and felt that social contact with their CF peers resulted in minimal risk: “What harm is in it - like the same bugs, really, like what harm are we doing?” (Fiona, age 15).

For Experienced participants, having *pseudomonas* therefore did not appear to be perceived as a highly negative event – most had *pseudomonas* and were admitted every three months, so therefore no change in treatment would be required if they obtained another strain of this bacteria, “as we are getting the treatment for *pseudomonas* anyway”. Experienced participants also perceived colonisation with these bacteria as ‘inevitable’. This low (or external locus) of control and fatalistic perspective appeared to help reduce anxiety about having *pseudomonas*, and appeared to enhance coping. According to Lazarus and Folkman (1984), this would be a form of emotion-focused coping. Adaptation to having *pseudomonas* appears to lead to the development of a fatalistic perspective on the inevitability of infection, that is, “why worry if you are going to get it anyway”, highlighting how participants have reframed the meaning of *pseudomonas* colonisation. This fatalistic perspective was also found in those who were high risk for HIV (Irwin, Valdiserri, & Holmbert, 1996), which helped them live with the uncertainty of high risk, but in turn reduced the likelihood of individuals engaging in preventive behaviours. Similarly, this ‘cognitive adaptation’ appeared to help individuals cope with anxiety related to risk, although the ‘cost’ is reduced action to prevent cross-infection, as individuals perceive they have little control and therefore *pseudomonas* cannot be prevented. Furthermore,

participants perceived there were no personal benefits from segregation, which was perceived to impose restrictions during admissions leading to the loss of previously enjoyed resources, activities, and socialisation. Participants appeared to have low motivation to adhere to segregation, and indeed challenged the need for the policy by highlighting the inconsistencies and ‘irrationality’ of the rules. This ‘cognitive distortion’ appeared to allow them to reject evidence or information that was not consistent with their view.

Clinical Implications

The Transactional Model of Stress and Coping appears to be a useful way of understanding the differences in appraisals found in this study, and helps to identify areas of possible intervention in order to help young people with CF cope with risk and uncertainty. Using this model, it appears that information about risk needs to be targeted towards individuals in a focused manner, taking into account primary and secondary appraisals and meanings of segregation and bacterial infection, and also building upon existing methods of coping.

As those who are educated about risks still engage in risk related behaviours (i.e. Hersey & Martin, 1994; Lymer, Schutz & Isaksson, 1997), continued efforts should be made to explore and challenge the appraisals made by young people with CF. However, this needs to be handled with caution in order to reduce excessive fear, vigilance, and anxiety, as reported by Ullrich et al. (2002) and Ullrich (2004; 2007). One way in which this might be approached might be to tailor interventions individually and according to prior experience of bacteria.

For Inexperienced participants who are showing high levels of anxiety that may be interfering with their quality of life, effective intervention should focus upon

developing cognitions aimed at moderate control (rather than high control) - beliefs that suggest one can delay but not prevent *pseudomonas* colonisation, and the normalisation of this bacteria. For Experienced participants, however, intervention needs to specifically target the fatalistic beliefs that are associated with low motivation to engage in protective behaviours (Lauby, Bond, Eroglu, & Batson, 2006). Fatalistic beliefs should be challenged by staff to ensure that young people with CF understand the importance of the prevention of colonising multi-resistant *pseudomonas* and other bacteria such as *cepacia*, and the need for continued adherence to segregation. Personal benefits of adherence to segregation should be highlighted (i.e. fewer exacerbations and less admissions if unique strain of *pseudomonas* versus multi-resistant strain), and cognitions that elicit a moderate sense of control should be strengthened. In this way, those with *pseudomonas* will hopefully see that there are personal benefits of adhering to segregation.

Section Summary

Anxiety regarding cross-infection of bacteria was generally low in the current study, although participants reported that they did wish to minimise the risk of cross-infection. It appears that the appraisals made by young people with CF, and the way in which they cope (i.e. preventive behaviours versus cognitive adaptation) have helped to minimise anxiety about risk. It may be that there are some young people who do indeed experience anxiety about cross-infection - strategies to help young people with CF manage risk information can be guided by the Transactional Model which appears to elegantly capture the differing appraisals of those with and without *pseudomonas*. This model also highlights ways in which to encourage those who have

pseudomonas to adhere to segregation. Finally, anxiety in carers has been noted as an increasing problem (Ullrich et al., 2002; Ullrich, 2004; 2007; Russo, in preparation).

The Loss of CF Peer Support

The second way in which segregation has impacted upon young people with CF is by reducing the opportunity to receive support from others with CF. Cross infection has led to new cohorts of young people with CF having no contact with others with CF, which is different to past cohorts where mixing was encouraged. The two concepts peer support as outlined in Chapter One – that of ‘social support’ and ‘social comparison’ – will be used to explore the reasons why the loss of contact with CF peers may be difficult for young people with CF.

‘Social Support’

The concept of Social Support, as incorporating general support and belonging, information and tangible support, was well supported in the current study. Participants clearly highlighted that their CF peers were important to help with coping with repeated hospitalisations, and the process of normalisation in the context of living with a progressive disease. Having access to CF peers allowed them to seek practical advice and support at times of increased stress (e.g. regarding procedures, deterioration). Participants stressed that it was easier to relate to others with CF and feel a sense of belonging due to the common bond of shared experiences. These comments are similar to those reported by D’Auria et al. (2000), who reported that CF peers were unique in providing acceptance and understanding of their disease that healthy peers could not relate to. Some commented that it was difficult to obtain information from staff, either through communication difficulties, lack of closeness or

preference for information from others who have been in the situation before. Older participants described how they played the role of protecting their healthy peers by restricting discussion about their disease and experiences during hospitalisation, resulting in isolation. Goffman's (1963) stigma theory is useful to conceptualise the difficulties in communication that those with more severe disease described, a process he terms as 'interaction-uneasiness' (Wilson & Luker 2006).

According to the concept of Social Support, segregation has resulted in the loss of contact with similar peers, leaving a gap in the level of support received during hospitalisation, making it difficult for young people with CF to access this highly valued and important method of coping. Experienced participants clearly felt frustrated by this loss of support.

'Social Comparison'

The concept of Social Comparison outlines contact with similar others allows for an appropriate reference group to compare to at times of uncertainty and it is this comparison that facilitates coping (see Chapter One). In the current study, social comparison processes were used extensively by all participants.

Comparing to healthy peers. All participants explicitly reported feeling 'normal' – just like any other person - despite having CF. These findings are similar to the qualitative studies as outlined in Chapter One (e.g. Admi, 1996; Christian & D'Auria, 1997). However, participants appeared to recognise that they were different to their healthy peers by using social comparison of experiences, health status, physical performance, and ability to cope (see Table 14). Comparing to healthy peers led to negative feelings as they related to the identification of differences in appearance, behaviours or health, which appeared to be reminders of their disease.

The exception was when comparisons were made regarding coping, where participants perceived they were able to cope in many situations where their healthy peers could not (see Table 14). This confirms the view that participants perceived themselves to be resilient, resourceful, and optimistic.

An increasing awareness of difference impacted upon closeness and intimacy with their healthy peers. D’Auria, Christian and Richardson (1997) asserted that during middle childhood, children with CF were aware that peers saw their CF behaviours as different, which challenged their own view that they were normal. They therefore attempted to hide differences and avoid self disclosure in an attempt to reduce differences. In the current study, even Inexperienced participants who were new to admission described their feeling of reassurance that there were others with CF who ‘understood’. This highlights the importance of having contact with, or even simply being aware of similar others, as they serve the important role of ‘normality’ which in turn appears to enhance the process of normalisation.

Table 14. Illustrative Examples of Social Comparison to Healthy Peers

Illustrative example	Interpretation	Outcome
<i>I’m kinda used to it. I wouldn’t want my friends to have to come into hospital all the time.Because, it’s hard enough for me to come into hospital, never mind them.</i>	Can cope better than her friends	Positive resilient
<i>[I feel] Horrible because you just can’t do the same as everyone else.</i>	Activities limited due to health	Negative, worry

Comparing to CF peers. In the current study, participants engaged in upward comparisons (e.g. comparing the coping of others who were more severe than them); and downward comparisons (e.g. recognising that others were more severe) with other

young people with CF which helped them to reduce anxiety about their own health and situation (see Table 15). Participants who compared their life situation to other young people with CF tended to report positive emotions. Social comparisons that result in positive emotions have been shown in adults to lead to better psychosocial adjustment (e.g. Dibb & Yardley, 2006; Klein, 2002). Staab et al, (1998) found that adolescents and adults with CF who used social comparisons had a higher quality of life.

Table 15. Illustrative Examples of Social Comparison to CF Peers

Illustrative example	Interpretation	Outcome
<i>That you are not the only one, not the only... there's other people that have it and they are worse than you. (Claire j)</i>	Others worse than her	Positive adjustment
<i>Talking to people like, CF patients in here, it's really easy because they know what you are going through, but nobody else seems to know. (Gemma)</i>	Only others can relate	Positive belonging

According to the concept of Social Comparison, segregation has resulted in the loss of access to this important CF normative group.

Participants reported that they found it harder to compare their experiences to others when they had no contact with their CF friends. This is likely to lead to increased feelings of difference as using healthy peers as comparison often leads to negative emotions (see Table 14). Furthermore, the process of ‘normalisation’, that is, feeling that life with CF is normal despite the treatments demands, appears to rely upon contact with others with CF, and this may be significantly hampered if young people are only able to compare to their healthy peers. Social comparison appears to

facilitate the process of normalisation, which has been shown to help adapt to this disease (Gibson, 1988; Gjengedal, Rustoen, Wahl & Hanestad, 2003).

Importance of social comparison during adolescence. Seeking social support from similar peers is perhaps a strategy that occurs particularly during the adolescent period, as suggested by D'Auria et al. (2000). For example, in a review on the coping strategies used by children and adolescents with chronic illness, Ryan-Wenger (1996) concluded that seeking social support was the most frequently used coping strategy. Furthermore, studies on young people with chronic illness in the hospital setting have identified that adolescents rate contact with other patients as one of the most positive aspects to their hospitalisation (Stevens, 1988). It may be that adults with CF use this strategy less frequently - in a survey of coping strategies used by 174 adolescents and adults with CF (age 16 - 51 years), only 20% reported that they sought support from others with CF (Abbott et al., 2001). There is evidence that some adults with CF make informed decisions not to mix (Lowton & Gabe, 2006). The following excerpt is taken from a 26 year old 'expert patient' account of living with CF, and highlights the ambivalence raised between the desire to avoid feeling alone versus the difficulties of maintaining friendships with CF peers:

Today, I welcome and respect the practice of segregation to prevent cross-infection. Technology has lessened the impact of [cross] infection, but the condition is still not easy to bear. I wish I could sit in a room of people who know what it is to live with it. I know many people with cystic fibrosis, although none of them are close friends. This is a choice I have made. The close friends with cystic fibrosis that I had previously have all died. Having friends who have cystic fibrosis can become a burden. I know I have this disease and I live with it every day, but to have it staring back at me through the eyes of another can be daunting. (Wicks, 2007, p. 1270)

It may be that those young people who are frequently admitted to hospital, that is, those with more severe disease, initially seek the company of their CF peers.

However, with increasing disease and the death of their peers, they may become reluctant to continue to focus upon these friendships. If this is the case, then segregation and its impact will be most salient during late adolescence.

Clinical Implications

Currently, some young people with CF require additional psychological support due to individual or family circumstances which contribute to psychological distress during hospitalisations, or difficulties in adjustment to CF. For these young people, increasing the availability of social support from within the community and hospital setting may be appropriate. The problems of relating to healthy peers identified in this and earlier studies (e.g. D'Auria et al., 1997) should be discussed and young people may indeed benefit from problem solving skills or information about how to discuss CF with their healthy peers and ways to manage potential differences. Continued emphasis should be placed upon providing alternatives to face-to-face contact with other CF peers, or contact with other children with chronic illnesses who also spend time within the hospital setting. For those with established friendships, maintaining friendships using email and internet facilities should be explored, using Web sites such as the UK CF Trust Web site and young person chat room (www.cftrust.org.uk/forum). Being contained during admissions makes young people with CF and their carers more reliant upon staff to provide this information about treatments and interventions – professionals should also suggest alternative ways of obtaining accurate information, such as from the CF Trust, or from approved CF Web sites.

D'Auria et al. (2000) suggested that access to peer group discussions of friendships with CF peers were essential for helping adolescents develop a sense of

hope when living with the disease. However, this is no longer reality for adolescents with CF due to cross-infection. Access to a CF ‘normative’ group - particularly at times of uncertainty - needs to be facilitated whilst still minimising the risk of cross-infection. One solution is to enable access to CF peers through online measures. Currently the electronic support groups in the UK are not as well established as in North America where programs exist for hospitalised CF patients (e.g. Hopkins Teen Central – Johnson, Ravert & Everton, 2001). These programs enable those with CF to contact each other, but could perhaps be expanded to enable young people with CF to see how they compare to others. Or alternatively, it may be useful to explore other ways in which normative points of reference can be undertaken, perhaps using hypothetical CF points of reference (i.e. the ‘typical’ young person with CF); or to use normative data from the CF Centre in order to communicate how an individual is managing their disease in comparison to others of a similar age. Finally, at times of high uncertainty and high anxiety, it might be considered beneficial to arrange ‘safe’ face-to-face contacts between CF peers in order to reduce uncertainty. These suggestions are summarised in Table 16.

Table 16. Interventions to Facilitate Social Support and Social Comparison

For general social support	To facilitate social comparison
Enable contact with others of similar age in the hospital setting (without CF)	Development of online ways on comparing self to others with CF (using ‘personal profiles’)
Build upon community and family social supports	Development of the ‘typical CF profile’ for different age groups
Encourage communication with healthy peers	Alternatives to face to face contact
Continued contact with existing CF peers using non face-to-face methods	Arrangement of ‘safe’ meetings at times of high uncertainty (e.g. prior to surgical procedures and difficult decision-making)

Section Summary

The two concepts of peer support are supported in the current study. However, the concept of Social Comparison particularly highlights the potential negative impact of segregation upon young people with CF. The lives of those with CF, particularly those with more severe disease, are different to their healthy peers. Awareness of these differences leads to negative emotions. Ways in which to facilitate access to CF peers needs to be explored in order to minimise the potential difficulties in adjustment during the adolescent years.

Coping With the Hospitalisation Experience Under Segregation

The third way in which segregation appears to have impacted upon young people with CF is by changing the way regular hospital admissions are experienced. Previous research has shown that children with chronic illness experience both positive and negative aspects of hospitalisation (Coyne, 2006; Denholm, 1988; Sartain, Maxwell, Todd, Haycox, & Bundred, 2001), and these general findings are similar to those reported by participants in the current study (see Table 17).

Table 17. Positive and Negative Aspects of Hospitalisation

Positives	Negatives
Health improvement	Miss friends
Visits from family	Reminder of illness
Time out of school	Miss schoolwork
Presents	Miss prearranged social activities
Time away from siblings	Procedures
Mixing with CF peers	Boredom
Fun with staff	Loneliness
Learning from other patients ^a	Separation from family
Discussion about ‘taboo’ topics (i.e. death)	

^a learning about disease management, treatments and living with the disease

The next section discusses the experiences of hospitalisation pre- and post-segregation and the ways in which participants appeared to cope with these experiences.

The Experience of Hospitalisation Pre- and Post-Segregation

There were differences in accounts according to whether participants had prior experience of hospitalisation. Overall, Inexperienced participants' reports of hospital admission under segregation appeared similar to those reported by young people in other studies (e.g. Carney, et al., 2003; Coyne, 2006), compared to Experienced participants. For example, Boyd and Hunsberger (1998) found that children with chronic illness who experienced repeated hospitalisations were concerned with IVs, procedures, fear of death, lack of independence and control, isolation from peers, and boredom due to lack of activities. In the current study, Experienced participants reported that they rarely felt bored during past admissions as always there were other patients to chat with, and generally they reported their past admissions to be positive and fun. It is likely that young people in the current study differed from young people in other studies recalling more positive aspects because they experienced both types of hospital admission with significantly different degrees of restrictiveness and control.

Experienced participants described admission under segregation as significantly different to past admissions in terms of losses, extra burdens, and positive experiences (see Table 18). It could be concluded that segregation removed the most enjoyable aspects of admission for young people with CF.

Table 18. The Additional Burden of Segregation During Hospitalisation

	Losses	Extra burdens	Positives
Inexperienced Participants	General restriction	Boredom Loneliness	Reduced risk Reduced anxiety Relief at boundaries
Experienced Participants	General restriction Loss of resources Disruption of social networks Loss of companionship	Increased time alone Increase in negative emotions (boredom, loneliness, worry, frustration) Change in staff relationship	

Under segregation, participants lost their independence and relied upon staff to meet their needs, particularly regarding extra food and snacks which are essential for their CF diet. Experienced participants reported a change in the frequency and quality of contact with CF staff, perceiving that contact focused on tasks of care and few personal interactions. More recent qualitative studies have highlighted the significance of interpersonal and interactional aspects of care (Attree 2001), and in the current study Experienced participants reported that they had lost this aspect of their admission experience. Furthermore, nurses had also become ‘enforcers of restriction’ which led to negative interactions with patients. This led to dissatisfaction with the hospital experience, and the perception that staff did not understand. McKay and Hensey (1990) reported that staff underestimate the emotional impact of living with a chronic illness, and do not provide enough opportunities to discuss issues.

Coping With Hospitalisation Under Segregation

The current study showed that hospitalisation and procedures were the most stressful events for Inexperienced participants, whereas being alone in hospital was considered the most stressful for Experienced participants. Previous methods of

coping, such as seeking support from similar others, social comparison, and social distraction were no longer available during admissions under segregation, leaving Experienced participants initially struggling to manage the change and losses. For Experienced participants, new strategies needed to be developed in order to cope with admission under segregation.

Again, the Transactional Model of Stress and Coping appears useful to describe the differences in coping found amongst participants. The following section is organised around the model's concepts of problem- and emotion-focused coping.

Problem- and emotion-focused strategies. Problem-focused strategies were used by all participants to manage time on their own during their hospitalisation under segregation. These strategies related to four main ways of coping: *gaining control over their surroundings* and *planning interactions* (which were both behavioral strategies); and *having an optimistic outlook and using comparisons* (which were both cognitive strategies). These strategies and examples of each are outlined in Table 19.

Controlling the environment by making their rooms seem homely, or by having control over the extent of isolation were effective strategies used by participants. Asking for food, resources, or even explicitly asking staff to spend time with them were ways in which to reduce time spent alone. Cognitive strategies that seemed to help facilitate adjustment to the changes associated with segregation included having an optimistic outlook, which included positive reframes and positive self talk; and using comparisons to other wards.

Three main emotion-focused strategies were used to cope with segregation: *distraction* (which was a behavioral strategy); and *avoidance* and *acceptance* (both cognitive strategies). These are also summarised in Table 19 overleaf.

Table 19. Coping Strategies Used by Participants During Hospitalisation Under Segregation

PROBLEM-FOCUSED STRATEGIES			EMOTION-FOCUSED STRATEGIES		
Strategy	Example	Illustrative quote	Strategy	Example	Illustrative quote
GAINING CONTROL	Making familiar	<i>"I try to just do what I can like put books out and jammys out and stuff to make it feel homely"</i>	DISTRACTION	Enjoyable activities	<i>"I played the guitar a lot of the time, because I enjoy doing that"</i>
	Connecting to outside world	<i>"there's more...like that's why I keep my door open cause there's more going on out there"</i>		Alternative activities	<i>"Yeah, but I try to do homework, so I have less to do when I get out"</i>
SEEKING SOCIAL INTERACTION	Planning contact	<i>"I asked the play specialist as she was walking out, so she's going to try and be with more a bit more tomorrow"</i>		Forward focus	<i>"I usually have something to look forward to ... and that would make me a bit more happier during the admission"</i>
	Initiating contact	<i>"I usually stop them and go 'can I have a slice of toast please'"</i>	ESCAPE / AVOIDANCE	Non-adherence*	<i>"I was going to the kitchen, and she was at the door so we just said hello, and the nurse said 'get round to your room'"</i>
	Seeking alternatives	<i>"Yeah like, cause because we found a way of phoning each other"</i>		Leaving ward	<i>"I go home for a wee while, it's better, much better, it breaks it up a little"</i>
COMPARISONS	Downward Comparison	<i>"It could be a lot worse. What you have here is good. A lot of my stuff I would compare to being over in [the surgical] ward"</i>		Avoidance*	<i>"stay at home and wait a couple of weeks -I just wouldn't want to come in all that often"</i>
	Low expectations	<i>"I didn't think they would be as nice"</i>		Wishful thinking *	<i>"I wish we just has the same type of pseudomonas, then we could just talk"</i>
OPTIMISTIC OUTLOOK	Positive reframe	<i>"But you can have a good time when you are here, so you just try to make the most of it"</i>	ACCEPTANCE	Passive acceptance	<i>"I just get on with it, it's just different"</i>
	Positive self talk	<i>"I'll be saying to myself 'aww you've only a few more days to go, and it's ok',"</i>		Adaptation	<i>"cause whenever you keep coming in you kind of get used to it, all the times are just going to be like the last time, really boring"</i>

* strategy associated with a negative emotion

Some of the emotion-focused strategies used were effective at adapting to segregation. For example, participants who used the behavioral strategy of distraction, such as engaging in pleasurable or time-consuming activities, appeared to manage time on their own more effectively. Strategies that were associated with avoidance of spending time alone on the ward were associated with less positive experiences, although having regular planned time away from the ward appeared to be effective for many. Those who were not adherent to segregation and left their rooms to talk with others often then had negative interactions with staff, leading to feelings of frustration and helplessness.

Differences in coping strategies across participants. In the current study, there appeared to be a difference between Experienced and Inexperienced participants in terms of coping with segregated care and being on their own. Those who were new to hospital appeared more able to use the cognitive problem-focused strategies of optimistic outlook and comparisons, and were able to use the emotion-focused technique of distraction effectively. This is consistent with other research exploring the use of coping strategies by young people during acute admissions to hospital (Boyd & Hunsberger, 1998; Spirito, Stark & Tyc, 1994).

Experienced participants were more likely to use the behavioral problem-focused strategies of gaining control and seeking interaction, although found it difficult to find anything positive about segregation. They also were reluctant to engage in distraction activities, and instead used other less-effective emotion-focused strategies, mostly related to avoidance (such as leaving their rooms to talk with other participants, wishful thinking, or avoiding coming in to hospital). Some of the Experienced participants had experienced several admissions under segregation at the time of interview, and they reported that they had learned to accept segregation (an

effective emotion-focused strategy), which helped them adjust to the changes. Boyd and Hunsberger (1998) highlighted that young people who experience repeated hospitalisations use emotion-focused strategies, as they learn that they cannot alter the circumstances surrounding their admission, therefore they have to learn to manage these stressors rather than change them. It may be that Experienced participants have to experience several admissions under segregation to be able to use more effective emotion-focused strategies.

Most of the problem-focused strategies used were effective in adapting to segregation. Those who used more 'adaptive' emotion-focused strategies (i.e. distraction and acceptance) were more likely to have agreed to segregation being implemented.

Male participants appeared to be more able to use distraction activities, whereas female participants appeared to plan more activities that sought interaction with others, including staff and family members. Gender differences in coping with CF were identified by Abbott et al. (2003), although they reported that females used distraction more than males to cope with CF in general, a finding which contradicts the current findings. However, no gender differences in coping with hospitalisation were identified by Spirito, Stark and Tyc (1994). It may be that the activities provided in the rooms for patients are of more interest to males (i.e. computers and game consoles); perhaps reflecting gender differences in preferred activities during the teenage years.

Overall, these differences in coping should be considered as patterns and associations rather than significant differences.

Clinical Implications

Segregation changed the nature of hospitalisation for Experienced participants, and appeared to decrease the feeling of control and interfere with relationships with staff. This has implications for satisfaction of care, and trust in the CF team. The following suggestions may be helpful in facilitating adjustment to segregation.

Some individuals may have increased difficulties in managing hospital admissions, and it appears that it may take several admissions under segregation before individuals can learn to cope effectively with the changes. Furthermore, there appear to be individual differences (based on gender and ability to tolerate boredom) that may make hospitalisation under segregation more difficult for some. These individuals can benefit from discussions about coping strategies that have helped others manage the difficulties associated with segregation. Specifically, the use of problem-focused activities should be encouraged, and the use of effective cognitive emotion-focused strategies should also be highlighted. Attention should be given to the preferences of female participants for engaging in social interaction rather than distraction by activities. More appropriate resources that appeal to females should be provided in rooms to facilitate solitary distraction activities (as outlined in Russo, et al. 2006b; Russo, 2007a). Those who are unable to adapt require further intervention to facilitate coping in order to prevent young people with CF from avoiding hospitalisation, which has obvious health implications.

All members of staff should be involved in consistently enforcing segregation in order to communicate the importance of minimising cross-infection. A clear plan for managing non-adherent behaviours needs to be outlined. Episodes of non-adherence need to be managed firmly with limited negative interaction. Consideration should be given to those who repeatedly challenge the rules of

segregation, with an emphasis upon helping young people meet their needs for social interaction or peer contact in alternative ways. Education about behavioural management may be useful for front line staff to facilitate consistent enforcement of segregation.

The impact of segregation upon staff needs to be further highlighted. In an unpublished audit of the staff perception of the segregation policy (Russo, 2006a), staff commented on the increased burden upon their work. Two studies (Chan et al., 2006; Koller et al., 2006) highlighted the difficulties in achieving clinical care recommendations when children were isolated. In the latter research, the authors highlighted public parental opposition of the enforced treatment in isolation in light of the negative psychosocial impact expressed by children, carers, and health care workers. Whilst most carers and young people with CF at the study CF Centre supported segregation (Russo et al., 2006) a small minority did not support it. This has led to dissatisfaction in care received.

Section Summary

Segregation has particularly impacted upon Experienced participants who have had to learn new ways of coping with hospitalisations. Certain coping strategies appear more effective than others. For example, gaining control over the environment, having an optimistic outlook, using comparisons, and distraction all appeared to be associated with a more positive experience of segregation. Vulnerable patients may benefit from prompting on the use of these more effective strategies that have helped others. Young people admitted to hospital need appropriate resources in order to make time on their own more acceptable. Consideration should be given to how segregation has impacted upon staff.

Potential Impact Upon the CF Community

The final way in which segregation may negatively impact upon young people with CF is by ‘fragmenting’ the CF community. Several professionals have highlighted the potential negative impact that segregation and fear of cross-infection may have upon the CF community (e.g. Lowton & Gabe, 2006; Ullrich et al., 2002). Most of these concerns focus upon the short and long term impact of stigma of those who experience different bacterial infection, particularly those who experience *cepacia* but perhaps in the future also those who have *pseudomonas*. The issue of stigma as experienced in the current study is discussed next.

The Experience of Stigma

Stigma is a social construction that concerns itself with perceived differences (Goffman, 1963). In the current study, there was no reported stigma from having *pseudomonas*, most likely because it was perceived to be common amongst people with CF. Stigma was however reported by those who had been isolated in the past in a separate ward. The stigma for *MRSA* in particular was felt from within the general public, rather than from within the CF community. This may be due to the fear of *MRSA* amongst the general public due to inaccurate media reporting which in turn influences public perception about this bacteria (Madeo, 2001). It was interesting to note that those who had experienced prior isolation due to *MRSA* experienced less stigma during subsequent admissions to the CF ward, even under segregation. Being around others with CF appeared to reduce the feeling of being different as they were near ‘their own’, as outlined by Goffman’s (1963) stigma theory.

Only one participant in the current study had previously had *cepacia* that had since been eradicated, and this person did not report any experiences of being stigmatised from within the CF community. However, in a study exploring carers' experiences, widespread fear of those with *cepacia* were reported (Russo, in preparation), directly related to the death of two young people with *cepacia* shortly before the commencement of the study. Young people with *pseudomonas* appeared confident that segregation measures already in place minimised their exposure to *cepacia*.

In the current study, young people with *pseudomonas* reported that they would like to continue their contact with their CF peers, although this was difficult as they no longer could see them during admissions to hospital. Inexperienced participants reported that they would like contact with similar others in the future, and so the sense of isolation may indeed lead to them seeking out similar others.

Potential Isolation of Families With CF

By emphasising the importance of delaying the onset of *pseudomonas*, carers appear to be hyper-vigilant and are attempting to engage in preventative and avoidant behaviours in order to reduce environmental exposure to bacteria (Ullrich et al., 2002, Ullrich, 2004; Ullrich, 2007). It is clear that carers have perceptions of control that are driving these behaviours; however the effectiveness of excessive protective behaviours has been called into question given the impact upon quality of life. Clearly more research is needed on the carer experience and perspective in order to minimise the longer term negative impact upon the CF community that has already been seen to be dispersing, as outlined by Lowton and Gabe (2006).

Clinical Implications

It is clear that education about how *MRSA* affects those with CF (see Chapter one) is required in order to address some of the common misconceptions about *MRSA* in the general public. The bigger challenge, however, is how to minimise the distress and anxiety related to *cepacia*, as experienced by carers. Although it should be recognised that some families with CF will not wish to have contact with others, facilitating opportunities for this to occur might be helpful to those who wish to continue contact for reasons of support and the sharing of information.

Section Summary

Professionals have commented that the CF community has gone from a cohesive group to one of individuals due to the fear of cross-infection, potentially leading to isolation. At present, this ‘fragmentation’ is not seen from the patient perspective, although is clearly experienced from the carer perspective.

Overall, the current study has allowed for the exploration and discussion of the issues that have arisen as a result of the introduction of segregation and concerns about cross-infection. The Transactional Model appeared to be a useful framework for conceptualising the differences in perceptions of risk and vulnerability as identified in the current study. However, the concept of social comparison also appears to be significant in providing a framework for understanding the negative impact of segregation upon young people with CF. Although social comparison is also considered to be one of a range of coping strategies, these findings suggest that social comparison is a key process that facilitates adjustment to CF, and is essential to the process of normalisation. It is proposed that both individual psychological processes

(i.e. appraisals and coping) and interactional processes (i.e. social support, social comparison, and normalisation) need to be considered in an overall model when considering the impact of segregation. Further refinement and ‘testing’ of this expanded model is suggested in order to determine whether the findings of the current study can be generalised to other CF populations.

The final section discusses the methodological issues related to the current study, highlighting strengths and weakness where appropriate, and suggesting further areas of study.

2. METHODOLOGICAL CONSIDERATIONS

Strengths of the Current Study

In the past, researchers exploring coping in young people have called for the use of clinical interviews given the lack of sensitivity of current questionnaire measures (e.g. Eiser, Hill & Vance, 2000). Using a qualitative approach to explore the experience of hospitalisation under segregation has allowed for an in-depth understanding of the issues and concerns of young people with CF (e.g. Attree 2001). The use of IPA principles and guidelines has allowed for a consistent and thorough analysis of the data, with quality control checks to ensure rigour and trustworthiness of the data. The use of the phenomenological perspective in particular has allowed for the identification of meanings that are relevant for young people related to segregation and infection control. This inductive approach has highlighted the salience of some of

the emergent themes, such as the importance of social comparisons and contact with similar others, the differences in appraisals of *pseudomonas* and segregation according to prior experience, and the range of coping strategies that are used by young people with CF during hospitalisation under segregation. It is unlikely that such a rich understanding could have been gained by simply using questionnaires or other traditional measures.

Participants also appeared to benefit from participation in this study. In addition to being a social interaction, several participants reflected that taking part in the study gave them a chance to share their views, experiences, and feelings. For some, the in-depth interviews allowed them to discuss issues and experiences that they had not communicated previously with staff or family members.

The findings of the current study have clinical and practical relevance for those living with and working in the field of CF. Information is needed on how to manage the issue of cross-infection without further burdening families and young people with CF. The current study helps guide the way for clinical practice that can perhaps minimise potential difficulties. Most importantly, this study has contributed to the existing literature on the topic of segregation, and has generated ideas on theories and concepts that can be explored further with a larger group of participants.

Limitations of the Current Study

The aim of phenomenological research is to obtain an in-depth understanding of the experiences of a small number of participants. Clinical recommendations have been made based upon the information that arose from the analysis from this small group of participants. It should be noted that generalisations in the statistical sense are not valid within the kind of methodology used here. Smith (2004) highlights: “Warnock

(1987) makes the important and profound point that delving deeper into the particular also takes us closer to the universal” (p. 42).

Although the clinical population of this CF Centre is similar to other CF Centres within the UK, making further generalisations from this study needs to be done with caution as no systematic analysis was undertaken on the association of experiences and illness severity, age, family background or socio-economic status. Furthermore, the arrangements and accommodation of the study CF Centre may differ from that of other CF Centres, and indeed as outlined in Chapter One, the practice of segregation differs across CF Centres in the UK. These limitations should be considered when evaluating the findings.

Other Considerations

Interpretative Phenomenological Analysis relies upon participants providing rich accounts of their experiences and this can be challenging when interviewing children. Whilst most participants gave rich accounts of their experiences of segregation and hospitalisation, some of the younger children and those who did not appear to find segregation difficult were less detailed. In hindsight, asking these and younger children to draw their experiences of segregated care might have produced interesting insights into their lived experiences of hospital admission, and could have been used to prompt for further insights. Sroufe, Cooper and De Hart (1996) suggested that from the age of six children can put together ‘histories of experience’ and to form an image of themselves. Other researchers have suggested that children from the age of eight years should be able to express views, feelings, and experiences during an interview (Dixon-woods, Young & Ross, 2006; Sartain et al., 2000). The use of alternative strategies such as drawings to generate discussion has been recommended

by several authors (e.g. Sartain et al., 2000); in addition to keeping interviews brief or undertaking repeated interviews in order to minimise boredom and fatigue.

The knowledge and experience of the researcher in the field of CF enhanced the process of IPA in several ways. The author was able to make appropriate interpretations of meanings due to familiarity with the context of the lives of those with CF (Solomon, 1997). However, such familiarity with the context and the issue of having dual roles with this clinical population at times was challenging to manage (Coghlan & Casey, 2001; Russo, 2007b; Walker, 2007). The self-awareness of the researcher allowed these issues to be explored during the process of interviewing and analysis and facilitated in the bracketing of prior knowledge to ensure that the analysis was not led by pre-conceptions held by the researcher (Ashworth, 1999). These issues are further outlined in Appendix 8.

3. DIRECTIONS FOR FUTURE RESEARCH

The current research answers some important questions about the impact of segregation upon young people with CF. The rich accounts provided by participants have highlighted a number of different areas that could benefit from further exploration.

First, further exploration of the processes involved in risk perception and prevention is required. The development of a tool that looks at balancing of risk, as has been developed in HIV (see Lauby et al., 2006) could be of great practical benefit for the CF community. Such a tool could explore the decisional risk/benefit ratio of social contact, perceived risks, risk behaviours and preventive actions. This may facilitate the development of intervention strategies that could improve adherence to segregation and reduce excessive worry and vigilance. Also, this would further

highlight ways in which to communicate risk effectively for people with CF and their carers without creating excessive anxiety. Similarly, an in-depth exploration of the meanings of *pseudomonas* colonisation and segregation from the perspective of the adult with CF and also the carer perspective would enhance our understanding of how meanings of infection may change according to the developmental and disease trajectory. Research exploring the carer's perspective on this topic has already commenced (Russo, in preparation).

Secondly, there is anecdotal evidence at the study CF Centre that the demand for home IVs has arisen since the introduction of segregation to enable families to avoid the negatives associated with hospitalisation under segregation. Whilst several studies have looked at medical outcomes of home versus hospital IVs (e.g. Esmond, Butler, McCormack 2006; Riethmueller, Busch, Damm, Ziebach & Stern, 2002), limited research has been undertaken on the experience of home IVs for young people with CF and their carers. Havermans and DeBoeck (2006) raised concerns regarding the increasing demands and burdens placed upon CF carers, and the extent to which families with CF normalise their antibiotic treatments despite experiencing significant stress and a huge burden of responsibility.

Finally, further exploration of the use of social comparison in young people with CF is required. The ways to facilitate the use of social comparison in the absence of direct contact with similar others should be explored further and evaluated in an attempt to help facilitate the process of normalisation in CF populations. Longitudinal research may be important in identifying any potential long term difficulties in adjustment due to cross-infection measures.

4. CHAPTER SUMMARY

Scientific evidence has shown that cross-infection measures such as segregation can prevent or at least delay colonisation of *pseudomonas* and more serious infections in people with CF, thereby increasing life expectancy. Segregation is increasingly used in CF Centres for both in- and out-patient care, and all people with CF are now discouraged from mixing with others with CF. In response to the concerns regarding the psychosocial cost of such policies, research to date has attempted to obtain the views of service users regarding cross-infection measures. However, these studies have explored satisfaction with rather than make any attempt to explore how young people make sense of these measures or indeed the impact of such measures upon patients and their carers. Existing literature on the views of children and adolescents undergoing treatment in hospital under conditions similar to segregated care is sparse, and does not paint a coherent picture on the difficulties experienced by young people with CF. This current study using IPA attempted to address some of these issues by obtaining in-depth views of young people with CF who experience hospitalisation under segregation.

Participants appeared to understand the consequences, both positive and negative, of segregation within the hospital setting. Overall, Inexperienced participants concluded from this ‘weighing-up’ process that the negative aspects of segregated treatment were worth enduring in order to reduce further the chances of cross-infection, thereby ensuring better health. In contrast, Experienced participants with already established friendships reported that there were few benefits of segregation for them as they had already had *pseudomonas*. Segregation for these participants resulted in significant losses to their admission experience - the loss of friendships, support, closeness with staff, and access to resources. These losses have

made it particularly difficult for Experienced participants to cope with admission as previously used coping resources were no longer available.

Contact with similar others is important – CF peers are unique as they share experiences and an understanding of living with CF. Due to the introduction of segregation there are now reduced opportunities to learn, normalize, socialize, and develop independence for their illness. This may have future impact upon adjustment. In addition, through the extensive use of social comparison, young people with CF have been able to adapt to life with CF through the ‘normalisation’ of their experiences. This is no longer available as a result of segregation which has implications for current and future cohorts of young people living with CF.

Despite the impact that segregation has introduced, participants appear to use a range of coping strategies to help them manage during their admission. The role of appraisals appears to be important in understanding the responses to, and level of support for, segregation. Furthermore, the study has highlighted that the methods used to cope with anxiety about cross-infection – preventive behaviours and cognitive adaptation – may for some people lead to excessive worry or alternatively interfere with their adherence to segregation and cross-infection measures.

There is a need for staff to consider further how to tailor information needs and care plans to young people with CF and their families. Overall, professionals should attempt to work collectively to afford more time to listen to the views of young people and carers, and devise ways in which to alleviate the negative psychosocial consequences of segregation.

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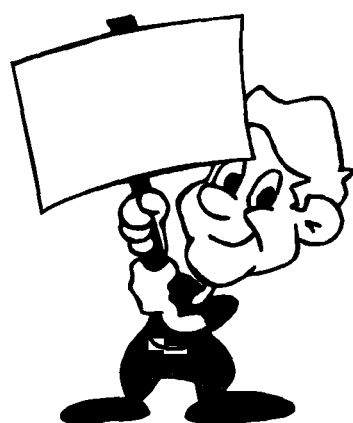
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APPENDIX

1. Segregation Information Leaflet



INFORMATION LEAFLET

REDUCING THE RISK OF CROSS INFECTION

AT THE BELFAST PAEDIATRIC CF CENTRE

Introduction

This leaflet explains the types of infections experienced by patients with CF, and describes ways that are used to stop or reduce the spread of infection. This leaflet also explains why it is now necessary to segregate all patients with CF who are admitted to hospital.

Infections in Cystic Fibrosis

Several different bacteria can be found growing in the lungs of people with CF. These bacteria can be found living naturally in many environments, and are usually harmless to people without CF. Sometimes growth of these bacteria produces symptoms such as cough. Treatment of these infections with antibiotics aims to prevent, eradicate or control infection.

Bacteria that are seen in CF include *Staphylococcus Aureus*, *Haemophilus Influenza* and *Pseudomonas Aeruginosa*. These bacteria have different strains, and some are easier to pass from person to person than others (cross-infection). As a person with CF gets older *Pseudomonas* is more commonly found in sputum samples and most patients who have *Pseudomonas* have a strain that is unique to them. Infection with *pseudomonas* can come and go (intermittent), or be present all the time (chronic). Once chronic infection occurs, it is almost impossible to remove. More recently, 3 particular strains of *pseudomonas* have been identified in other parts of the UK that are more resistant to antibiotics than other strains, making them more difficult to treat. For this reason, it is important that we try to prevent the spread of *pseudomonas* amongst patients.

How is the spread of infection currently managed?

Some of the methods currently used to prevent the spread of these bacteria on Allen Ward and Cherry Tree include regular hand washing, appropriate disposal of tissues and sputum cups, keeping equipment clean, and not entering other patient's rooms. Physiotherapists also wear disposable aprons and gloves during physio sessions, and visitors are also asked to wash their hands when they leave the room.

So why is there a need for a new policy?

Allen ward currently has communal areas, which presents as a higher risk for cross-infection. As long as patients still mix and share these areas, the risk of cross-infection will be present.

Although there is little evidence of cross-infection within the Belfast Centre, other centres in the UK have found direct evidence of cross-infection when patients are able to mix. Many clinics in the UK and America now use segregation to reduce this risk.

What is segregation?

Segregation is a method used to reduce the risk of infections spreading from one patient to another. Within hospital, this means being nursed in a single room with private facilities with no contact with other CF patients.

How is segregation currently used in the CF Centre?

Segregation has been used for several years in the CF Centre to prevent the spread of *B. cepacia* and *MRSA*. Patients with these infections are nursed in Belvoir Ward, (above Allen Ward), and have to remain in their single rooms for the duration of their admission. There are separate *B. cepacia* and *MRSA* out-patient clinics so patients with these infections do not mix with other CF patients. Patients with these infections are also advised not to mix with other CF patients in the community.

With these segregation measures in place, there have been no instances of cross-infection of these bacteria from within the hospital setting.

What is the new segregation policy?

Patients staying in Allen Ward and Cherry Tree in the future will have to remain in their rooms for the duration of their admission. All activities, including school, meals, and leisure time, will be undertaken in the patients' own room. The existing open and shared area in Cherry Tree will no longer be available, and leisure equipment (e.g. pool table, large TV) will be removed to reduce any risk of cross-infection.

New facilities and resources will be provided for each room. Patients remain free to leave their rooms if they are accompanied by their parents, preferably after 4pm when all school and treatments for the day have been completed.

What about boredom during admissions?

During admissions, patients have a structured routine of care including morning physiotherapy, school, lunch, afternoon physiotherapy, and visits to the gym. At other times, individual resources such as TV, video, and games are available to be used. Patients are also able to bring with them items from home to help pass away the time.

What about not being able to see other patients?

One of the biggest drawbacks of this policy is that children and adolescents will have limited opportunities to spend time together. Patients have built up friendships over the years, and we know this will be the hardest part of the segregation policy. To help with this, we will be looking at providing some means of communication between patients, such as computers with direct email facilitates between rooms, walkie talkies and other similar equipment. We want to do as much as we can to make things easier for all patients and families.

When will these new changes take place?

These changes are due to begin from September.

I would like to make some comments. How can I do this?

We want to hear your views and opinions on the new segregation policy. Along with this information leaflet you will find a questionnaire for the main carer to complete. You will also find a questionnaire for your child to complete if your child is over 10 years of age. Please complete and return by post or hand to any member of the CF team, and add any comments you wish to make.

What happens next?

Over the next few weeks, we will be reading all of your comments and suggestions from the questionnaires. We will also be talking with some young people and their parents during admissions to hospital about how they feel segregation will affect them.

A further information sheet will be sent in August with responses to all of the questions you have raised. More detailed information on how the segregation policy will affect you during admissions and for out-patient clinic visits will be given then.

Although this new policy will be difficult for some patients, overall the aim is to improve the quality of the care that is provided to you and your family. Your opinions and viewpoints on how we can do this will be most welcomed.

CF Team

2. Semi-structured Interview Guide

INTERVIEW GUIDE

TOPIC 1. General comment about hospital admission

What is it like for you to have to come into hospital?

TOPIC 2. This admission, time line

Before admission, finding out

Point of admission

Few days in

Weekend

Now

Once go home

TOPIC 3. Activities

TOPIC 4. Social interaction

TOPIC 5. Infection and infection control procedures

TOPIC 6. Segregation

Views

Differences (staff, family, coping, activities, feelings)

TOPIC 7. Coping with segregation

3. Ethics and Research Governance Approval



Research Ethics Committee
Room 1009
Education Centre
Royal Group of Hospitals
Belfast BT12 6BA
Northern Ireland
Tel (028) 9063 2649

19th March 2004

Ms K Russo
Department of Clinical Psychology
1st Floor
Royal Belfast Hospital for sick children
Falls Road
Belfast
BT12 6BJ

Dear Ms Russo

RESEARCH ETHICS COMMITTEE

Application No: 132/04

Title of Project: The impact of segregation policies in cystic fibrosis – the patient perspective.

The above project was considered by the Research Ethics Committee at a meeting held on Tuesday 16th March 2004. The Committee consulted the full protocol, considered the application form and the consent/patient information sheet and decided to give approval to your project on ethical grounds.

This approval is conditional on complying fully with the Research Governance arrangements in all the Trusts in which the Research is conducted and making a note in the patients' chart that he/she has participated in the study.

Yours sincerely

A handwritten signature in black ink, appearing to be 'T J Mc Murray', written over a diagonal line.

Dr T J Mc Murray
CHAIRMAN, RESEARCH ETHICS COMMITTEE
FACULTY OF MEDICINE

The ROYAL
HOSPITALS

ROYAL RESEARCH OFFICE
First Floor, Education Centre, RVH.
Telephone: (028) 9063 5372 Fax: (028) 9063 4812

28 April 2005

Ref No: RGHT000101

Ms Kate Russo
Department of Clinical Psychology
First Floor
Royal Belfast Hospital for Sick Children

Dear Ms Russo,

Re: Indemnity Certificate for the Research Project 'The Impact of Segregation Policies in Cystic Fibrosis – The Patient Perspective'

I am pleased to inform you that the above project has been approved by the Royal Group of Hospitals Trust and I am issuing you with your Certificate of Indemnity which is enclosed.

The only provisos are that you adhere and abide by the conditions below:

- The researcher(s) must adhere strictly to the research protocol.
- There must be no changes to the research protocol without prior consent of the Trust.
- There must be no changes in research staff without prior consent of the Trust.
- There must be no increase in the resources required without prior consent of the Trust.
- Researcher(s) must report all untoward incidents to the Trust.
- Any concerns in relation to the research protocol must be reported to the Trust.
- Any matter of interpretation in relation to the research protocol to be referred to the Trust.
- Researcher(s) adhere to good research practice principles in line with the ICH GCP guidelines.

Also find enclosed copies of the Trust policies on data protection and fraud and misconduct.

When the project starts please complete the enclosed Start Certificate and return to the Royal Research Office.

Yours sincerely

Emma Maginn

PP Professor Ian Young
Director of Research & Development

Enc

PATRON: HRH The Duchess of Kent

The Royal Victoria Hospital
The Royal Maternity Hospital
The Royal Belfast Hospital for Sick Children
The Dental Hospital

THE ROYAL GROUP OF HOSPITALS AND DENTAL HOSPITAL HSS TRUST
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and Language Therapy
Genito-Urinary Medicine Clinic
Haematology Unit (R&P)

4. Study Information Leaflets

Study - What is segregation like for kids?

INFORMATION FOR KIDS AND TEENS

A study is being done in the CF Unit to look at feelings about segregation. Patients who are admitted to hospital for two week IV antibiotics will be able to participate.

What is this study about?

There is now a segregation policy for stays in hospital, where you need to stay in your room for your whole admission. Not much is known about what this is like. This study is to find out what segregation has been like for you and your family. Knowing this can help us learn ways to help you, your family, and other kids just like you.

What will I need to do?

If you would like to be part of this study, you will be asked some questions about CF, segregation, and being in hospital. You will have a chance to talk about what it is like for you to come into hospital. Questions will take 30 minutes, and will be recorded on tape. Someone else in your family will also be asked these questions.

What happens next?

What you say will not be shared with the CF Team, or your parents. But the ideas of what you are saying will be added to what other kids say, and this information will then be shared with other centres. Your name will not be on this.

Do I have to do the study?

You do not have to take part in this study if you do not want to.

What happens next?

You will be asked during the last few days of your stay in hospital if you want to take part in this study. You can ask any questions you want at this point.

Study – what is segregation like for patients and their families?

INFORMATION SHEET FOR PATIENTS AND CARERS

This sheet provides information on a study that is being done at the CF Centre. All patients who are admitted for two week IV antibiotics, and their carers, are able to participate.

Why is this study important?

The Centre now uses a segregation policy, which requires patients to remain in their rooms for the whole of their hospital admission with no mixing with other patients. The aim of this study is to find out what it is like to experience the segregation policy. It is hoped that this information can be used in the future to improve services and resources for those who are segregated.

What is involved and how long will it take?

This study uses a 30 minute interview with young patients with CF, and also a similar separate interview with the parents/carers. All interviews will be done during your child's admission to hospital.

Why should I participate in this study?

This study will provide you and your child with an opportunity to talk about your experiences of hospital admission, segregation, and how it affects you and your family.

What will happen to the information?

Recordings of all interviews will be made, which will then be transcribed to allow for comparison with other interviews. Your personal details will be removed and will remain confidential at all times. The information discussed during the interviews will not be shared with the medical team, and will not be used for clinical purposes. The main findings from this study will be published and shared with other CF professionals, however no identifying information will be included.

What will happen if I do not volunteer to participate?

You do not have to take part in this study, and non-participation will not affect your child's treatment in any way.

If you are willing to participate, a consent form must be signed by yourself and your child, and interviews will then be carried out at a time that suits you and your child.

5. Study Consent Forms

The Impact of Segregation Policies in Cystic Fibrosis – the Patient Perspective

Declaration of Informed Consent

Please tick each statement that applies.

- ☐ I consent to take part in this study as outlined on the information sheet
- ☐ I have read and I fully understand the information about this study
- ☐ I understand that all information will be treated confidentially and stored anonymously, and will be used only for this study

Name of young person: _____

Age of young person: _____

Signature of young person: _____

Name of Parent/Guardian: _____

Signature of Parent/Guardian: _____

The Impact of Segregation Policies in Cystic Fibrosis – the Patient Perspective

Declaration of Informed Consent

Having taken part in the interview, I consent /do not consent **[please delete as appropriate]** to have the recorded interview used in this study.

Name of young person: _____

Signature of young person: _____

Name of Parent/Guardian: _____

Signature of Parent/Guardian: _____

6. Worked Example of IPA

Worked Example of Interpretative Phenomenological Analysis

To highlight the process involved in undertaking IPA, an example of the process is shown using an excerpt from the child interview with Participant 14, a female aged 13 years during her first admission to hospital. In this segment of interview, the participant is describing her experience of having CF, and her lack of opportunities to talk with others with CF.

Participant Interview Excerpt

35: K: *And what is it like knowing that there are other people with CF in here at the same time?*

36: P: *You see it's really strange, because you don't think .. cause.. you don't really normally walk about the street and think... because people always ask you what it is and stuff. But there is loads of people that have it. I didn't think there was that many.*

37: K: *So how does that make you feel?*

38: P: *That you are not the only one, not the only... there's other people that have it and they are worse than you. Stuff like that.*

39: K: *So that's very different to how you normally feel.*

40: P: *Yeah, usually you feel on your own, thinking that no one understands what you have to do and stuff.*

41: K: *Do you think some of your other friends understand?*

42: P: *Yeah, my best friend, like she really understands. She's the one that like, makes me take my tablets whenever I'm staying over in her house. She's like "now you have to do your physio and you have to take your tablets". I'm like "yes miss". She makes you do everything like.*

Level One analysis (written in the left hand column) involves making comments and observations of the information from the transcript. Observations can be about what is said, things that stand out, and are based on initial thoughts about the data. Level one analysis of the interview excerpt for Participant 14 is as follows:

Level 1 Analysis

	35: K: <i>And what is it like knowing that there are other people with CF in here at the same time?</i>
Used to being the only one with CF	36: P: <i>You see it's really strange, because you don't think .. cause.. you don't really normally walk about the street and think... because people always ask you what it is and stuff. But there is loads of people that have it. I didn't think there was that many.</i>
Reassurance knowing that others also have CF	
	37: K: <i>So how does that make you feel?</i>
Realises she isn't different	38: P: <i>That you are not the only one, not the only... there's other people that have it and they are worse than you. Stuff like that.</i>
social comparison of health status	
	39: K: <i>So that's very different to how you normally feel.</i>
	40: P: <i>Yeah, usually you feel on your own, thinking that no one understands what you have to do and stuff.</i>
CF makes you feel different, no-one can understand it	
	41: K: <i>Do you think some of your other friends understand?</i>
Good support from best friend	42: P: <i>Yeah, my best friend, like she really understands. She's the one that like, makes me take my tablets whenever I'm staying over in her house. She's like "now you have to do your physio and you have to take your tablets". I'm like "yes miss". She makes you do everything like.</i>
Friend prompts to do treatment	

Level Two Analysis involves the process of determining an ‘analytical code’ – a word or phrase which appears to sum up the essence of the comment. These codes can be psychological terms, words used by the participant. However, in comparison to level one, it involves a higher level of analysis.

Level 2 Analysis

LEVEL ONE ANALYSIS		LEVEL TWO ANALYSIS
	35: K: <i>And what is it like knowing that there are other people with CF in here at the same time?</i>	
Used to being the only one with CF	36: P: <i>You see it's really strange, because you don't think .. cause.. you don't really normally walk about the street and</i>	IMPACT OF CF - ISOLATION

<i>think... because people always ask you what it is and stuff.</i>		
Reassurance knowing that others also have CF	<i>But there is loads of people that have it. I didn't think there was that many.</i>	
	37: K: <i>So how does that make you feel?</i>	GROUP IDENTITY
Not different	38: P: <i>That you are not the only one, not the only... there's other people that have it and they are worse than you. Stuff like that.</i>	ADJUSTMENT to CF
social comparison of health status	39: K: <i>So that's very different to how you normally feel.</i>	
CF makes you feel different, no-one can understand it	40: P: <i>Yeah, usually you feel on your own, thinking that no one understands what you have to do and stuff.</i>	IMPACT OF CF - ISOLATION
	41: K: <i>Do you think some of your other friends understand?</i>	
Good support from best friend	42: P: <i>Yeah, my best friend, like she really understands. She's the one that like, makes me take my tablets whenever I'm staying over in her house. She's like "now you have to do your physio and you have to take your tablets". I'm like "yes miss". She makes you do everything like.</i>	BEST FRIEND ROLE OF SUPPORT
Friend prompts to do treatment		

The next stage of analysis at Level three involves listing all the higher level codes (i.e. level two codes) in order of appearance from the text. Samples of conversation are included to define meanings of the code and to identify location.

Level 3 Analysis

<i>Analytical code</i>	<i>Sample from text</i>	<i>Location in text</i>
Impact of CF – social isolation	<i>You see it's really strange, because you don't think .. cause.. you don't really normally walk about the street and think... because people always ask you what it is</i>	P4, para 36
Group identity with CF peers	<i>That you are not the only one, not the only... there's other people that have it</i>	P34, para 38
Adjustment to CF	<i>other people that have it and they are worse than you</i>	P4, para 38
Impact of CF - isolation	<i>usually you feel on your own, thinking that no one understands what you have to do</i>	P4, para 40
Social support normal peers	<i>She's the one that like, makes me take my tablets whenever I'm staying over in her house.</i>	P4, para 42

Level Four involves the conceptual analysis of themes of the transcript. From the ordered list of conceptual codes, codes are then grouped into common themes.

Level 4 Analysis

- Impact of CF – social isolation
- Impact of CF - isolation
- Group identity with CF peers
- Adjustment to CF
- Social support normal peers

Finally, level 5 involves reducing the level 4 categories to several major ‘themes’, and presenting this information in a table, using quotes and references to location in text to help define and locate themes.

Level 5 Analysis

Impact of CF

Feeling alone “*usually you feel on your own, thinking that no one understands what you have to do*”

Restriction

Strategies used to adjustment to illness

Social comparison with CF peers “*other people that have it and they are worse than you*”

Friends as reminders “*She...makes me take my tablets...*”

Contact with CF peers “*That you are not the only one.. other people that have it*”

7. Details of Research Activity and Dissemination

RELEVANT PUBLICATIONS DURING PERIOD OF RESEARCH

Peer Reviewed Journal Articles

Russo K, Donnelly M, & Reid AJ. (2006). Segregation - the perspectives of young patients and their parents. *Journal of Cystic Fibrosis*, May, 5(2): 93 - 99

Published Conference Proceedings

Russo, Donnelly & Reid (2006). The changing experience of hospital admission for young CF patients. *Proceedings of the 20th Annual North American Cystic Fibrosis Conference, Denver, Colorado, November 2-5, Paediatric Pulmonology, Supplement 29, Abstract number 555*

Russo, K., Burns, C., Reid, A., Donnelly, M. (2005). Segregation – the patient and parent perspectives. *Proceedings of the 28th European Cystic Fibrosis Conference, Crete, Journal of Cystic Fibrosis, Volume 4, Supplement 1, S115*

Papers in Preparation

Russo, K. Doing clinical research as a Clinical Psychologist – two sides of the same coin. Special edition: Doing phenomenological research in clinical settings.

Russo, K. The carer perspective of segregation.

RELEVANT PRESENTATIONS DURING PERIOD OF RESEARCH

Oral Presentations - International and National

2007. Negotiating dual roles in research – two sides of the same coin. *7th Annual Interpretative Phenomenological Analysis Conference, University of Sussex, Brighton, July 5-6*

2007. Invited speaker – Coping with segregation: practice implications. Segregation symposium, *30th European Cystic Fibrosis Conference, Turkey, June 12-16*

2006. Invited speaker - The impact of infection control measures on hospitalisations (and more): a presentation of research in progress. *20th Annual North American Cystic Fibrosis Conference, Denver, Colorado, November 2-5*

2005. A questionnaire study of the patient and parent views of the introduction of a segregation policy. *28th European Cystic Fibrosis Conference, Crete, June 22-25*

2005. Invited speaker – Introducing segregation: the Belfast experience. *British Psychosocial Group in CF Annual Study Day, Mountcalm Hotel, London, May*

- 2004. Invited speaker - Psychosocial impact of infection in cystic fibrosis. *British Psychosocial Group in CF Annual study day*, Mountcalm Hotel, London, April
- 2003. Invited speaker - Psychosocial impact of pseudomonas infection, 26th *European Cystic Fibrosis Conference*, Belfast, UK, June 4-7

Poster Presentations – International

- 2006. The changing experience of hospital admission for young CF patients. 20th *Annual North American Cystic Fibrosis Conference*, Denver, Colorado, November 2-5
- 2005. Segregation – the patient and parent perspectives. 28th *European Cystic Fibrosis Conference*, Crete, June 22-25

Hospital and Departmental Presentations (2005 onwards)

- 2007. The Psychosocial impact of segregation upon patients and carers with Cystic Fibrosis. *Department of Clinical Psychology Journal Club*, June
- 2006. A project completed – patient and parent views on the introduction of the segregation policy. *Presentation to the Royal Group of Hospitals Multi-disciplinary Research Group*, August
- 2006. Being a clinician-researcher – advantages and challenges. *Department of Clinical Psychology Journal Club*, March
- 2006. Feedback of an audit – staff perceptions of the impact of the segregation policy in the Paediatric CF Centre. *CF Team, Royal Belfast Hospital for Sick Children*, February
- 2005. Involving patients and carers in service delivery – introducing segregation to the cystic fibrosis Centre. *Clinical and Medical Rounds, Royal Belfast Hospital for Sick Children*, November
- 2005. Practical ward issues identified during data collection of the impact of the segregation policy – brainstorming session. *Feedback to CF Team, staff of Allen Ward and Cherry Tree House, Royal Belfast Hospital for Sick Children*, November
- 2005. Summary of segregation research presented at the Crete European CF Conference. *Friends of the Royal Travel Bursary Recipients Presentation Day, Royal Group of Hospitals*, October
- 2005. Introducing a segregation policy on the Cystic Fibrosis ward – a questionnaire survey of patient and parent views and opinions. *Department of Clinical Psychology Research Meeting, Royal Belfast Hospital for Sick Children*, June

2005. Problems with getting research off the ground. *Presentation to the Royal Group of Hospitals Multi-disciplinary Research Group, May*
2005. Psychological issues in cystic fibrosis. *Presentation at the Paediatric Psychology meeting, Department of Clinical Psychology, Royal Belfast Hospital for Sick Children, January*

WORKING PARTIES, CONSULTATION, and OTHER ACTIVITIES

2007. CF Trust Standards of Care Working Group (in press). A consensus document: Standards for the clinical care of children and adults with cystic fibrosis in the UK (3rd Ed.). Bromley: Cystic Fibrosis Trust UK.
2004. Services to meet the psychological needs of children and adolescents with Cystic Fibrosis in Northern Ireland: A consensus document. Department of Health and Social Services, Clinical Psychology Speciality Advisory Committee.

8. Reflective Appendix

Reflexivity involves the process of awareness of how the presence of the researcher and one's beliefs, views, experiences, and culture influence and shape thinking about the topic under investigation. By keeping a process diary, underlying assumptions and 'pre-understandings' can be made explicit. Reflecting upon these issues then allows the researcher to 'bracket' their pre-conceptions, allowing the relevant themes to emerge from the data.

This section aims to summarise and reflect upon entries in the process diary. Due to space limitations, only a small sample of my reflections are included. More detailed reflections on having a dual role (i.e. being a clinician and researcher) is currently being written up for publication.

Personal reflections – On being a white, female and Australian

This research used interviews with young people aged 7 – 17 years. To obtain an account of participant's lived experiences, it was important that I was aware of their culture and experiences. Being in my early 30's, I am somewhat outside the young 'culture' regarding language, experiences and values. I do not have children, although am able to engage relatively well with children and adolescents. Working with children on a daily basis has brought me closer to their experiences, however still provides challenges when interpreting events from a child perspective.

Knowing some of the participants helped to understand their own experiences of hospitalisation and made me more able to understand how being on their own impacted upon them. I found it particularly useful to have had prior experience of accompanying many children admitted to hospital at times when they were on their own, and just simply being with them and sharing that experience – not as a psychologist but as another human being.

All the participants in the study were white Caucasian, and were born and raised in Northern Ireland. Being from another country brings obvious differences to relating to others. Having lived in Northern Ireland for over 10 years has made me familiar with the culture, ways of being, language, and ways of relating, although I am aware that I could never be considered 'a local' with deep insights and understandings of the culture. I had, however, shared the participants 'life worlds' of being in Northern Ireland during the time when they were growing up. Despite differences in culture, religion and upbringing that would lead to differences in understanding, there were advantages to also being an 'outsider'. Young people were very interested in my country and background, and often talked freely prior to interviews about their desire to visit my country of origin. Interestingly, some children commented that I too was far away from my family, and therefore likely to have some awareness of what it was like for them to be in hospital away from their own family.

Professional reflections – The influence of my beliefs on the design of the study

There are several beliefs that I hold as a psychologist which I feel contributed towards the design of the study. Firstly, I believe that psychologists in health settings should take more of a preventive approach. Sadly, this is not the case in the CF service due to limited funding. According to the CF Standards of Care, for a Specialist CF Clinic of 200 young people, there should be 2 whole time equivalents (WTE) of a Clinical Psychologist. In reality only 0.2 WTE is funded, which limits the important preventive roles that could be taken and instead is diverted towards a 'crisis intervention' way of delivering a service.

Secondly, I believe in the involvement and inclusion of service users, regardless of age, in planning, delivery and evaluation of services. These two beliefs

very much pointed me in the direction of ‘action research’, that is, researching real life issues and dilemmas that are meaningful to the participants and as they occur. Also, in some way I feel that participation in the study allowed for young people to feel more in control of their treatment and CF admissions by having their say and sharing their ideas and experiences. As participants were empowered, which potentially could be seen as preventing difficulties associated with the introduction of segregation, the research seemed far more ‘ethical’ in light of the lack of funding for clinical services. I would have felt very uncomfortable with undertaking research in this field that did not directly benefit the participants given the restraints upon the service.

Somewhat related is my third belief, in that important research should be disseminated as widely as possible, and I have attempted to do that in order to ensure that the participants views are listened to and acted upon by those in a position to make a difference. It is these beliefs that have ensured that my motivation and interest in this research has remained high. I feel I have been able to remain open and attempted to listen to what the participants were telling me, rather than having any other agenda.

I was very interested in the phenomenological approach as it appeared to ‘fit’ appropriately with my own beliefs and values as a researcher. I had limited qualitative research training throughout my own training as a Clinical Psychologist, so I felt I had ‘unlearn’ patterns of thinking and learn new ways of viewing the world, along with a new language. I see great potential for phenomenological research in the health setting. Not only have I learned to become an effective researcher, I have also learned to become a better clinician by focusing on the skills of simply being, listening and facilitating people to share their experiences.

Pre-existing views on the topic of segregation

I first became interested in the topic of segregation in 2001 when I commenced work in the CF service. I could see the enormous benefit gained by the patients who were at that time able to mix, and indeed the ward was arranged in such a way that mixing was fun, full of activities and made admissions pass quickly. I was aware of the evidence that was beginning to emerge that all patients with CF should be discouraged from mixing, and my own view was that this would be detrimental to young people with CF. Most other psychosocial professionals working in the field also expressed their reservations about not allowing patients to have contact with each other, particularly during admissions. I had a feeling of disappointment when the decision was made to introduce segregation at our CF Centre, although it seemed to make logical sense. I was also aware that I had conflicting feelings about the issue – as a psychologist I felt that patients should continue to mix, but I also held the view that if it were my child with CF then I would actively *avoid* contact with other patients. I was aware that my view shifted following feedback from young people and their carers regarding the introduction of segregation, which was overwhelmingly positive (see Russo, Donnelly & Reid, 2006). Knowing their views, and also being aware of the evidence, made me feel confident that segregation was an appropriate way forward. It also highlighted that everyone engaged in the risk/benefit ratio, and that would never be a time when one would be completely comfortable with segregation. However, I was also aware that the experienced participants at our Centre found it difficult, and were initially reluctant to accept that it had been introduced. This led to the current research project.

Now, having completed this study and listened to the views of those who actually experience segregation, I still feel it is the best course of action for young people with CF. It seems a fair way of reducing the risks for all, whilst protecting individual privacy regarding bacterial infection, and all patients are treated equal regardless of infection status. I am aware that I feel frustrated when I see individual staff members making 'exceptions' by having patients with multi-resistant *pseudomonas* out of their rooms as I feel this leads to confusion amongst children. I personally believe that segregation should be consistently adhered to in order to facilitate adjustment.

There is one time when I feel exceptions should be made, and that is at times of high anxiety and uncertainty when young people would benefit from contact with someone who has been in a similar situation before. For example, if a young person is about to go to surgery for the insertion of a PEG tube, they appear to have lots of questions that they do not ask medical staff. I feel that if they are very distressed by it, or uncertain, that having a brief 'safe' contact with another young person with CF would be of enormous benefit.

Overall, I would not say that I am 'pro-segregation' or 'against segregation', but certainly my viewpoint has shifted as a direct result of the research I have undertaken. I have also attempted to highlight that it is not the Psychologists role to determine whether segregation could occur or not – our role should be to educate about the potential impact and identify ways in which to minimise difficulties.

More Professional reflections – on the dual roles of a Clinical Psychologist and researcher to the same clinical group

By far the biggest 'challenge' of undertaking this research was my dual role of being both a clinician providing psychological services to this group of participants, and also the researcher whose role is to be neutral and facilitating the 'telling of stories'. Some would argue that these roles may not need to be mutually exclusive. I find the issue of dual roles fascinating, and have presented and am currently writing further on this topic. To summarise, I recognised when there were conflicts between the two roles, and I felt I always acted from within the Clinical Psychology professional guidelines, which always prioritised the rights of the patient to privacy, respect, confidentiality etc over the needs of the research. I was very conscious of the potential for power to interfere with informed consent for participation, and took steps to minimise this where possible. Specific dilemmas I faced have been highlighted elsewhere (Russo, 2007b) and are soon to be published. These dilemmas arose due to both internal and external role confusion, with the biggest challenge related to the need for information during the research process and how this was managed. Also, although not mentioned in the literature, I found it difficult to 'leave the world of the participant' following the research, that is, my continued contacts with these participants were above and beyond that required of my clinical role. Again, I argue that there needs to be an increased awareness of the issues involved when there are dual relationships, particularly for Clinical Psychologists. I had the opportunity to discuss issues regarding dual roles with my research supervisor, and at times with a clinical supervisor. However, I feel that those undertaking research in similar positions require additional clinical supervision as part of their research plan, ideally from someone who has experienced these dual roles in the past.

9. Detailed Participant Profiles

Detailed Participant Profiles

<i>Pseudonym</i>	<i>Age</i>	<i>Severity</i>	<i>pseudo monas</i>	<i>Intact family?</i>	<i>sibs</i>	<i>Prior admissions</i>	<i>Experienced? Y/N</i>
Leo	14	Mod	No	Yes	Yes	6 monthly	No
Donna	10	Mod	Yes	Yes	Yes	3 monthly	Yes
Ian	15	Mod	Yes	Yes	No	3 monthly	Yes
Katie	14	Mod	No	Yes	Yes	Yearly	No
Brenda	15	Mod	Yes	Yes	Yes	6 monthly	No
Roisin	15	Severe	Yes	No	Yes ^a	3 monthly	Yes
Fiona	15	severe	Yes	Yes	No	3 monthly	Yes
Pam	17	Severe	Yes	Yes	Yes	3 monthly	Yes
Isaac	12	Mod	Yes	No	Yes	3 monthly	Yes
Betty	12	Mod	No ^b	No	Yes	3 monthly	Yes
Hugh	16	Mild	No	Yes	Yes ^a	First	No
Bradley	16	Mild	Yes	Yes	Yes	Yearly	No
Stephen	7	Mild	No	Yes	No	First	No
Belinda	13	Mild	No ^b	Yes	Yes ^a	First	No

^a siblings also had CF; ^b prior infection that had since been eradicated