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**THE REALITIES OF SEGREGATION THROUGH THE EYES OF
ADOLESCENTS WITH CYSTIC FIBROSIS: A QUALITATIVE STUDY
AND CLINICAL RESEARCH PORTFOLIO
VOLUME I**

(Volume 11 bound separately)

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MA (Hons)

Submitted in partial fulfilment of the requirements for the degree of Doctorate in
Clinical Psychology (D Clin Psy)

Mental Health and Wellbeing

University of Glasgow

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Firstly, I would like to thank all of the young people who participated in this study, your strength and resilience truly amazed me. I hope that this study has done you justice.

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Particular shout out goes to the other half - thank you for all your support, as well as the very non-psychological advice...it really did help!! Other special shout out goes out to my dad - thank you for always encouraging me to follow my dreams and giving me the confidence and self belief that I could do this.

Right it's about time I went off and had some fun!!

CHAPTER ONE: SYSTEMATIC LITERATURE REVIEW

4 - 29

Family functioning and adherence to treatment in children and young people with cystic fibrosis: a systematic review.

CHAPTER TWO: MAJOR RESEARCH PROJECT

30-70

The realities of segregation through the eyes of adolescents with cystic fibrosis; a qualitative study

**CHAPTER THREE: ADVANCED CLINICAL PRACTICE I
CRITICAL REFLECTIVE ACCOUNT (Abstract Only)**

71-72

Feeling out of depth when dealing with dynamics: a reflective account

**CHAPTER FOUR: ADVANCED CLINICAL PRACTICE II
CRITICAL REFLECTIVE ACCOUNT (Abstract Only)**

73-74

Service re-design: considering the role of clinical psychology in facilitating this process.

APPENDICES**Systematic Review**

75 - 80

Appendix 1.1 Author guidelines for publication

Appendix 1.2 Quality rating tool

Appendix 1.3 Quality rating of studies included in systematic review

Appendix 1.4 Definition of family functioning factors & rating criteria

Major Research Project

81-111

Appendix 2.1 Author guidelines

Appendix 2.2 Ethics approval letter

Appendix 2.3 Information pack containing information sheets (participant & parent version), participant 'opt-in' form & consent form, and parent 'assent' form.

Appendix 2.4 Interview topic guide

Appendix 2.5 Transcript from interview

Appendix 2.6 Major research project proposal

CHAPTER ONE: SYSTEMATIC REVIEW

Family functioning and adherence to treatment in children and young people with cystic fibrosis: a systematic review.

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KEYWORDS: family functioning, adherence, children and young people, cystic fibrosis, systematic review

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Abstract

Background: Adherence to treatment is often a major concern when managing children and young people with cystic fibrosis, amongst other chronic diseases. A plethora of studies now exist examining this and a range of predictors have been identified; including that of family functioning.

Aim/objectives: This systematic review aims to evaluate the literature on family functioning and adherence in children and young people with cystic fibrosis. The objectives include elucidation of the full range of family factors associated with adherence, and determining whether any are key factors. Particular attention has also been paid to evaluating the methods used to measure adherence.

Method: A systematic search strategy was utilized in order to identify relevant articles. These were screened using strict inclusion and exclusion criteria. Each study was then rated for methodological quality and data was extracted from the identified papers. Seven studies were found to be of ‘good’ or ‘acceptable’ quality and hence, were deemed suitable for this review.

Results: Ten family factors were found to be significantly associated with adherence. These were separated into; family specific, parent specific and parent-child factors. Unfortunately the majority of studies did not offer analysis beyond this; therefore it was difficult to ascertain if any were particularly pertinent. Family adaptability and cohesion was however the most frequently measured concept, and of those studies that did examine variance, was found to have the highest amount of influence on adherence.

Conclusions: There is substantial evidence that family functioning plays a significant role in predicting adherence in children and young people with cystic fibrosis. The literature is less clear about which components of family functioning, however, are central to the relationship. Tentative conclusions can be drawn that family cohesion and adaptability may be particularly important, although further research is required. In light of this, clinical recommendations and suggestions for future research are outlined.

1. Introduction

Cystic fibrosis & treatment

Cystic fibrosis (CF) is the most commonly inherited disease in Caucasians affecting 1 in every 2,500 live births in Northern Europe (Zindani et al., 2006), and primarily affects the lungs and pancreas. Treatment generally consists of a multi-modal regime including; airway clearance therapies (i.e. chest physiotherapy or exercise), antibiotics, and vitamin supplements and pancreatic enzymes which must be taken with all meals. A high calorie diet is also recommended. The quantities of medication and treatment vary, but are largely based on disease severity (Zindani et al., 2006). As yet, no cure has been developed for CF. Adherence to treatment however, is associated with improved health status, longevity (Patterson et al., 1993) and quality of life (Kotwicki et al., 2001). Adherence can be defined as “the extent to which a person’s behaviour is consistent with healthcare recommendations” (Abott et al., 2009, pg.597).

Despite the benefits of treatment, non-adherence is a major problem in the management of CF (Zindani et al., 2006, Modi et al., 2006), and in other chronic illness groups in general (Michaud et al., 2004). Adherence rates vary with treatment type, and with method of assessment; a study using objective measures for example, has reported adherence to be below 50% (Modi et al., 2006). Adherence rates appear to be higher for medication than airway clearance, exercise and diet (Passero et al., 1981, Zindani et al., 2006). One explanation is that complexity and level of interference with daily life influences adherence (La Greco, 1990). Due to the negative health implications of treatment non-adherence, research exploring reasons into this phenomenon has increased over recent years. A brief summary will now be provided.

Predictors of adherence

Koocher et al., (1990) interviewed 223 patients and their families in order to develop a conceptual framework for non-adherence. Three main themes were identified; inadequate knowledge, psychosocial resistance, and education non-adherence. Most empirical support has been found for the first two of these categories. Inadequate knowledge refers to those patients who have failed to develop an accurate

understanding of the disease and treatment protocol through lack of information. This has been supported by studies such as Gudas et al., (1991) and Bucks et al., (2009) who reported knowledge about the disease often predicts adherence. The second category, psychosocial resistance, considers the influence of context on the individual, including psychosocial and demographic factors. Factors such as; optimism (Gudas et al., 1991), coping style (Abbott et al., 1994), locus of control beliefs (Myers & Myers, 1999), and illness and treatment beliefs (Bucks et al., 2009), have all been identified as influencing adherence in people with CF.

Demographic factors such as age (Gudas et al., 1991, Geiss et al., 1992, Zindani et al., 2006) and disease severity (Gudas et al., 1991, Myers, 2009), for example, have been consistently found to predict adherence. These studies found younger children (under age of 12), and those with more severe forms of the disease, were more likely to adhere. Over the lifespan, adherence has been found to be particularly low during adolescence (Gudas et al., 1991). This has been attributed to the rapid changes, both physically and emotionally, which occur during this time, including an increasing desire for independence and peer group acceptance which may be particularly significant (Suris et al., 2004). Gender on the other hand, has yielded mixed results; Czajkowski et al., (1987) found females more likely to adhere, Patterson et al., (1993) & Patterson et al., (2008) reported males were more likely to adhere, and Myers (2009) reported no significant difference.

Family environment was also highlighted as a predictor of adherence (Koocher, 1990). The treatment routine for CF is renowned for being tiring, complex, and time consuming and inevitably the success of this depends on gaining help from others, particularly during younger childhood. The impact and strain on families caring for a child with a chronic illness has been well documented (Patterson 1985, Harrop et al., 2007, Berge et al., 2004). Encouragingly, although most families struggle to cope to a certain extent, the majority cope well, emphasising the resilience within this group (Bluebond-Langner et al., 2001). Studies have explored factors which cause variability in a family's ability to cope, particularly as this has been found to relate to family adherence (Patterson et al., 1985). There has been an increase in research investigating the relationship between family factors and adherence, debate has also included the most effective methods to measure this,

particularly in relation to adherence. Given this, and the fact there has been no systematic evaluation of this literature, a systematic review seems timely.

2. Review Aim & Objectives;

This review aims to investigate the relationship between family functioning and adherence to treatment in children and young people with cystic fibrosis.

Objectives;

Describe and evaluate family functioning factors that have been associated with adherence

Identify any key factors

Investigate the methods used to measure adherence

3. Methods

Search Strategy

The following electronic databases were searched; Ovid MED-LINE (1948 – March 2011), EBM Reviews (1991 – March, 2011), EMBASE (1980- March 2011), PsychInfo (1967 – March 2011), CINHAL (1981 - March, 2011). Google Scholar was also searched in addition to this. The following search terms and boolean operators were used:

[adherence or non-adherence or compliance or non-compliance or management]

AND

[family {adjacent} functioning or communication or environment or adjustment or resistance or relationships or relationship quality or cohesion or expressiveness or problem solving or balance or dynamic or dynamics or organisation or resources or roles or coping or responsibilities or demands or stress or integration or flexibility or conflict]

OR

[parent(s) {adjacent} communication or coping or relationship or relationships or conflict or conflicts]

OR

[marital {adjacent} coping or relationship or relationships or conflict or conflicts]

AND

[cystic fibrosis or CF]

AND

[adolescent or paediatric or pediatric or youth or child or children or young people or young person or teen or teenager or teenagers]

Text word and subject heading searches were carried out across multiple databases, and individual databases. A hand search was also carried out through The Journal of Cystic Fibrosis from 2000 – 2011, as well as a reference list check from identified studies. The search generated a total of 664 studies; removal of duplication and irrelevant studies through the screening of titles led to 82 papers being determined as possibly relevant (see figure 1). The following inclusion/exclusion criterion were applied to the abstracts from these studies to screen for suitability.

Inclusion/ Exclusion Criteria;

- Published in a peer reviewed journal
- Published in English Language
- Participants must include children or young people with cystic fibrosis (up to age 20) and/or their parent(s)
- A type of adherence to treatment in children and young people with CF (i.e. medication,

physiotherapy, dietary management) must be measured and reported in some form.

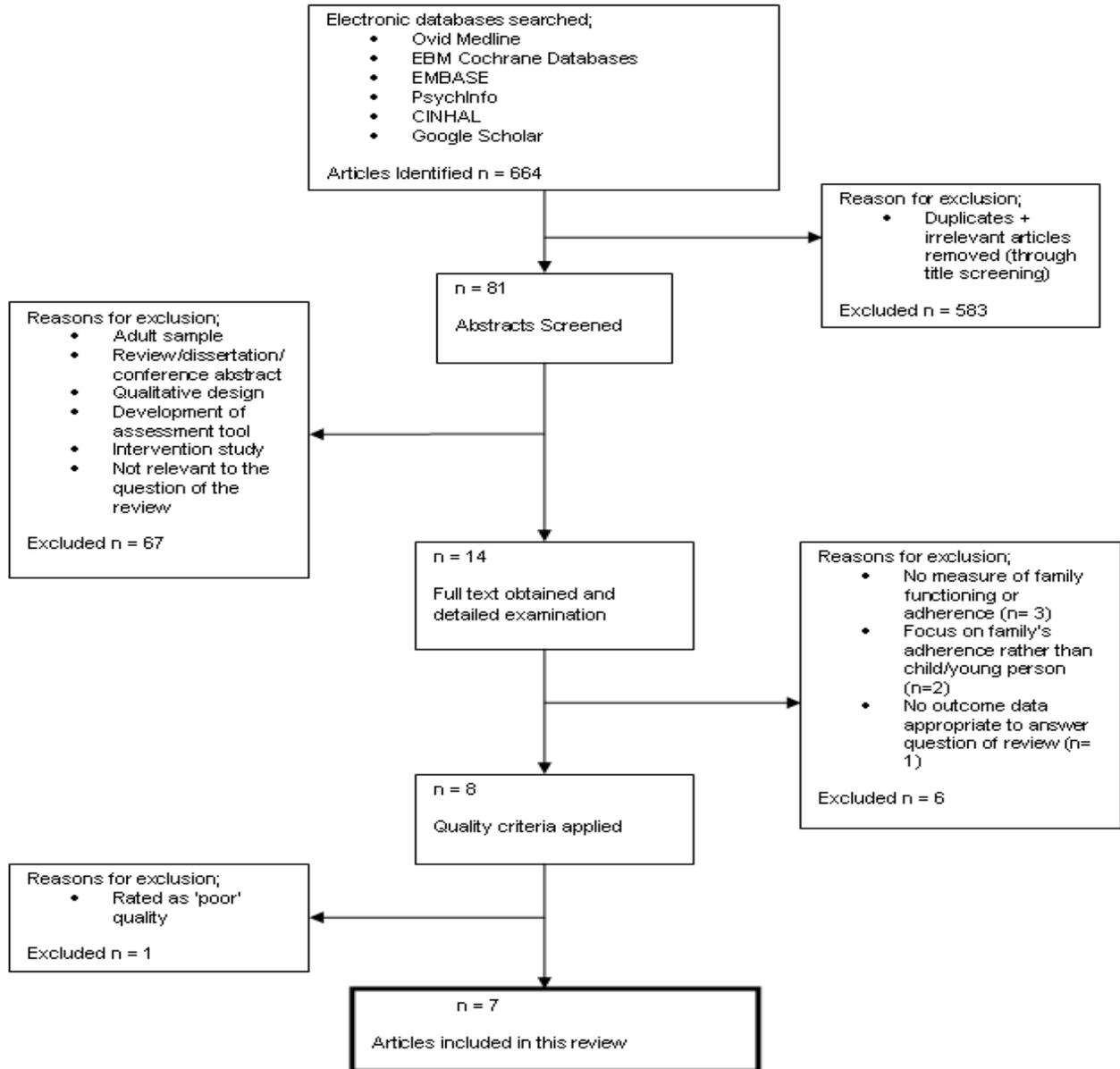
- Family functioning (of some form) must be measured and reported.

Exclusion Criteria;

- 1.) Reviews, dissertations, and single case studies.
- 2.) Qualitative methods.

Studies which failed to meet these requirements were excluded from the study. Full text was then obtained for the remaining 14 studies. Following a closer examination, 8 studies were identified as being possibly suitable to include in this review (reasons for exclusion are detailed on figure 1).

Figure 1: Flow chart of study selection



Quality Assessment

Each study included in the review was assessed using a quality assessment tool adapted by the author.

Reference was made from the SIGN (Scottish Intercollegiate Guidance Network) 50: Methodology Checklist

for Case Control Studies (A Guideline Developer’s Handbook, 2004) guidelines. The tool and scoring guide

are detailed in appendix 1.2. Each study was scored (out of a total of 26 points) on the following areas:

selection of participants, assessment, confounding factors and statistical analysis. Generally 2 points were given if the area was well covered, 1 point if it was adequately covered and 0 was given if poorly covered.

On certain items, more weighting was given than for others. For example, extra weighting was given if

studies used an electronic method to measure adherence, or if a control group was used. The total scores were then converted into percentages. Percentages above 80% were given a 'good' quality rating, those between 50-80% scored an 'acceptable' rating, and studies under 50% were given a 'poor' rating. All papers were rated independently by an experienced researcher and discussion took place in order to reach agreement on all items.

4. Results

Quality rating of studies

Overall, three studies (38%) were rated as 'good' quality, four (50%) were rated as 'acceptable' quality, and one (12%) was found to be of 'poor' quality (see appendix 1.3). It was deemed appropriate to exclude any papers of 'poor quality' therefore, one paper was removed at this stage (see figure 1).

Table 1 provides an overview of the studies included in the review and highlights the following information; characteristics of participants, adherence and family functioning measures, the family functioning factor(s) investigated, and any significant findings found.

Table 1: Overview of reviewed studies

STUDY	PARTICIPANTS	ADHERENCE MEASURES (i.e. self report, electronic device)	FAMILY FUNCTIONING FACTOR INVESTIGATED(*see appendix 1.4 for definitions)	FAMILY FUNCTIONING MEASURES	SIGNIFICANT FINDINGS
DeLambo et al., (2004)	96 children and adolescents (aged 9-16 years) with CF & their parents Disease severity - 'mild'. No control group	The Treatment Adherence Rating Scale (TARS) SELF REPORT – (CHILD AND PARENT VERSION)	Family Relationship Quality (RQ) Family Problem Solving (PS)	The Iowa Family Interaction Rating Scale (IFIRS) OBSERVATION	<u>Based on child's report:</u> Relationship quality (RQ) predicted adherence to airway clearance & medications (p=0.018); with higher quality predicting better adherence. <u>Based on mother's report:</u> RQ significantly predicted adherence to aerosol medication (p = 0.01) and 9.6% of the variance in adherence (p<0.001) <u>Based on father's report:</u> RQ significantly predicted adherence to airway clearance/aerosolized medications (p<0.01) and 14.9% of the variance (p=0.001).
Eddy et al., (1998)	41 children and adolescents (aged 3 – 11 years) with CF & their mothers. Disease severity – 'mild'. No control group.	Medical Compliance Questionnaire SELF REPORT- CHILD VERSION & PARENT/ STAFF VERSIONS.	Parenting Stress Dyadic adjustment Family Adaptability & Cohesion	The Dyadic Adjustment Scale (DAS) Parenting Stress Index- short form. Family Adaptability and Cohesion Evaluation Scale-third edition (FACES-III). SELF REPORT - PARENT RATINGS.	<u>Based on medical staff ratings of adherence:</u> Higher parenting stress and more parent-child dysfunctional interactions predicted lower rates of adherence to physiotherapy (p< 0.05). Less cohesive family environments predicted lower levels of adherence with medications (p<0.05) physiotherapy (p<0.01) and oral intake (p<0.01). Lower adaptability scores were associated with poor adherence for children with special diets (p= 0.05). <u>Based on parent ratings of adherence:</u> High dyadic adjustment and low parenting stress were found to predict adherence in the children that were identified as having special diets (p<0.05).
Mitchell et al., (2004)	33 children (3 – 6 years) with CF and their families. Disease severity – not available. 33 children without a chronic illness were used as a control.	Diet Diaries. PARENTAL REPORT.	Overall Family Functioning	Mealtime Family Interaction Coding system (MICS). OBSERVATION.	Families of children with CF scored significantly lower than control families on the MICS overall rating of family functioning (P< 0.02, ES= 0.84).

Modi et al., (2008)	103 children and young people (aged 10 - 17) with CF. They were split into two groups: 1. aged 10-13 2. aged 14-17 Those in younger group were used as the control (exact numbers for each group was unavailable). Disease severity – majority were classed as 'mild'.	Electronic monitor Daily phone diary (DPD) – no. of hours spent on regimen.	Parental supervision	Daily phone diary (DPD) – number of hours of parental supervision.	Higher levels of parental supervision predicted the frequency and duration of adherence to nebulised treatments. Time spent with mothers but not fathers significantly predicted better adherence ($p < 0.0001$).
Patterson et al., (1993)	91 children and young people (aged 5 – 20 years) & their families Disease severity - variable. No control group was used.	Telephone Interview - PARENTAL REPORT.	Family Resources Family Coping	Family Environment Scale Coping Health Inventory for Parents SELF REPORT – PARENT RATINGS.	Higher levels of family organisation predicted adherence to chest physical therapy ($p < 0.005$). Higher family expressiveness and time resources predicted compliance with aerosol therapy ($p < 0.05$) Overall, 38% of the variance in adherence levels in relation to chest physiotherapy could be explained by higher family organisation and time resources as well as two patient variables (age and gender).
Ricker et al (1998)	50 children (ages 9 to 18) & parents Disease severity – not available. Norms from the assessment measures were used as a control.	Criterion measure: 24-hour recall method on 3 occasions. Telephone interviews. CHILD/YOUNG PERSON.	Family cohesiveness and adaptability.	Family Adaptability and Cohesion Evaluation Scale (FACES-III) SELF REPORT – PARENT RATINGS.	FACES-III and CF-FBC (child form) accounted for 20.7% ($P < 0.0006$) of the variance as overall adherence rate as the dependent variable.
White et al., (2009)	53 children and young people (ages 9 – 17) & their parents Disease severity – not available. Norms from the assessment measures were used as a control.	The confidential cystic fibrosis management profile (CCFMP) – SELF REPORT – YOUNG PERSON & TEAM REPORT	Family cohesion Family adaptability/ flexibility	Family adaptability and cohesion evaluation scales, version II (FACES II). SELF REPORT – PARENT RATINGS.	Higher levels of family cohesion predicted adherence ($P < 0.001$). Greater balance between cohesion and flexibility in families predicted child reported adherence ($P < 0.025$) and parent reported adherence ($P < 0.025$).

Demographic Information

Overall, a combined total of 500 children and young people took part in the studies included in this review; 467 children with CF and 33 children without, and 500 parents (either one or two parents). All but one study provided information regarding the gender of the youngsters with CF in the study; 237 were male (53%) and 206 were female (47%). The age of the children and young people with CF ranged from 6 months to 20 years of age, and the mean age across studies was calculated at 9.3 years of age (excluding data from one study as this information was not available). Six studies included children and adolescents in their sample (75%) and two studies included only children (under age 12) (25%) within their samples. Five out of the eight studies (62%) provided information on the ethnic backgrounds of the sample; 127 (95%) children and young people with CF were white (95%), and 16 (5%) were of other ethnic background (most of which was African American). Four out of the seven studies provided a mean rating for disease severity (FEV¹ or Schwachman index), one study stated it was not able to measure this due to the lack of an appropriate measure for the sample's young age range, two studies reported that they measured FEV¹ but did not provide the reader with the mean ratings, and one study did not mention whether it had recorded the disease severity of its sample or not. Of those that reported the mean disease severity, all of them used samples which had a mean rating of 'mild'.

Research Designs Used

Five of the studies were cross sectional (DeLambo et al., 2004, Eddy et al., 1998, Mitchell et al., 2004, Modi et al., 2008, White et al., 2009) whilst two used a longitudinal design (Patterson et al., 1993, Ricker et al., 1998). Three studies did not use a control group (DeLambo et al., 2004, Patterson et al., 1993, Eddy et al., 1998). Two studies used reference group data from standardized measures (Ricker et al., 1998, White et al., 2009) and one study used a different age group of children (under 14) with CF (Modi et al., 2008). One study (Mitchell et al., 2004) recruited a control group of children who were matched to their CF counterparts by age, gender, socioeconomic status, number of siblings, and health status. Having a matched control group allows inferences to be made between the CF and non-CF group, and is important to eliminate alternative explanations or variables. Caution should therefore; be made when interpreting the results, particularly from those studies who failed to use a control group.

Treatment Modality

Different terms for aspects of the management of treatment of CF appeared to be used interchangeably throughout the studies. For simplicity and to allow the reader to compare studies these were categorised into three areas; airway clearance (e.g. physiotherapy, postural drainage, exercise) medication management (e.g. antibiotics, enzymes, vitamins) and dietary regimen (e.g. diet, calorie intake). The table below provides an overview of each study and the type of treatment adherence that was focused upon.

Table 2 – Overview of treatment modality

Study	Airway clearance	Medication Management	Nutrition
DeLambo et al., (2004)	✓	✓	✓
Eddy et al., (1998)	✓	✓	✓
Mitchell et al., (2004)			✓
Modi et al., (2008)		✓	
Patterson et al., (1993)	✓	✓	
Ricker et al., (1998)	✓	✓	
White et al., (2009)	✓	✓	✓

Three studies (29%) appeared to consider all areas of treatment adherence including airway clearance, medication management, and nutrition (DeLambo et al., 2004, Eddy et al., 1998, and White et al., 2009).

Two studies (29%) focused on airway clearance and medication management only (Patterson et al., 1993, Ricker et al., 1998). One study (14%) looked at medication management only (Modi et al., 2008) and another study (14%) examined nutrition only (Mitchell et al., 2004).

Adherence measures

A variety of methods across studies were employed to measure adherence. Two studies utilised telephone recall methods with the young people alone (Modi et al., 2008; Ricker et al., 1998). One of these studies (Modi et al., 2008) also used an electronic monitoring system to measure adherence to nebulised medication. Another two studies used solely parent or, clinician self- report through either telephone interviews (Patterson et al., 1993) or diet diaries (Mitchell et al., 2004). Three studies used a self- report questionnaire from the child/young person as well as the parent and/or clinician (DeLambo et al., 2004; Eddy et al., 1998; White et al., 2009). The Treatment Adherence Rating Scale (TARS), Medical Compliance Questionnaire (MCQ) and the Confidential Cystic Fibrosis Management Profile (CCFMP) were used respectively. These measures were all developed specifically for the study; DeLambo et al., (2004) was the only study to carry out exploratory factor analysis, finding good construct validity.

Family functioning measures

Majority of studies (57%) used self- report questionnaires, filled out by parents, to measure aspects of family functioning. The most common measure was a 30 item scale, the Family Adaptability & Cohesion Evaluation Scale- Third Edition (FACES –III) (Olson et al., 1989) which was used by three studies (Eddy et al., 1998, Ricker et al., 1998, White et al., 2009). Good reliability and validity has been found for this measure (Olson et al., 1989). Other self- report measures included; The Dyadic Adjustment Scale (Eddy et al., 1998), Parenting Stress Index (Eddy et al., 1998), Family Environment Scale (Patterson et al., 1993), Coping Health Inventory for Parents (Patterson et al., 1993), and CF Family Behaviour Checklist (Ricker et al., 1998). Two studies (29%) rated videotaped observations of family interaction using observation checklists (DeLambo et al., 2004, Mitchell et al., 2004). The Iowa Family Interaction Rating Scale (IFIRS) and Mealtime Family Interaction Coding System were used respectively. One study (14%) used a novel daily phone diary method to examine specifically parental supervision (Modi et al., 2008).

Findings

Family Functioning & Adherence

One study which examined overall family functioning found a significant difference between those families with CF and without, ($p < 0.05$, $ES = 0.84$) indicating significantly lower ratings in those families of children with CF (Mitchell et al., 2004). Furthermore, this study went on to examine whether there was a relationship between family functioning and calorie intake (i.e. form of adherence). An association, although not significant, was found between overall family functioning and calorie intake ($p=0.16$) in the CF sample. It should be noted that this study included young children (3-6 years) in the sample therefore these findings cannot be generalised to older children or adolescents with CF.

The remaining six studies assessed specific aspects of family functioning. In total, eleven factors related to family functioning were assessed across the different studies and significant associations were found for ten of these. Positive associations (i.e. adherence increases) were found when the following factors were present; family relationship quality, adaptability and cohesion, resources, expressiveness, and time resources, and parental supervision, adjustment & relationship satisfaction. Negative associations (i.e. adherence decreases) were found when the following factors were present; parenting stress and parent-child dysfunctional interactions. It was considered helpful to separate these into; family specific factors, parent specific factors and parent-child specific factors (see appendix 1.4).

➤ **Family Specific Factors**

Quality of relationships & problem solving

One study (DeLambo et al., 2004) assessed family relationship quality as well as problem solving skills. After controlling for demographic variables and illness severity, positive ratings of family relationship quality were found to correlate with higher rates of adherence to airway clearance & medication, based on the children's reports ($p=0.018$) and also the parental reports of adherence. Observed family relationship quality was found to predict 9.6% of the variance in child's adherence to airway clearance/aerosolized medications when based on the mother's reports ($p<0.001$), and 14.9% of the variance when based on the father's reports ($p=0.001$). DeLambo et al., (2004) also assessed problem solving skills; however, after controlling for relationship quality, observed family problem solving was not a significant predictor of

adherence. The authors offered the explanation that in the situation of poor family relationships, then there is likely to be limited or restricted opportunity to develop good family problem solving skills (DeLambo et al., 2004).

Family Adaptability & Cohesion

Three studies (Eddy et al., 1998, Ricker et al., 1998, & White et al., 2009) assessed the impact of family adaptability and cohesion on adherence, using the Family Adaptability and Cohesion Evaluation Scale-third edition (FACES-III) (Olson et al., 1989). Eddy et al., (1998) found lower adaptability scores were associated with child non-compliance for physiotherapy ($p = 0.08$) and diet ($p = 0.05$). Medical staff ratings of higher medication compliance correlated with higher family adaptability. In contrast, parent ratings of higher levels of family adaptability were associated with lower compliance with physiotherapy and medication.

Both Eddy et al., (1998) & White et al., (2009) reported that higher family cohesiveness was associated with better adherence rates. Eddy et al., (1998) found that lower levels of adherence were correlated with less cohesive family environments; this was also found for parents' ratings of compliance with physiotherapy. No p-values or effect sizes were reported for these. Another study (White et al., 2009), also reported finding higher levels of family cohesion alongside higher rates of youth-reported adherence ($p < 0.001$); they also noted a greater balance between cohesion and flexibility in families produced higher rates of child reported adherence ($P < 0.025$) and parent reported adherence ($P < 0.025$). Ricker et al. (1998) reported that family adaptability and cohesion accounted for 20.7% ($P < 0.0006$) of the variance for the overall adherence rate.

Family Organisation & Time Resources

Patterson et al. (1993) measured family organisation and time resources using the Family Environment Scale. Higher levels of family organisation were associated with higher rates of chest physiotherapy adherence ($p < 0.005$) and higher levels of family time resources were also positively associated with aerosol therapy ($p < 0.05$). Overall, 38% of the variance in adherence levels in relation to chest physiotherapy could be explained by higher family organisation and time resources as well as two patient variables (age and gender).

Family Expressiveness

Patterson et al., (1993) found higher levels of family expressiveness were associated with better rates of aerosol therapy compliance ($p < 0.05$).

➤ Parent Specific Factors

Dyadic Adjustment

Eddy et al., (1998) examined the impact of the parental relationship on adherence levels using the Dyadic Adjustment Scale (DAS). Eddy et al., (1998) found parent-rated dietary compliance correlated significantly with dyadic adjustment in those children who were identified by their parents as having special diets ($p < 0.05$). Better dyadic adjustment predicted better oral intake in this subgroup of children. There was also an association between higher ratings of child compliance in those families where higher levels of consensus in the marriage were reported, although no p-values are provided (Eddy et al., 1998).

Parenting Stress

One study (Eddy et al., 1998) measured parenting stress and the impact on adherence using the Parenting Stress Index-short form. Higher parenting stress was associated with poorer medical staff ratings of child compliance with physiotherapy ($p < 0.05$). Significant correlations were also reported between parenting stress and parent-rated dietary compliance in the children identified by their parents as having special diets ($p < 0.05$).

➤ Parent-Child Specific Factors

Parent-child dysfunctional interactions

One study (Eddy et al., 1998) measured parent-child dysfunctional interactions using the Parenting Stress Index – Short form. It was found that parent-child dysfunctional interactions were related to poorer medical staff ratings of child compliance with physiotherapy ($p < 0.05$).

Parental Supervision

One study (Modi et al., 2008) investigated the impact of parental supervision on adherence levels in children and young people using a daily phone diary method where the amount of time children spend with their parents was recorded. Amount of parental supervision was found to be a significant predictor of adherence to the frequency of nebulised treatments (Modi et al., 2008) with increased time predicting adherence. Time spent supervising treatments by mothers (and not fathers) was a significant predictor of better adherence ($p < 0.0001$).

5. Discussion

This is the first systematic review to examine the relationship between family functioning and adherence in children and young people with cystic fibrosis. Seven studies have been reviewed and the findings of these will now be discussed in relation to the objectives of this review.

Family Functioning & Adherence

Eleven factors related to family functioning were identified and ten were consistently found to predict adherence. Overall, this provides strong evidence that family functioning is an important aspect to consider when examining adherence, which is consistent with research in other chronic illness groups (Michaud et al., 2004). Nevertheless, the literature was difficult to interpret beyond this for a number of reasons. There is ambiguity in the term ‘family functioning’ which has resulted in a range of terms and measures being employed, making it difficult to compare across studies. On further inspection however, there is often overlap or a lack of distinction between these factors, resulting in similar concepts being investigated in studies but under slightly different terminology. For example, relationship quality was measured in one study, whereas family cohesion was measured in others, yet there is presumably overlap between these. Additionally, one study investigated ‘family resources’ which incorporated family cohesion, expressiveness and conflict amongst other things, resulting in the individual role and impact of each factor being unclear. Ultimately, this makes it difficult to determine which factors are distinct in their own right (i.e. over-arching) and which are lower order, and feeding into these. Therefore, family functioning appears to have become an ‘umbrella term’ used to describe and incorporate a variety of different terms and concepts, some of which are

used interchangeably. Whilst this is helpful to capture the complexity involved in understanding this area, it makes it problematic when attempting to draw clear conclusions from the literature.

In addition to this, majority of studies failed to calculate the amount of variance in adherence behaviour that was accounted for by family functioning. Due to this, it is difficult to conclude, which, if any, are key factors. Nevertheless, three studies did report levels of variance for the specific family factors they investigated (DeLambo et al., 2004, Patterson et al., 1993, Ricker et al., 1998). When combined, adaptability and cohesion accounted for the highest level of variance for any of the individual factors investigated (Ricker et al., 1998). Furthermore, they were the most frequently measured concepts, postulating that they may, anecdotally, be considered as central in adherence. Overall this appears to suggest that families who appear overly rigid or inflexible may be at particular risk of non-adherence, whereas those who are both flexible and adaptable may promote adherence.

Comparison with Diabetes literature

Family conflict has been identified as a key predictor of adherence in the diabetes literature (Anderson, 2004, Miller-Johnson et al., 1994); which is of significance given that it could be considered related to cohesion, albeit opposite. One study, investigated a range of parent-child relationship dimensions (e.g. discipline, warmth, behavioural support) but found parent-child conflict most consistently predicted adherence (Miller-Johnson et al., 1994). One hypothesis was that the treatment regime places parents and families under greater pressure, leading to an environment which is more susceptible to arguments; subsequently placing children at a greater risk of non-adherence (Miller-Johnson et al., 1994). Interestingly, this has recently been discussed in the CF literature with regards to parental anxiety. For example, suggestions have been made that parental anxiety, which has been found to be higher in the CF population than general population (Besier et al., 2011) may lead to parent-teen conflict, if the anxiety is linked to increased care and overprotection (Besier et al., 2011). The presumption is that a conflict occurs if there is a mismatch between this and the young person's desire for independence and autonomy. Another study (Davis et al., 2001) in the diabetes literature however, reported warmth as the key factor; arguing that greater warmth leads to a reduction in conflict, which then

leads to an increase in cohesion and the child's sense of self control, and as a consequence improves adherence (Davis et al., 2001).

Methods for measuring adherence

A variety of methods exist, and are used for measuring adherence. Self-report questionnaires, for example, were popular amongst the studies reviewed. Self-report measures, however, have frequently been cited as problematic due to social desirability and recall bias (Canning, 1994, DeLambo et al., 2004, Modi et al., 2006, Passero et al., 1981). Multiple raters have been recommended to overcome this problem (LaGreco, 1990, Matusui, 2000, Modi et al., 2006) and many of the studies supplemented their self-report questionnaires with parental or clinician versions. Nevertheless, poor agreement between parents and medical staff (Eddy et al., 1998), and parents and children (DeLambo et al., 2004) was found. Alternatively, two studies used daily phone diaries (Modi et al., 2008 & Ricker et al., 1998). These have been reported to have good reliability and validity (Quittner et al., 2000) as well as reducing social desirability and recall difficulties (Modi et al., 2006). Other advantages which have been noted are that this method allows increased insight into the processes related to poor adherence, e.g. what the child/young person was doing prior to non-adhering (Modi et al., 2006). Unfortunately, however, this method has also been reported as time consuming, complex and inappropriate for younger participants (Modi et al., 2006). In a bid to overcome these difficulties, objective measures, such as electronic monitors, have been developed (Modi et al., 2006; Quittner et al., 2000, White et al., 2009). Obvious benefits of this approach have been emphasised such as that recordings of adherence will be exact and accurate, and free from subjectivity or the bias that comes with patient reporting. This method has been proposed by some as the "gold standard" (Abott et al., 2009) however, others have argued that it is expensive and therefore impractical. Hence, each method appears to hold its own strengths and weaknesses, and no one method appears to be the clear ideal. In order to overcome this predicament, Modi et al., (2006) argue in favour of a multi-method assessment.

Methodological Strengths & Limitations of the Literature

Majority of the studies used participants who were representative of the wider population, in terms of age range, gender ratio, and disease severity. A high proportion of studies examined a range of adherence

treatment modes within the one study; allowing comparisons to be made across these domains, and explanations were often offered accordingly. In addition to this, discrepancy between reporter's adherence scores, such as between parent and young people, were also highlighted and limitations acknowledged. Nevertheless, the lack of controls devised of healthy young people or other chronic illness groups, makes it difficult to determine whether the findings are exclusive to children and young people with CF alone. As a consequence it is difficult to generalise these findings to the wider CF population. One possibility for studies not using a control group may be due to anticipated difficulty in accessing healthy children, or the foreseen bias this may introduce into the sample. For example, Mitchell et al., (2004) recruited healthy young people into their sample using self selection. Alternative methods of recruitment for these types of samples should be considered, such as invitations sent around local geographic areas. Furthermore, many of the studies used small sample sizes, again limiting the validity of the findings. Finally, a large proportion of the studies used cross sectional designs; meaning only associations could be drawn and inferences could not be made regarding the direction of effect or causality. Larger sample sizes, prospective designs and use of healthy matched control groups would improve the literature in this field.

Future Research

Although a range of family functioning factors have been investigated, a large amount of uncertainty still remains in terms of which of these factors are, particularly, key in predicting adherence. It would be valuable for future studies to use factor analysis to compare factors, in order clarify which factors are central in this relationship. It would also be advantageous if future studies could identify which specific aspects of these factors are relevant, this would allow further insight to be gained into the mechanisms that are involved. Future studies should continue incorporating multi-treatment components when measuring adherence but should also consider using multiple methods to do this (i.e. self-report as well as electronic measures) (Modi et al., 2006).

Clinical Implications

The results have important implications for clinical practice with children and young people with cystic fibrosis. Where adherence is a problem, a systemic approach should be taken and considerations of family

specific, parent-child, and parent specific factors should be made, and included in formulations and treatment plans accordingly. At a preventative level, particular attention should be paid to families with low levels of cohesion & adaptability as they may be at higher risk of adherence problems. Support has already been found for behavioural, systemic based interventions in paediatric chronic conditions (Kahana, Drotar, & Frazier, 2008). Evidence has also been found for behaviour therapy in improving family relationships and parent-child conflict in a diabetes population (Wysocki et al., 2006). These gains were also found to be maintained at 6-12 month follow- up (Wysocki et al., 2001). Behavioural family therapy, therefore, is a viable option and should be considered as an appropriate form of intervention in a CF population.

- **Conclusions**

Findings have supported the notion that family functioning is an important predictor of adherence in children and young people with cystic fibrosis. Ambiguity in terminology, variability in methods and lack of advanced analysis, limit furthering these conclusions. Tentatively, however, these findings appear to indicate that family cohesion and adaptability may be particularly key; and hence targeting those families who appear to have low levels of such may be beneficial. Although family functioning is a multi-faceted term, and whilst respecting and valuing this, it would be helpful to gain clarity on the core concepts, to allow insight to be gained into the mechanisms that are at play.

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CHAPTER TWO: MAJOR RESEARCH PROJECT

**THE REALITIES OF SEGREGATION THROUGH THE EYES OF ADOLESCENTS WITH
CYSTIC FIBROSIS: A QUALITATIVE STUDY**

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Lay Summary

Separating people with cystic fibrosis from each other (inside and outside of hospital), is a method now used to reduce the spread of infections. This has been found to improve the health of people with CF and help them live longer. Little is known however about how this makes people with CF feel about themselves, their relationships with others, and how they cope with the disease. The aim of this study was to explore young people's understanding of CF and what it is like being separated. Interviews were carried out with 8 young people (aged 13-15) with CF, at The Royal Hospital for Sick Children, NHS Greater Glasgow & Clyde. These interviews were recorded and typed out word for word. They were then read over a number of times and patterns were searched for. Three broad themes were found; 'Acceptance of Source' refers to participants overall acceptance of being in source isolation after weighing up the pros and cons, 'Personal Models of CF' refers to how they perceive their CF from a medical and psycho-social perspective, and 'Normalisation' emerged through descriptions of methods employed to help them feel 'normal' and cope with CF. Conclusions were drawn that although support was found for separation this is not without a psycho-social cost. For example, being separated was found to lead to loss of opportunity to openly discuss and share their health concerns with others. Interestingly, contact with others with CF was viewed as important. In light of this, creative solutions are required to minimise any potential negative impact. A number of recommendations have been made and areas for future research have been outlined.

Abstract

Introduction: The segregation of patients with Cystic Fibrosis, purposefully keeping them apart from one another, has become common practice in order to reduce infections being passed from one CF patient to another. There is sufficient medical evidence to support these measures as an effective method of preventing early deterioration of the lungs, yet, there has been virtually no research exploring the psycho-social impact of such a policy. This study aimed to fill this void and become the first study to explore segregation from the perspectives of young people with cystic fibrosis.

Method: A qualitative design was used and eight young people with Cystic Fibrosis, (aged 13-15) were interviewed at The Royal Hospital for Sick Children, NHS Greater Glasgow & Clyde. Following transcription, in-depth analysis using Interpretative Phenomenological Analysis was carried out.

Results: Analysis of transcripts led to the identification of three super-ordinate themes; ‘Acceptance of Source’ which refers to participants overall acceptance of being in source isolation, after weighing up the pros and cons, ‘Personal Models of CF’ which refers to both medical and psycho-social perceptions of having CF, and ‘Normalisation’ emerged through descriptions of methods used to help to them feel normal and cope with CF. It is proposed that loss of any one of these factors may have a negative impact on adjustment.

Conclusions: Support was found for the practice of segregation however this is not without a psycho-social cost (i.e. loss of opportunity to openly discuss their health with others and have their experiences validated). These young people also appeared to have heightened awareness of the wider impact of the policy upon their parents. Contact with CF others was recognised by these young people as valuable. Innovative solutions are urgently required to address these potential costs. In light of this, a number of clinical recommendations have been made and areas for future research have been outlined.

Keywords: cystic fibrosis; young people; adolescents; segregation; source isolation, qualitative analysis.

1. Introduction

Cystic Fibrosis (CF) is a life threatening genetically inherited disease which primarily affects the lungs and digestive system (The Cystic Fibrosis Trust, 2004) making individuals with the condition more vulnerable to repeated chest infections. The three main bacteria that can cause infections in people with CF include; Staphylococcus Aureus, Pseudomonas Aerguginosa and Burkholderia Cepacia (The Cystic Fibrosis Trust, 2004). Medical research has highlighted the link between chronic infections and progression of lung disease which is often a major predictor of survival for CF patients (Kosorok et al., 2001, Kock, 2002). Thus, minimising the number of infections is a priority in order to maximise life expectancy for this group of patients. Unfortunately, cross infection can occur amongst people with CF (bacteria can be passed from one person to another) causing infections to be spread. Given the serious health implications associated with this, guidelines have been introduced to minimise this risk. One of the primary recommendations from the Cystic Fibrosis Trust (2004) is segregation, i.e. keeping CF patients apart.

Policies of Segregation

Policies of segregation generally advise that patients with CF should avoid mixing with other CF patients both inside and outside of the hospital to avoid infections being spread. The exact policy varies between sites and is at the discretion of the individual CF service (The Cystic Fibrosis Trust, 2004). In 2001, the Royal Hospital for Sick Children (RHSC) in Glasgow, implemented a segregation policy which indicated that the type of infection the patient had would determine the level of segregation or isolation (please note these terms are used interchangeably). For example those with infections such as B.Cepacia, are nursed in source isolation (i.e. required to remain in a single private cubicle, with en suite facilities at all times) whereas those with P. Aeruginosa can be nursed in a ward (open bed bay), providing there are no other children with CF admitted. In

general, all children with CF are not permitted to socialise with each other or attend group activities in the hospital, unless these activities are only by children that do not have the condition. The policy extends outside of hospital, and families are also advised to avoid socialising with other CF families.

Research on segregation in a CF population

Medical research has found strong support for segregation as an effective method of reducing cross infection between patients (Festini et al., 2006). Yet there is limited research which has investigated the impact of such a policy, from a psycho-social perspective. Two studies have looked at patient and carer satisfaction towards the policy. Russo et al., (2006) administered questionnaires to children (aged 10-17) and their carers, using an open ended questionnaire. The findings indicated support for the policy with 91% of parents, and 92% of children in favour of segregated treatment (Russo et al., 2006). Caution should be taken, however, when generalising these findings. This study was carried out prior to the policy being introduced; meaning participants were asked to *imagine* what segregation would be like, before actually experiencing it. Additionally, although participants were overwhelmingly supportive of the policy, they did acknowledge that there would inevitably be a social and emotional cost. Negative emotions and connotations were identified such as; boredom, loneliness, stigma for the child, and increased pressure on families (Russo et al., 2006).

An earlier study by Griffiths et al., (2004) which also used a questionnaire design, measured patient (aged 12 +) and parent satisfaction (n=190) after the policy was introduced. They reported 85% of parents and 63% of patients were supportive of the segregation measures. In comparison with Russo et al., (2006) findings, this may indicate that the acceptance of segregation, particularly with patients themselves, may decrease after implementation. More recently, Masterson et al., (2008) assessed the compliance and attitudes of 44 patients (aged 9-39) and 27

parents towards segregation, through interviews and questionnaires respectively. Approximately one quarter of individuals reported being non-compliant with the policy (Masterson et al., 2008). Reasons for this included lack of awareness of the risks involved, or, choosing to have social contact with others with CF in spite of the risks.

Potential psycho-social impact of segregation

To date there are no published prevalence figures for psychopathology in segregated CF populations. Quittner (2008) however has reviewed the literature regarding depression in those with CF (i.e. not just segregated patients) and concluded that there is a higher than average rate of depression in children, adolescents and adults living with CF. Elevated rates have also been found for anxiety in; children and young people (Thomson et al., 1992), boys specifically (Bregnballe et al (2006), and adults (Pearson et al., 1991) with CF. Research has also suggested a correlation between psychopathology and lower quality of life ratings (Riekert et al., 2007).

Research amongst other illness groups however have, investigated the impact of source isolation. For example, the following three studies have all explored source isolation, each using a different research design including; questionnaire (Ward, 2000), cross sectional (Gammon, 1998) and longitudinal (Lalotitis, 2003). Overall, evidence appears to indicate that being in isolation increases negative emotions such as boredom, confinement and loneliness (Ward, 2000), increases levels of anxiety and depression (Gammon 1998, Lalotitis, 2003) and lowers levels of self esteem and control (Gammon, 1998). Unfortunately small sample sizes were often used, limiting the power of these findings.

The literature, therefore, seems to suggest that the potential impact of segregation on those with CF may be two fold; having CF heightens their risk of psychopathology in the first instance, and being in source isolation may exasperate this risk. It should also be noted that this policy is in

contrast to other illness groups where typically, interaction with other children with the same condition is frequently encouraged. For example, group interventions for children with cancer (Heiney et al., 1988) and chronic illness in general (Olsson et al., 2005) have been reported as an effective intervention in helping to reduce feelings of isolation, normalise difficult emotional experiences, and promote acceptance of health difficulties. Segregation however, prevents these types of opportunities, and limits the psychological interventions that may otherwise be available. There are potentially wider implications of the policy such as the consequences these restrictions have for this client group and their families, outside of hospital. Again, no empirical research has investigated this although concerns regarding the potentially harmful psycho-social consequences of segregation have been raised previously by professionals in this field (Duff, 2001).

Rationale

Given that policies of segregation are now becoming common practice, the lack of research in this area is alarming. Consequently, it is imperative that further investigation is carried out into the psycho-social impact of segregation upon those with CF and their families. Adjusting to living with a chronic illness can be difficult at any age however it has been identified as particularly difficult during adolescence (Michaud et al., 2004); a time which is often characterised by the increasing importance of peer friendships. Therefore segregation during this age has the potential to be quite distressing, for this reason, adolescents were chosen for this study.

Due to the lack of research in this area, a qualitative design was felt to be the most appropriate approach and interpretative phenomenological analysis (IPA) was used. IPA attempts to explore individual's personal experiences through investigating and understanding the phenomenon and the meaning that has been attached to this (Smith & Eatough, 2007). It has also been well cited as an approach that is ideally placed to explore health topics; particularly when relatively little is

known about the way people perceive, and make sense of their illness (Smith & Eatough, 2007, Smith & Osborne, 2003). IPA was selected for this reason; however it also has a number of other strengths. IPA attempts to understand the experience from as much of the participant's perspective as possible whilst also recognising the role of the researcher in this process; this creates a double hermeneutic process or a two way interpretation (Smith & Osborn, 2003). Unavoidably the researcher's own perceptions and beliefs will influence how they make sense of and interpret the participant's narrative. The strength of IPA, however, is that this is acknowledged and researchers are encouraged to reflect upon this during analysis, therefore minimising researcher bias (Smith and Osborn, 2003). IPA, therefore seemed very appropriate for this study.

2. Aim & Objectives:

The overall aim of this study was to explore the experiences of segregation in an adolescent Cystic Fibrosis population, and to consider this within a developmental context. Particular attention was paid to their experience of being in source isolation (i.e. single cubicles where they are required not to leave).

3. Method

Procedure

Before commencing with recruiting participants, ethical approval was granted by the West of Scotland Research Ethics Committee (reference: 10/S0709/51; Appendix 2.2) and the NHS Greater Glasgow & Clyde Research and Development Directorate.

Purposive sampling was used to recruit participants from the RHSC, Yorkhill, NHS Greater Glasgow & Clyde. Patients who met all of the inclusion criteria and none of the exclusion criteria

(see Table 1) were recruited via CF nurse specialists. Of those identified, all were provided with an information pack which contained; an information sheet (participant/parent version), a participant opt-in form, and consent/‘assent’ form (Appendix 2.3). Those who choose to ‘opt in’ to the study (i.e. find out more about what would be involved) were provided with further information by the chief investigator (FM). If following this, they gave consent to take part, interviews were carried out on the hospital grounds. Nine participants opted in to the study, eight were interviewed. One individual did not take part due to being discharged from hospital prior to the chief investigator being on site. Recruitment and interviews took place between November 2010 and May 2011.

Table 1: Participant criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> • Diagnosis of cystic fibrosis • Between the ages of 12 and 15 • In-patients at RHSC, Glasgow • Experience of being in source isolation on at least one occasion 	<ul style="list-style-type: none"> • Non-English speaker • Presence of a learning disability • Concern over their mental state (this was decided by the CF team).

Participants

Eight young people participated in this study. A small sample size was used; as recommended for qualitative studies (Smith & Eatough, 2007, Smith & Osborne, 2003). An adequate number has been proposed by some as around five to six (Smith & Osborne 2003; pg.54) however there is no right or wrong answer to determine the perfect sample size. As a rough rule of thumb interviews should continue until theme saturation is achieved and no new themes emerge from the data (Lyons & Coyle, 2007). This may be more of a reliable method than choosing a ball point figure, as it ensures that the area has been fully explored before interviews cease. Using small sample sizes allows the analyst to immerse themselves in each individual participant’s cognitive and perceptual experience (Smith and Eatough, 2007).

Five males and three females between the ages of 13-15 participated in the study. Patients transfer from the RHSC, Glasgow to adult services at 15. In order to preserve a homogeneous sample it was decided to recruit only from one service. All participants were current in-patients at the time of the interviews, and all consented voluntarily to taking part in the study. Participant characteristics can be found in Table 2, pseudonyms have been provided in order to protect anonymity.

Table 2: Participant Characteristics

Participants	Age at Interview (year & month)	Gender (M) - Male (F) - Female	No. of times been admitted to hospital in last year	Other family member with CF? If yes, relationship:
Andrew	14:1	M	4	
Matt	13:0	M	4	Sibling
Claire	14:5	F	2	
Susan	14:7	F	0	Cousin
David	13:5	M	4	Sibling
Jill	14:3	F	4	Sibling
John	15:3	M	5	
Paul	14:4	M	6	

All reported that they had no contact with other CF families; however, 3 of the participants had siblings with CF, and 1 participant had a cousin with CF.

Interviews

Exploratory interviews took place on an individual basis and were conducted by the chief investigator, in a private room, on hospital grounds. In line with health and safety arrangements, hospital infection control protocols were adhered to. An interview guide was developed with the

clinical psychologist who worked with this client group (see appendix 2.4). Open questions, using developmentally appropriate language, were designed to enquire about participant's understanding and beliefs around cystic fibrosis. Some of these were based around Mayer & Leventhal et al., (1985) model of cognitive illness representations; identity, cause, consequence, time-line and control/cure. Open ended questions were also developed around their experience of being in source isolation, and how the policy affects them outside of hospital. This interview guide was used as a prompt only, to open up discussion. It was not followed prescriptively. Instead a flexible, curiosity driven approach was adopted throughout the interviews, which promoted full exploration of the participant's train of thought (Smith & Eatough, 2007). Clinical techniques such as empathic listening, summarising and reflecting were also used to facilitate this process. The advantages of this approach is that it is conducive to gaining a rich account of the participant's experience; allowing complex and novel themes to be followed which may otherwise be constrained. The topic guide was piloted using the first three interviews to check for internal validity of the interview. These were considered to be congruous with the overall aims and principles set out by the study, therefore were included in the analysis.

Interviews lasted approximately 40 minutes and were audio recorded using a digital recorder. Following this they were anonymised and transcribed verbatim by the chief investigator (FM). Any themes that emerged during the interviews were made note of by the researcher after the interview.

Data Analysis

A number of step by step guides have been offered in the literature regarding how to conduct IPA, thereby allowing a transparent and clear process to be followed. The steps for carrying out IPA outlined by Smith & Eatough (2007) were followed for this analysis. Familiarity with the data began during transcription, however interviews were repeatedly read following this and

points of interest were documented (see appendix 2.5). Through an iterative process, theme titles were identified and clustered together. Connections between these clusters were then sought, in a bid to develop higher level, super-ordinate themes. Each transcript was considered in detail before moving on to examine the others, allowing an idiographic approach to be taken. A coding sheet, where theme titles could be referred back to and reviewed, was also used to aid this process.

This process allowed a close interaction to take place between the analysis and the text; enabling the researcher to check back and forth from what was said by the participant to how it was being interpreted (Smith & Osborn, 2003). All transcripts were read and four were analysed in detail, by an experienced researcher who is familiar with the use of Interpretative Phenomenological Analysis. Researchers then engaged in a discussion regarding the emerging themes to check for content validity and reliability and a high level of agreement was found.

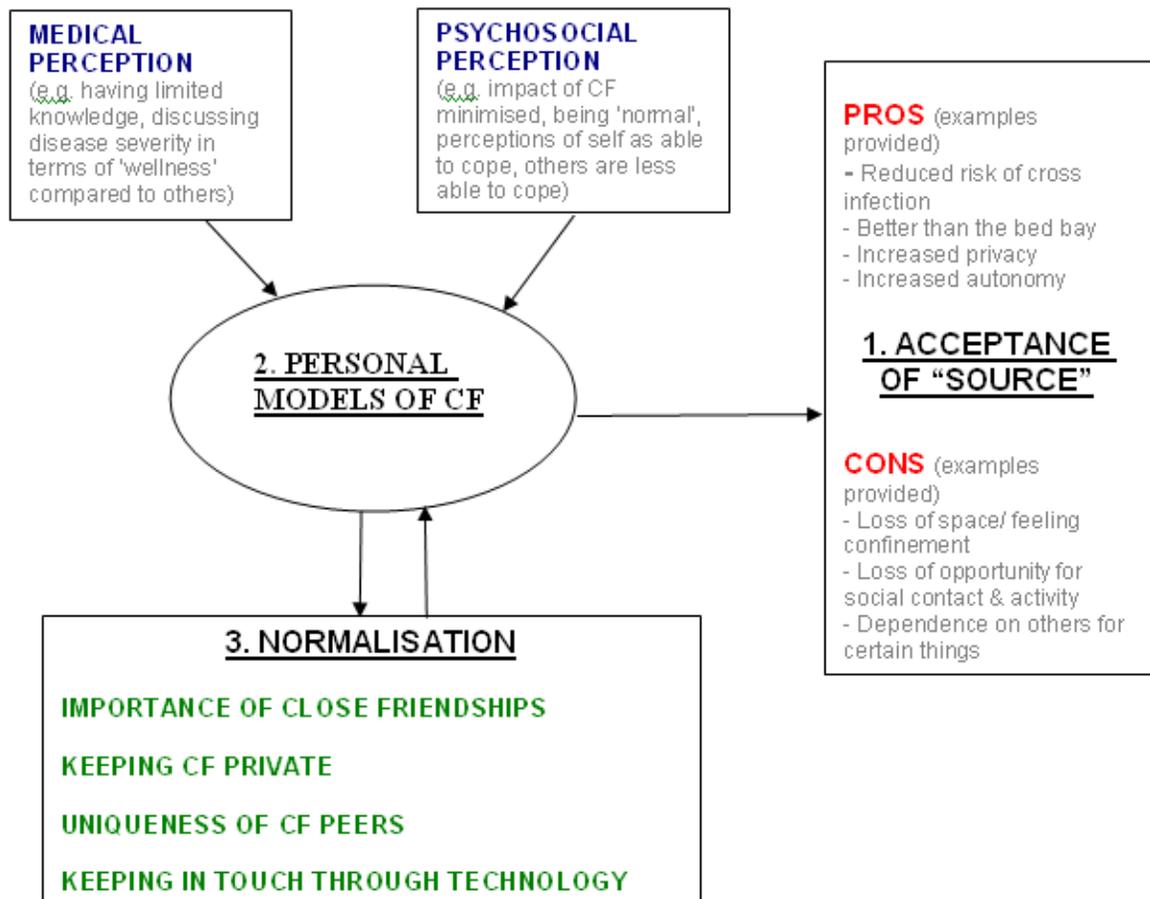
Reflexivity

Reflexivity, as discussed earlier, is a particular strength of IPA. It refers to the process of reflecting upon the way in which our own beliefs, attitudes, and experiences may influence how we interpret someone else's experience (Reid et al., 2005). An important feature of IPA is that the researcher acknowledges these influences. The principal researcher does not have cystic fibrosis, nor has she ever worked with young people with cystic fibrosis. She does however know someone personally with the disease and has also worked in a paediatric setting. Due to this she had some prior knowledge and insight into some of the challenges and barriers that this client group face. As a result of this, she was aware of her own admiration and respect for the strength and courage often shown by young people in the face of ill-health and adversity. Although this was reflected on prior to beginning the study it is possible that this may have influenced the analysis.

4. Results

None of the participants appeared distressed prior, during, or after any interviews, nor did they display any signs of anxiety. A number of participants even commented that they enjoyed the process as they seldom get the opportunity to talk about their experiences of segregation. All participants were able to communicate clearly, although some participants found it easier to reflect on their experiences than others, for example younger males seemed to find this more difficult. Accessing thoughts and feelings can be difficult for this developmental age therefore struggling to reflect on this was to be expected to some extent. Due to this, where necessary, the researcher, attempted to provide more specific questions in order to open up discussion, whilst still remaining open and exploratory. Three super-ordinate themes were identified; ‘Acceptance of “Source”’, ‘Personal Models of Cystic Fibrosis’, and ‘Normalisation’ (see Diagram 1). Extracts from the interviews have been selected to illustrate each of the themes.

Diagram 1: Model of emergent themes



THEME 1: 'ACCEPTANCE OF SOURCE'

All participants reflected upon a number of drawbacks associated with being in "source" (which they used as an abbreviation for source isolation) but overall, majority agreed that the positives outweighed the negatives, and with this came a sense of acceptance of the policy. Only one participant said if given the choice they would not follow the policy. A few participants admitted that they had overstepped the rules at times, for example talking to other patients with CF across corridors (whilst remaining in their rooms). Some participants also mentioned that they found source isolation more difficult to cope with when they were younger as they struggled grasping the rationale for the procedure.

➤ **'PROS'**

First and foremost most participants made reference to the obvious health benefit of reducing any risk of cross infection;

"I think it's good, I mean I wouldn't want to be beside someone who is going to give me a bug or the same if I am going to give them a bug....Because it's bad for both of us, you know what I mean?" (John, P5:L2).

In addition to this, another advantage identified by participants was the fact that being in source was perceived as better than being in an open bed bay. The bed bay was overwhelmingly described as a negative experience. Many participants described it as a place that was noisy and difficult to sleep in, many also commented on feeling uncomfortable lying next to strangers. They also mentioned that the entertainment (e.g. TV) was often geared more towards that for younger children, as was the bedtime routine. Therefore in comparison, source isolation was quite inviting. All participants valued the privacy that being in a single room offered and the benefits associated with this, such as; feeling more secure in their surroundings, sleeping better, having control and choice over their entertainment, and feeling relaxed and able to talk openly when family came to visit;

"Because you are allowed to shut your curtains at night and either no-bodies is allowed in so you're not going to get walked in on...."

(Andrew, P2:L13)

"like last night and it was just like me and my mum and we just lay on my bed and watched DVD's and TV but you can't do that out there"

(Claire,P7:L36)

A number of participants also referred to enjoying the autonomy and ironically, the increased sense of independence that they gained through being in source. For example, some participants mentioned that they enjoyed being able to make decisions and choices such as how they would spend their time.

Matt: *“Feels kinda like a holiday*

Interviewer: *Feels like you’re on holiday, that sounds good. What is it that makes you feel like you are on holiday?*

Matt: *Well yeh just watching TV and playing games all day, or just lying in bed till late”*

(P2: L19).

There were mixed views on how being in source can affect relationships within the family. Some suggested they got on better with family members;

“I fight with him (brother) all the time but now because I rarely see him and then when he does come in he is usually dead nice so I don’t really argue with him” (Paul, P4:L31)

Whilst others felt that being in source could increase arguments with family members;

“cause they’ve (parents) got nuttn tae dee and aaw, you start like arguing a bit with them and all that” (David, P4:L25).

➤ **‘CONS’**

Although source isolation was viewed as favourable to the bed bay, a number of negatives were described including; loss of space and feelings of confinement, loss of opportunity for social

contact and activity, dislike for the actual environment in the rooms (i.e. too hot, dull, lack of fresh air) and the dependence on others for basic needs such as food and drink.

“It's really boring because your in like a kinda room and if you get cramp and stuff and you want to walk about and your only able to walk about in a wee square or in spaces that you are allowed in” (Andrew, P3: L2).

“you're like, not able to talk to other people or children that are in the ward and all that and like going down to the play area and that and playing” (David,P3:L4)

“I mean sometimes I do get more stressed out the fact that I'm locked in a room and if like I want a drink I've got to shout and wait on the nurses to get it for me” (Claire, P5:L39).

Retaining structure and routine to their day was also described as difficult.

“I find that like when I'm in here I end up like sleeping to like 2 o'clock because like even if I get up I'm just like sitting in a room and doing the same, I could put the television on and there's nothing on, there's no point, you feel like there is no point in getting up at all” (Thomas, P3, L13).

As a consequence, negative emotions such as boredom, frustration, and loneliness were commonly reported. Some participants also reflected on the significance of being placed in a room where they were not permitted to leave, and the stigma attached to this. Some participants even likened source to that of being in prison and feeling as though they are being punished.

“Yeh it kinda was like... "you're not well and your in here" and everybody else is walking about”

(Paul, P9:L2).

“it's like if you have been bad or something and you go here no one can come in and stuff it's kinda like that and you see everybody having fun playing about and stuff and you want to do that but you can't” (Andrew, P8:L27).

THEME 2: PERSONAL MODELS OF CYSTIC FIBROSIS

This theme refers to medical and psychosocial perceptions of CF that became apparent throughout participants narratives. It is proposed that these personal models of CF influence their ‘Acceptance of “Source”’. References to this theme will be made throughout to highlight the links to the reader. This theme is also proposed to have a reciprocal relationship with the last super-ordinate theme of ‘Normalisation’, which will be referred to later in this section.

➤ ‘Medical Perception’

In terms of medical understanding of the disease, all participants were able to explain that CF is a disease that affects their lungs, which was passed onto them by their parents, through genes. They were also able to explain that they can control the symptoms of CF by adhering to the treatment programme i.e. physiotherapy exercises, taking medication. Furthermore, they demonstrated understanding that they are more prone to infections than the average person, and that those with CF pose an increased threat to them. Having basic knowledge such as this, is therefore likely to influence and promote acceptance to the policy (link to theme 1) in that they are able to recognise the risks to their health if they do not adhere.

They were however, found to hold a number of misconceptions in terms of names of infections, the likelihood of cross infection (often over-estimating the risk) and the prevalence of cystic fibrosis.

“strepopseudomonas you're in because it's like a really bad disease in CF that you get it's...you can get it from anything you can get it from shoes, potatoes.” (Andrew, P2:L30).

“I was talking to my friend in school about it and she says her wee cousin has got CF as well...so starting to see that it is a lot more common” (John, P6:L28).

They also admitted that although they had a basic understanding of the disease their knowledge was limited which could cause them some difficulty when being questioned by curious peers.

“although I do have it and I do know a lot but I just don't know a lot, a lot, a lot.” (Andrew, P1:L21)

“See I have this trouble all the time with my pals because they were like asking about it, it's something to do with your lungs, ah ha, it's the lungs and you get infections and that” (Claire, P1:L4).

Nearly all participants discussed their health in terms of ‘wellness’; comparing their own health to people they know or have heard of with CF. If they compared favourably, this led to positive feelings;

“she's been in like all the time and who else, two other boys they are in all the time so I feel quite lucky at the moment cause I'm not actually in that often”. (Claire, P1:L26).

If they compared less favourably, this led to negative feelings;

“I get annoyed...my brother (who has CF) is fine he can do what he wants and then I'm in hospital for like two weeks”, (Jill, P4, L11).

➤ **Psycho-social perception**

Participants all reflected upon the impact of CF on themselves, although it should be noted that female participants generally appeared to find this easier than their male counterparts. Many described going through phases (including the male participants) where they felt less able to cope than at other times, often when they were experiencing illness symptoms. On the whole, however, participants largely came across as up-beat and optimistic about CF, almost at times minimising the impact of the disease on their lives.

“Em I take tablets and that from when I'm eating em I take medication in the morning, and at night and I do physio morning at night so but apart from that everything's normal” (Claire, P1:L8)

“most of the time I don't really get bothered about it em, CF I don't really get bothered about it eh I just sort of get on with what I'm doing”(John, P2:L3).

Interestingly, many of participants referred to the fact that despite having CF, they felt, or were, ‘normal’.

“I just feel normal, I'm just myself, I don't feel like I have an illness” (Jill, P5:L14).

Viewing themselves as normal, and minimising the experience of being in source isolation as just part of regular life, could promote 'acceptance' to the experience (link to theme 1). Of significance was that although they perceived *they* could manage living with CF, a large proportion shared concerns regarding the impact on family or friends.

"it's not just people with CF that suffer it's your parents, or your friends , and they might like struggle with it and I know she (Mum) takes on all my stuff so she has that to deal with as well as me" (Susan, P8:L14).

Many referred to being aware of the extra strain that being in source isolation placed upon their families, such as balancing daily trips to the hospital with other responsibilities and demands. As a result of this, Claire for example, described attempting to dissuade her parents from visiting in order to reduce their stress levels.

"they feel like they have to be here like every day and I'm like "you don't have to like you don't have to sit up here from like nine in the morning to like nine at night you can't" but they were like "but we need to come up" but I'm like "you but like if you, if you just left me for a day like to sit with my laptop" I was like "I wouldn't mind that" like cause I know it is hard for them" (Claire, P7:L14).

Participants also acknowledged the wider impact that the policy has on their families. For example, many of the participants claimed that their parents were the first person they would go to regarding any CF concerns but they were also aware of the pressure that this sometimes placed upon them.

“I think if the segregation wasn’t there it would take a bit of the weight off my mum’s shoulders as well” (Susan, P5, L41).

Parents own need for support from similar others, was also highlighted by Claire who described how her own mother found great relief and comfort in meeting other parents of children with CF

“my mum will sit there for just like hours and like the two of them just like discuss things but like its good cause the two of them can relate to each other (Claire, P8:L7)

Although this is not strictly permitted by the policy it highlights the benefits that some parents can gain from this interaction, and provides some insight into the emotional support that segregation may be preventing.

THEME 3: NORMALISATION

“I think people want to feel even for a while that they don’t have CF” (Susan, P9:L19).

Participants described a number of, what emerged as, key factors; in helping them feel ‘normal’, and fundamentally, cope with CF. These include; ‘Importance of Close Friendships’, ‘Keeping CF Private’, ‘Uniqueness of CF Peers’ and ‘Using Technology to Keep in Touch’. The process of ‘Normalisation’ describes each of the factors involved in this process, however, it should be noted that not all participants reported each of these (although many did), and this may reflect how well adjusted or ‘normalised’ they are. It is proposed that having a moderate level of each factor could lead to healthy adjustment, whereas having too much or too little in an area may contribute to difficulties in adjustment. Adjustment however, we know from the literature is also influenced by a range of other factors (Wallander & Varni, 1989) suggesting that a complex interplay between

factors may exist here. A reciprocal relationship between ‘Personal Models of CF’ and ‘Normalisation’ is proposed; where each informs the other.

➤ **‘Importance of Close Friendships’**

All participants talked about peers and friendships in some context during the interview, highlighting the particular importance of these relationships during this developmental stage. A few participants differentiated between close friends and those that were acquaintances in terms of the level of support offered;

“Yeh all my good friends are, like the friends I've been friends with for a while and then the others, nobody's not supportive, just some are more supportive than others” (Paul, P5:L35)

“they know (close friends) that like I need to come in and need to get IVs (.e. intravenous antibiotics) and it's like they're always good with me like and “have you took your tablets?” and I'm like “ah yes”” (Claire, P4:L9)

From these friendships, what was apparent was how they promoted normality in their lives (e.g. through doing regular ‘normal’ activities and distracting them with non-CF conversation). When they did miss school due to illness, these friends would be the ones that would keep in touch with them, either through visiting in hospital, or talking on the phone/computer.

“they come up and they tell me what's happening at school and all that” (Claire, P4:L13).

Through this process, their perception of being ‘normal’ and their minimised perception of the impact of CF is maintained (link to theme 2; e.g. psychosocial perception).

➤ **'Keeping CF Private'**

Although participants had disclosed to some close friends or peers that they had CF, many participants talked about limiting the amount they talked about it and in some cases not telling them at all.

David: *"Some of them dee but some of they just don't"*

Interviewer: *What's that like?*

David: *"I don't really know cause I just get on with it and naebody ever knows"* (P6: L12)

Reasons for this were linked to the peers often having very little or no prior knowledge of the disease making conversation regarding CF difficult, which was also compounded by their own limited knowledge in CF. Others, said they felt embarrassed or judged by their peers.

Jill: *"wi' with my friends I don't feel too good talking about it wi' ma friends cause it's a bit weird"*

Interviewer: *What's weird about it?*

Jill: *"I don't know I just feel awkward talking about it wi' ma friends"* (P7:L30)

Reflections from participants also suggested that it was important that they were viewed by others as themselves, first and foremost, rather than someone with CF. Susan talked about how others talked about people with CF;

"they are defining a person by CF and not just saying "oh they happen to have it" and I think it's kinda letting the CF taking over" (Susan, P9:L19).

Keeping CF private may therefore be a way of preserving their own identity, and maintaining their perception of being 'normal' and their minimised perception of the impact of the disease .

➤ **‘Uniqueness of CF Peers’**

Although participants reported valuing the support from family and friends, many acknowledged there were limits to this. For example, some explained that they did at times feel frustrated that those without the disease could not always understand.

“I think, kinda you are going through a rough time someone might be like "oh my gosh I totally felt like that last month" and you know my family have always been like yeh we can understand and it's like "you can't"” (Susan, P5, L20)

Their CF peers on the other hand, can fulfil this role and identify with them what it is like having the disease. Some participants referred to even feeling relief or comfort just through hearing about others with CF. Knowing that others are going through a similar experience may also help to minimise their perception of the impact of CF, for example through promoting thoughts that others are also going through the same experience (link to theme 2; e.g. psychosocial perception).

For those participants with siblings with CF some reported experiencing relief from the sense of being able to share the experience;

“Well eh, nice things well....aye cause you know that what you are feeling they can feel it too, you know like, if you are annoyed by taking all this medicine and that and you know that they are annoyed with it too” (David, P5:L26).

Some participants made reference to the fact that due to segregation however, these opportunities to share experiences of having CF, and feel validated by others, were limited.

“I think the whole thing is that because you are not allowed to talk to someone with CF face to face there is no one who can really identify with what you are going through” (Susan P5:L17).

Of significance was that majority of participants expressed an interest in having contact with someone else with CF. Most participants said they would be interested in finding out how they coped with the disease; seeming more interested in the emotional impact of CF rather than focussing on medical aspects.

“Just how they are and stuff like em, how they cope with their CF and stuff and if it bothered them or anything” (Jill, P4, L32).

Interestingly, many participants said that the times they most wished to speak to another person with CF was when they perceived their own ‘wellness’ as poor. Although participants recognised these friendships may be helpful, they also commented that they would not replace their need for regular or ‘close friendships’.

Current contact with others with CF (e.g. those with siblings) did not seem to affect how keen they were for contact with others with CF. Gender, however did appear to play a role in the degree to which they were interested in having contact with others with the condition. All female participants verbalised a strong interest, or had a strong interest at some time, to meet others with CF. Male participants, although most said they were interested, appeared less enthusiastic or somewhat indifferent about this prospect, in comparison with the female participants.

➤ **‘Keeping in touch through technology’**

Most participants referred to the importance of technology and electronic methods to keep in touch with their main sources of support, both whilst in source and outside of hospital in order to

retain normality. The telephone, for example, was identified as being key for communication with important others, such as family and friends, particularly when in hospital. The internet including chat rooms (e.g. MSN) and social networking sites (e.g. Facebook) were mentioned as being important in order to maintain contact outside of hospital.

“MSN, facebook... I'm glued to it, I can not get off it, when I'm in the house I just don't leave it, Facebook and MSN don't leave it” (Jill, P8, L24).

“Because I play online games, at home, and I talk to people on MSN from school and just stuff like that” (John, P6:L9).

It is proposed that as well as promoting a sense of normality, again this helps to maintain their perception of themselves as ‘normal’ and their minimised perception of the impact of CF. Claire, mentioned that social networking sites could be helpful to make contact with others with CF.

“Well I've got them all on facebook...so I like sit and talk to them on that” (Claire, P2:L32).

She reported enjoying benefits of this such as being able to send each other messages of support when in hospital for example. Claire did stress however, that her close friends were still her main source of peer contact and that this contact did not go beyond the realms of the internet.

A few other participants reported going on CF chat rooms in order seek contact with others with CF. This was consistently reported as a disappointing or negative experience; either through the sites not being set up to meet their needs, poor regulation on the sites leading to ‘horror’ type stories being shared, or the website being non-UK based and irrelevant due to different health care systems. Susan, for example, talked about The CF Trust Forum, which is the main UK

charity and online support system, being very medically focused, with very little opportunity for her psycho-social needs to be met.

“I just think it just all very centred around CF and your treatment and things involving your treatment and not actually how you feel about CF” (Susan, P8:L4).

5. Discussion

The aim of this study was to explore the experiences of segregation in young people with cystic fibrosis and particularly source isolation. Incidentally, the data collected was greater in terms of breadth and depth than had been anticipated; and participants often touched on wider issues. The following superordinate themes were identified; ‘Acceptance of “Source”’, ‘Personal models of CF’, and ‘Normalisation’. Each theme is distinct in its own right; however, a linear relationship was found between ‘Personal models of CF’ and ‘Acceptance’, and a reciprocal relationship is proposed between ‘Personal models of CF’ and ‘Normalisation’. A visual representation of this can be viewed in Diagram 1.

The first theme ‘Acceptance of “Source”’ is unique, given that there are no other studies published on the experience of source isolation in adolescents with cystic fibrosis. Although participants recognised a number of disadvantages of the experience, they placed greater weight on benefits such as reducing the risk of cross infection, and privacy; which in turn, is likely to have accounted for their high level of acceptance. Another factor to consider, in relation to acceptance, is the age of this particular cohort and when the segregation policy was introduced; these are a group of young people who have never known anything different to segregation. This is likely to have reduced the likelihood of them struggling to accept it. Furthermore, despite the adolescents in this study being accepting of source isolation, they did identify experiencing negative emotions such as boredom, frustration and loneliness which was consistent to Russo et

al., (2006) findings. This may account for some participant's admittance at overstepping the rules of segregation, occasionally, whilst in hospital. It should also be acknowledged that this theme may not be generalisable to younger children with CF. For example, some participants referred to finding source more difficult when they were younger. This makes sense in that younger children are less likely to place value on having privacy in hospital, in comparison to their adolescent counterparts. In addition to this, younger children may also find being unable to participate in organised activities on the ward more distressing.

The second theme 'Personal models of CF', for the first time, offers a framework for clinicians to understand how young people with CF perceive and conceptualise their illness, from both a medical and psycho-social perspective. Some aspects of this model however, can be compared to previous literature, and well established psychological concepts. Firstly, participants were found to have limited knowledge of CF, which is similar to previous findings; in an adolescent (Christian and D'Auria, 1997) and adult sample (Waine et al., 2007, Lowton et al., 2006).

Cognitive limitations due to developmental stage could play a role in this, although this would not account for the difficulty previously found in adults. Having limited medical knowledge appears to be problematic in the sense that it can act as a barrier to communicating with others about the illness; paradoxically however, it may also have a protective role. Lack of knowledge and insight into the reality of CF may shield young people from the harsh reality of having a chronic progressive disease; however having inaccurate perceptions of illness, has been linked to poor adherence (Wallander & Varni, 1989). Participants also referred to concepts such as wellness, control and how manageable they perceived CF, some of which is similar to Leventhal's (1985) model of illness representations. It is important to note, however, that this model was not referred to during the analysis stage and a bottom up approach was used. Participants also referred to comparing themselves against others with CF in order to gauge their level of 'wellness'. This is consistent with that of social comparison, a coping strategy often cited as used in health contexts.

Social comparison is thought to contribute to a child's self esteem and self-image (Christian and D'Auria, 1997). Segregation limits the opportunity these young people have to use self comparison with others with CF, which may result in them comparing themselves to healthy peers more frequently. This could be problematic, particularly as they get older and their health declines (Russo, 2008).

Interestingly, the adolescents perceived themselves as resilient, able to cope, and 'normal', whilst perceiving others, particularly family members, as more vulnerable and less able to cope; this is surprising as adolescents are normally noted for their egocentricity. Parents and siblings tend to be over-protective of a child with a chronic illness or disability (Eiser, 1993). Taken together, these findings suggest young people and their families may have mutual hypersensitivity to stress placed upon the other. Of note however, is that parents of children with CF have been found in two cross sectional studies to have significantly higher ratings of anxiety and depression (Pfeffer et al., 2003, Besier et al., 2011) and lower life satisfaction (Besier et al., 2011). This perception by the participants therefore may reflect reality.

Concern was also expressed by participants with regard to their parent's lack of available support. Openly communicating about their child's illness and seeking emotional support is an important factor in adjustment and improving psychological well being in parents (Wong & Heriot, 2008). Therefore does preventing parents meeting with other CF parents, impact on their mental health and in turn affect their child's mental health and ability to cope? One hypothesis may be that parents of children with CF who have reduced social support due to the segregation policy may be less able to contain their own emotional response in turn making it increasingly difficult to model 'good coping'.

Lastly, the theme of 'normalisation' refers to factors described by participants used to help them cope and adjust to living with the disease. Of particular interest was that participants admitted to keeping CF private from others, although this has been cited previously in studies (Graetz et al., 2000, Christian and D'Auria, 1997) as a protective strategy by youngsters to ensure that they are accepted by their peers and treated as 'normal'. It may also be related to their difficulty in understanding their own illness, hence making it difficult to verbalise to others. Without segregation however, they would at least have the option of discussing such concerns with their CF peers. One may question what the long term consequences may be for this client group, having limited opportunities to openly discussing their health.

Of significance, was that most participants described having an interest in contact with others with CF (although this was reported to fluctuate in relation to their physical health). This is consistent with Masterson et al., (2008) who reported that an astonishing 70% reported that they would like to have contact with someone with CF. Benefits such as helping them prepare for the challenges of what may lie ahead were reported by one study (D'Auria, 2000). Again, this adds to the concern around the potential impact of segregation (i.e. through limiting the opportunities that would otherwise be there) on coping and adjustment.

'Using technology to keep in touch' however, was, described by participants as a meaningful way to retain contact with their regular peers, as well as for some CF peers. Using the internet to make contact with others with CF seems an ideal, creative solution; experiences can be shared while at the same time not jeopardising their health. Evidence with other illness groups has started to accumulate suggesting this can often be a helpful and successful solution (Uden Kraan et al., 2008). Yet participants from this study reported that they were often disappointed with the CF forums available as they often did not meet their needs, and were more geared towards providing medical information. They also suggested that there is a risk, if these websites are not properly

regulated, of 'scaremongering' occurring, only serving to increase rather than decrease anxiety. Therefore further development is required before this can be offered as an adequate solution, however online support groups do offer a promising hope, for this client group.

6. Conclusion

These findings provide a psychological perspective to what is an area desperately lacking in research, and as it stands, is represented only by a medical point of view. Although on the whole the young people presented as a very adaptive and resourceful cohort; due to segregation, certain aspects of their emotional and social needs were identified as being compromised. Segregation limits the opportunities that these young people have to openly discuss their health with those who are most likely to be able to validate and identify with these experiences. Of importance, was that this was recognised by these young people, most of whom, expressed an interest in having contact with others with CF. This study proposes that this contact may help to promote healthy coping and adjustment. How to facilitate and support this, without risking these young people's physical health however, does present a challenge; electronic methods of communication may be one solution. The findings from this study also indicated that young people with CF may have heightened levels of awareness of stress placed upon their parents, and the role of segregation in this. There may therefore, be wider implications of segregation which as yet, have been uncovered.

Future Research

This study has provided preliminary findings, however, it is crucial that further investigation is carried out to expand upon these findings and provide further understanding into the mechanisms that lead to coping and adjustment in a segregated cohort. It would also be beneficial for a prospective study to be carried out to investigate the trajectory of these mechanisms and how this may change with age and disease severity. Furthermore, quantitative studies are required to

ascertain quality of life and psychopathology rates in a segregated cohort. Lastly, qualitative research exploring the wider impact of segregation from a parent perspective would be particularly worthwhile.

Strengths & Limitations

There are a number of strengths of this study such as the homogeneity in the sample, as well as the fact that participants were interviewed whilst in source isolation, adding to the validity of the findings. Admittedly, the study could have been improved if there was an equal distribution of males and females in the sample, and details regarding disease severity. Due to time restrictions and the reality of the gender representation of those participants that were in hospital over this time period, this was not possible. Another strength of the study was that transcripts were checked by an experienced IPA researcher, helping to ensure content validity and reliability. Despite this, it must be acknowledged that although the researcher attempted to remain as objective as possible, it is acknowledged that personal thoughts and beliefs may have had some influence over the interpretation of the data.

Clinical Implications

Given that this is a novel study, there are a number of important clinical considerations as well as recommendations for healthcare professionals involved in the care of young people with cystic fibrosis.

- 1.) Ensuring that young people with CF have accurate and up to date knowledge of their condition is crucial for a number of reasons. Firstly, having an accurate level of knowledge can dispel any myths and unnecessary anxiety, and could also help to improve adherence in this age range. Secondly, having limited understanding of CF themselves makes it difficult for them to explain CF to others, who otherwise could act as a support.

- Providing information about CF should be done in line with their emotional and cognitive stage, and may need to be repeated at various stages of their development.
- 2.) Importantly, clinicians need to be open to exploring the conflict between need for contact with CF peers whilst avoiding cross-infection, with these young people. Clinicians should also be aware that their desire for contact with CF peers may increase at times where their disease severity increases, which will unfortunately also be the time that it is most dangerous for them to have contact with others with CF. It is imperative therefore, that innovative solutions are developed which allow for their needs of validation and identification to be met, but at the same time do not sacrifice their physical health. Equally so, it is important to note that not every young person with the CF has the desire for contact others with CF, and consideration also needs to be made as to how best support these young people.
 - 3.) Online support forums have been identified as the most viable way to do this, however, education and information needs to be provided on how to go about using these systems in as safe a way as possible, and reducing any possible risks. This would then allow young people to make an informed decision about whether having contact with others with CF is something they wish to pursue.
 - 4.) There are also wider implications for the improvement of these online systems in general; the findings from this study suggested that they tend to be more directed at meeting people's needs for medical information, rather than for psycho-social support. There is, therefore, scope for advances to be made in this area.
 - 5.) Another possibility is for the use of video diaries, made by other young people with CF, which could then be passed onto others, documenting their experience of CF. This may have the advantage over online support forums in that it could be more easily monitored and regulated by health professionals to ensure safety and accurate information is being shared.

6.) Finally, this study also provides further support for the use of systemic, family based approaches to be used, given that the findings highlight links between parental coping/adjustment with that of the child.

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CHAPTER THREE: ADVANCED CLINICAL PRACTICE I
CRITICAL REFLECTIVE ACCOUNT

Feeling out of depth when dealing with dynamics

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Abstract

Reflective practice has been advocated as an important and fundamental skill for clinical psychologists working within the health service. I have chosen to reflect on my work with one particular family during my specialist 'Autistic Spectrum Conditions' placement, as this proved to be an important part of my learning and development as a clinician. I have used Gibbs' model of reflective practice (1988) to help facilitate this reflection. Included in this I have drawn upon other sources of learning such as discussions with my supervisor and, additional reading on psycho-dynamic literature. The broader role of the clinical psychologist in relation to complex cases is then discussed.

CHAPTER FOUR: ADVANCED CLINICAL PRACTICE II
CRITICAL REFLECTIVE ACCOUNT

**Service re-design: Considering the role of clinical psychology in
facilitating this process.**

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Abstract

The National Occupational Standards for Clinical Psychologists (BPS, 2002) prescribe key generic roles for a Clinical Psychologist. Trainee clinical psychologists are required to identify and reflect on the processes involved in fulfilling these competencies. In this reflective account, I have considered the forthcoming introduction of The Care and Partnership Approach (CAPA) into the Child and Adolescent Mental Health Service (CAMHS) service in which I am currently based. Through attending a team meeting, various discussions with colleagues, and experiences of working with families in the service; I reflected on the potential benefits of introducing this service model, as well as the challenges which appear to exist. I have considered the role clinical psychology could play in overcoming these barriers in order to promote successful and effective service re-design.

APPENDICES

Appendix 1.1 – Author publication guidelines

British Journal of Health Psychology

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full

For full details see: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8287/homepage/ForAuthors.htm](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8287/homepage/ForAuthors.htm)

Appendix 1.2 - Quality criteria rating tool

QUALITY RATING TOOL			
Name of paper:		Author/date:	
Checklist completed by:			
INTERNAL VALIDITY			
1.1	The study addresses an appropriate and clearly focused question.	2 1 0	Well covered Adequately addressed Poorly addressed
SELECTION OF SUBJECTS			
2.1	Participants are recruited using an acceptable method.	2 1 0	Random, convenience or geographic samples Highly selective e.g. volunteers Poorly addressed
2.2	Details are provided of participant characteristics and are representative of the target group (e.g. gender, age, ethnicity, socio-economic status, disease severity)	2 1 0	Well covered and representative sample Details are provided but appear unrepresentative of the target group Poorly addressed
2.3	A control group is used	3 2 0	Healthy children or another illness population Norms from a standardised measure No control group
2.4	Inclusion & exclusion criteria are clearly stated	2 1 0	Well covered Adequately covered Poorly addressed
2.5	Sample size is justified/ power calculation stated.	2 1 0	Well covered Adequately covered Poorly addressed
ASSESSMENT			
3.1	The outcomes are clearly defined.	2 1 0	Well covered Adequately covered Poorly addressed
3.2	Adherence to treatment is measured appropriately	2 1 0	Observation OR specific measurement devices e.g. electronic monitors Self -report tool from young person AND one other i.e. parent or physician Self report tool from young person only

3.3	Family functioning is measured appropriately	3 2 0	Observational methods Standardised self report tools only Non-standardised tools
CONFOUNDING VARIABLES			
4.1	The main potential confounders (i.e. disease severity) are identified and taken into account in the design and analysis.	2 1 0	Well covered Adequately covered Poorly addressed
STATISTICAL ANALYSES			
5.1	Results are clearly reported	2 1 0	Well covered Adequately covered Poorly addressed
5.2	Confidence intervals, effect sizes, p-values etc. are provided where appropriate.	2 1 0	Well covered (all are detailed) Adequately covered (one or two are detailed) Poorly addressed
Total score (out of 26):			
Percentage (%):			
Overall quality rating:			

***Overall Quality Rating Key**

Good (80%) = > 20

Acceptable (50%+) = > 13

Poor (<50%) = < 13

Appendix 1.3 - Quality rating for each study

Study	Quality Score (out of 26)	Percentage (%)	Overall Rating
DeLambo et al., (2004)	20	77	Acceptable
Eddy et al., (1998)	15	58	Acceptable
Giess et al., (1987)	9	35	Poor
Mitchell et al., (2004)	24	93	Good
Modi et al., (2008)	22	85	Good
Patterson et al., (1993)	15	54	Acceptable
Ricker et al., (1998)	18	69	Acceptable
White et al., (2009)	21	81	Good

Appendix 1.4 – Definitions of family functioning factors & rating criteria

Family Functioning Factors	Studies	Measures Used	Definition /Rating Criteria
Overall Family Functioning	Mitchell et al., (2004)	McMaster Mealttime Interaction Coding System (MICS)	Definition not available. “The family’s ability to effectively meet the physical, emotional, and psychological needs of each of its members. Families who rate in the unhealthy range may be disjointed and chaotic. Families who rate in the healthy range accomplish all important aspects of the meal with adequacy, if not with ease. Although problems may exist, they are understandable and do not disrupt the overall job of nourishing the family” (Mitchell et al., 2004).
<i>Family Specific</i>			
Quality of Relationships	DeLambo et al., (2004)	The IOWA Family Interaction Rating Scale	“Low score indicates an unhappy, conflicted or brittle relationship. A high score indicates a high, open, and emotionally satisfying relationship. RQ scores have been positively associated with scores on the warmth/support, communication, listener responsiveness, and positive mood subscales. RQ scores have been negatively correlated with scores on the hostility, contempt, antisocial, and defiance” (DeLambo et al., 2004; pg.347).
Problem solving	DeLambo et al., (2004)	The IOWA Family Interaction Rating Scale	Definition not available. “Measured using a four scale composite including family enjoyment, agreement on problem description, agreement on solution and implementation commitment. Low scores indicating poor family PS skills and high scores good family PS skills” (DeLambo et al., 2004; pg.347).
Family Resources	Patterson et al., (1993)	Family Environment Scale (FSE)	Three conceptual domains were considered; <ol style="list-style-type: none"> 1.) the family relationship dimension, comprising subscales Cohesion, Expressiveness, and lack of Conflict. This emphasises closeness and support within the family unit. 2.) an emphasis on personal growth dimension with the subscales Independent, Socially Active, Morally Oriented, Intellectual Oriented, Achievement Oriented. This emphasises autonomy and individuality of each family member. 3.) the system maintenance dimension with the subscales Organisation and Control. This emphasises keeping the family unit functioning effectively. <p style="text-align: right;">(Patterson et al., 1993; pg. 384)</p>
Family Coping	Patterson et al., (1993)	Coping Health Inventory (CHI)	Three subscales were included; <ol style="list-style-type: none"> 1.) Maintaining Family Integration and Optimism 2.) Maintaining Self-esteem 3.) Understanding the Medical Situation

			The term 'balanced coping' was used by selected the lowest score of the subscales.
Cohesion	Eddy et al., (1998) Ricker et al., (1998) White et al., (2009)	Family Adaptability & Cohesion Evaluation Scale – Third Edition (FACES-III)	FACES-III is designed to assess families in relation to the circumplex model proposed by Olson et al. (1979). The following definition was provided for cohesion as “the emotional bonding members have with one another and the degree of individual autonomy a person experiences in the family system” (Olson et al., 1979; pg3). On the cohesion scale families may be classified as disengaged, separated, connected or enmeshed. Higher scores suggest more adequate cohesiveness.
Adaptability	Eddy et al., (1998) Ricker et al., (1998) White et al., (2009)	Family Adaptability & Cohesion Evaluation Scale – Third Edition (FACES-III)	Adaptability was defined as “the ability of a marital/family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress” (Olson et al., 1979; pg.3). On the adaptability scale families can be classified as rigid, structured, flexible, or chaotic. Higher scores suggest more adequate adaptability.
<i>Parent Specific</i>			
Adjustment	Eddy et al., (1998)	Dyadic Adjustment Scale (DAS)	The DAS is designed to assess the quality of both married and unmarried dyads. It includes 4 subscales – (a) dyadic satisfaction (b) dyadic cohesion (c) dyadic consensus (d) affectional expression
Parenting Stress	Eddy et al., (1998)	Parenting Stress Index (PSI)- Short Form.	The PSI measures the magnitude of stress in a parent-child system and identify the sources of stress, and includes 3 subscales: (a) parental distress (b) parent-child dysfunctional interaction, and (c) difficult child.
<i>Parent-Child Specific</i>			
Dysfunctional interactions	Eddy et al., (1998)	Parenting Stress Index-Short Form.	The PSI measures the magnitude of stress in a parent-child system and identify the sources of stress, and includes 3 subscales: (a) parental distress (b) parent-child dysfunctional interaction, and (c) difficult child.
Parental supervision	Modi et al., (2008)	Daily phone diary method.	Time spent with their parents was recorded.

Appendix 2.1 – Author publication guidelines

British Journal of Health Psychology

Author Guidelines

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The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full

For full details see: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8287/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8287/homepage/ForAuthors.html)

Appendix 2.2 – Ethics approval letter

WoSRES
West of Scotland Research Ethics Service

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27 OCT 2010



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Date 26 Oct. 10
Your Ref
Our Ref
Direct line 0141 211 2123
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E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss Mackay

Study Title: A qualitative study of the experience of segregation in adolescents with cystic fibrosis.
REC reference number: 10/S0709/51

The Research Ethics Committee reviewed the above application at the meeting held on 19 October 2010. Thank you for attending to discuss the study.

Ethical opinion

The Committee discussed the application and agreed that there were no ethical issues of significance.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

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

Conditions of the favourable opinion

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

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

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification

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Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

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

Conditions of the Favourable Opinion:

1) The Participant Information Sheet for both the Parent and Child requires to be amended as follows:

Parent

- At 'What if my child changes their mind' the words 'then this is ok they will not get into trouble for this' should be deleted. The words 'without affecting your child's clinical care' should be inserted.

Child

- At the 'Introduction' you should introduce yourself, i.e. My name is Fiona and I would like to invite you to take part etc.
- At 'Step 3' there is a word missing, i.e. 'If it is okay with you this will be recorded' 'will' has been omitted.
- The paragraph starting 'After the interviews' there is a word missing, i.e. 'also known as being transcribed' 'as' has been omitted.
- At 'Do I have to take part' - if the child does not want to take part they do not need to complete the 'opt-in' form. The Administration Staff could put a note on the file that the child does not wish to participate.

There should also be details of an independent contact who would be available to ask questions and give advice on the research. This could be someone from the Cystic Fibrosis Team.

2) **Consent**

- The Committee agreed that it was not necessary to wait a further 24 hours after consent has been given.

3) **Storage of Data**

- There was reference in the application to the use of laptop computers. However the box at A36 was not ticked. Please confirm in writing that this should have been ticked.

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

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		
Protocol	1	03 September 2010
Participant Opt In Form	1	03 September 2010
REC application		06 September 2010
Covering Letter		
Participant Information Sheet: Parent – to be revised	1	03 September 2010
Participant Information Sheet – to be revised	1	03 September 2010
Participant Consent Form	1	03 September 2010
Parent Assent Form	1	03 September 2010
CV - Student - Fiona Mackay		
Referees or other scientific critique report		27 August 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

After ethical review

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

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

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

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

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

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

10/S0709/51

Please quote this number on all correspondence

Participant Information Sheet:

A qualitative study of the experience of segregation in adolescents with cystic fibrosis

Introduction

My name is Fiona and I would like to invite you take part in a research study that is being carried out by the University of Glasgow. Before you decide, it is important for you to understand why the research is being carried out and what is involved. Please take some time to read over the following information before deciding if you would like to go any further.

What is this study about?

This study is about young people with cystic fibrosis and their experience of the segregation policy, specifically at the Royal Hospital for Sick Children, Yorkhill. In particular; what it is like being segregated/ or in source isolation? Are there things you like about it, don't mind or really hate about being in isolation?

What is the purpose of this research?

Although the segregation policy was introduced a number of years ago there has been very little research on what it is actually like for people. The aim of this project is to find out more so that recommendations can be made to hopefully improve things.

What happens if I decide to take part?

Step 1 - If after reading this sheet you decide you would be happy to learn more about it then complete and sign the 'opt in' form and give it back to the member of staff who gave the forms to you in the first place. Please could you also discuss this with your parents and make sure they have been given the information sheet and 'assent' form (this is for your parents to say it is okay for you to take part).



Step 2 - Fiona will then arrange a suitable time to meet you briefly in hospital, she will organise this through the hospital staff. This will allow her to tell you more about the study, as well as providing an opportunity for any questions you may have to be answered, before deciding whether you wish to take part. If following this you decide you would like to take part then Fiona will ask you to complete and sign the consent form, as well as collecting the 'assent' form from your parents. If after this you decide you don't want to take part, that is okay too, it is your choice.

Step 3 - An interview time will then be arranged where Fiona will visit you again in hospital. This will involve having a discussion around segregation and what things you may like or dislike about it. This meeting could last up to an hour but really depends on how much you have to say! If it is okay with you this will be audio recorded.

And that's all you have to do!

After the interviews, we will listen to the recording of our discussion, as well as those of the other young people involved in the study and this will then be typed up on a computer (also known as being transcribed). This will then be pulled together and written up as a report.



Will my taking part in the study be kept private?

Yes, only those involved in the study will know that you have taken part and only the research team will have access to what was said during the interview. We will change your name so that no-one will know what you have said. The recordings and transcripts (paper copies of your interview) will be kept in a locked filing cabinet on university grounds.

Do I have to take part?

No, you do not have to take part! It is completely up to you. If you do not want to take then please let a member of staff know and you will not be asked again.

What if I change my mind?

You can change your mind at any point, for example if you say 'yes' and then decide you no longer want to take part, that is okay.



Are there risks or benefits to taking part?

There are no obvious risks to taking part in this study. It is hoped that through the results of this study recommendations will be made to the Cystic Fibrosis team on how things can be improved for young people who are in isolation or segregated.



Who has reviewed the study?

This study has been reviewed by the department of Psychological Medicine, University of Glasgow, as well as the West of Scotland Ethics Committee who granted approval for the study to be carried out.

Any questions?

If you have any questions about the study and would like to find out more then please sign the 'opt in' form discussed above and Fiona will be able to answer these when she visits. However if you would like to speak to her before this meeting then you could call her on **07833095375** or email her at: f.mackay.1@research.gla.ac.uk.

Alternatively if you wish to discuss this with someone independent from the research team please ask to speak to: Dr Anne Devenney, Consultant in Paediatric Respiratory Medicine, Cystic Fibrosis Team, RHSC, Yorkhill.

Thank you for reading this. I look forward to hearing from you!

Introduction

Your child has been invited to take part in a research study that is being carried out by the University of Glasgow. Before your child decides whether they would like to take part, it is important for you to understand why the research is being carried out and what is involved. Please take some time to read over the following information and talk to others about the study if you wish. We have also provided an information sheet for your child.

What is this study about?

This study is about young people with cystic fibrosis and their experience of the segregation policy, specifically at the Royal Hospital for Sick Children, Yorkhill. In particular; what it is like being segregated or in isolation and, if there are good and bad things about this. The person in charge of this research study is Fiona Mackay who is a Trainee Clinical Psychologist.

What is the Purpose of this research?

Although the segregation policy was introduced a number of years ago there has been virtually no research on what it is like for people. The aim of this project is to find out more so that recommendations can be made to hopefully improve things.

What happens if your child decide to take part?

Step 1 - If your child decides this is something they might be interested in then we will ask them to complete and sign the 'opt in' form saying that they would like to be hear more about it.

Step 2 - Fiona will then organise a suitable time through the CF team to visit your child briefly in hospital. This will allow Fiona to tell your child more about the study, as well as providing the opportunity for questions to be answered. They will then be asked if they would like to take part in the study. If they decide they do not want to, then that is absolutely fine. No one will be pressured to take part. It is not necessary for you to be present at this meeting however if you would like to be there or have questions too, then please feel free to join us. The CF team will be able to tell you when this meeting is going to take place.

If following this meeting your child decides they would like to take part then Fiona will ask them to complete and sign a consent form. We would also ask that if you are happy for your child to take part if you could please sign the parent 'assent' form provided. **If**

you are not planning to be present for this meeting could you please sign this before hand and leave it with your child.

Step 3 – A suitable interview time will then be arranged with the clinical team where I will visit your child again in hospital. This will involve having a discussion around segregation and what things they may like or dislike about it. This meeting could last up to an hour but really depends on how much they have to say! It will also be digitally recorded, if this is okay with you and your child.

Following the interviews, we will listen to all the recordings which will then be transcribed and analysed. This will then be pulled together and written up as a report.

Will my child's taking part in the study be kept private?

Yes, only those involved in the study will know that your child has taken part and only the research team will have access to what your child said during the interview. Their name and all other identifiable information will be anonymised meaning that no one will know that it is your child. The recordings and written transcripts will be kept in a locked filing cabinet on university grounds.

Does my child have to take part?

No, they do not have to take part! It is completely up to them. If they decide they do not wish to take part then they should tell this to the member of staff that they gave them this information sheet.

What if my child changes their mind?

They can change their mind at any point, for example if they say 'yes' and then decide later on they don't want to, this is fine. This will not affect your child's clinical care.

Are there risks or benefits to taking part?

There are no obvious risks to taking part in this study. It is hoped that through the results of this study clinical recommendations will be made to the CF team in order to improve things for young people who are segregated or in isolation.

Who has reviewed the study?

This study has been reviewed by the department of Psychological Medicine, University of Glasgow, as well as the West of Scotland Research Ethics Committee who granted approval for the study to be carried out.

Any questions?

If you have any questions or you would like to discuss this further then please call Fiona Mackay on **07833095375** or email her at: F.Mackay.1@research.gla.ac.uk. Alternatively if you wish to discuss this with someone independent from the study please contact: Dr Anne Devenney on **0141 2010137** or email her at: anne.devenny@ggc.scot.nhs.uk.

Thank you for reading this.



PARTICIPANT OPT IN FORM



Title of Project: A qualitative study of the experience of segregation in adolescents with cystic fibrosis

Name of Researcher: Fiona Mackay

Patient Identification Number (for research team use):

Please tick box

1. I agree for the researcher, Fiona Mackay, to briefly visit me in hospital to tell me more about the study.

2. I understand that this visit will be organised through the Cystic Fibrosis team and they will let me know once it has been arranged.

3. I understand that if my parents want to know more about the study they can also be present at this meeting.

Name of Patient

Date

Signature

Name of Person
taking consent

Date

Signature

Thank-you for your help!



PARTICIPANT CONSENT FORM



Title of Project: A qualitative study of the experience of segregation in adolescents with cystic fibrosis

Name of Researcher: Fiona Mackay

Patient Identification Number (for research team use):

Please tick box

- 1. I have read and understand the information sheet dated.....
(version.....) for the above study. I have had the chance to ask questions and these have been answered.
- 2. I understand that it is my choice to take part and that I am free to stop at any point.
- 3. I agree for my interview to be digitally recorded, and made private so no one knows that it is me. I also understand it will be out word for word, on a computer.
- 4. I understand that this information will be kept in a safe place.
- 5. I agree for my interview to be read by the research team and for my some of what I said to be used in the report, as long as it is in private form.
- 6. I agree to take part in the above study.

Name of Patient	Date	Signature
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Name of Person taking consent	Date	Signature
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Thank-you for your help!



PARENT ASSENT FORM



Title of Project: A qualitative study of the experience of segregation in adolescents with cystic fibrosis

Name of Researcher: Fiona Mackay

Patient Identification Number (for research team use):

Please tick box

- 1. I confirm that I have read and understand the information sheet dated.....
(version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my child’s participation is voluntary and that they are free to withdraw at any time and this will not affect their medical care or legal rights.
- 3. I agree for my child’s interview to be digitally recorded, anonymised and transcribed. I understand that this information will be stored in a locked filing cabinet in secure university grounds.
- 4. I agree to my child’s interview transcript being read and analysed by the research team and quotations being used in any reports or publications (once identifying information has been removed).
- 5. I agree to for my child take part in the above study.

Print Child’s Name

Print name (parent)

Date

Signature

Name of Person taking consent

Date

Signature

Please leave this form with your child for the researcher to collect at the meeting.

Appendix 2.4: Interview Topic Guide

INTERVIEW TOPIC GUIDE

The below questions were used as a guide only to initiate discussion. Prior to commencing interviews, participants were reminded that they could have a break at any point and that there were no right or wrong answers. They were also reminded that the information would be anonymous.

A. CYSTIC FIBROSIS

Q: If you imagine you have been asked to explain CF to someone who knows nothing about it what would you say?

Prompt: How is it caused? How does it affect your body? How much control do you have over it? How does it affect you on a day to day basis?

Q: What do you think about having CF?

Prompt: How do you feel about having CF?

Q: Compared to other children with CF do you think you have been in hospital more or less?

Prompt: If you are not sure, take a guess.

B. SEGREGATION POLICY

Q: What's your understanding of what the segregation policy means?

Prompt: Have you heard of the segregation policy? What do you think it means?

Q: What do you think about this?

Prompt: Is it a good/bad idea, can you tell me more about this?

Q: What do your parents/family think about the policy?

Prompt: Can you tell me more about that? How does the policy affect them?

Q: What has been your experience of being in source?

Prompt: Can you tell me a bit about what it is like being source?

C. IN SOURCE

Q: Can you describe what being in source is like?

Prompt: Can you tell me more about that?

Q: What have you liked/disliked about this experience?

Prompt: Can you tell me more about that?

Q: How do you usually feel when you are in source?

Prompt: Can you tell me more about that?

Q: How do you cope with being in source?

Prompt: Is there anything that you do more or less when you are in source? Can you tell me more about that?

Q: How does being in source affect your relationship with your family?

Prompt: Can you tell me more about that?

Q: How does being in source affect your relationship with friends?

Prompt: Can you tell me more about that?

Q: How does being in source affect your relationship with staff?

Prompt: Can you tell me more about that?

Q: Can you think of anything that would improve your experience whilst being in source?

Prompt: Can you tell me more about that?

Q: Have you always followed the rules when in source?

Prompt: Can you tell me more about that?

D. OUTSIDE OF HOSPITAL

Q: Can you describe in what ways the policy affects you outside of the hospital?

Prompt: are you allowed to socialise with other children with CF?

Q: Do you have friends with CF? If so could you tell me more about this.

Prompt: How do you stay in contact? What kind of things do you like to do/talk about together?

Q: What's good/bad about having friends with CF?

Prompt: Can you tell me more about that?

Q: If you don't have friends with CF, would you like to?

Prompt: Can you tell me more about that?

Appendix 2.5 Example of an interview extract & coding

	Coding/ Notes
I: So you were saying there that sometimes you have felt liked you wanted to speak to other people and sometimes you felt no...kinda going between the two almost?	
P: Yeh ha ha I think it just depended on how I felt I think if I was feeling really bad about my CF then I want to talk to someone else but if I was feeling fine then I was like "I'll just go and talk to my friends about other things" so just kinda depends	- disease severity impacting on desire for contact with CF others - friends as support and distraction
I: Can you say anymore about that?	
P: I think the whole thing is that because you are not allowed to talk to someone with CF face to face there is no one who can really identify with what you are going through	- segregation preventing feelings of identification with others
I: Sure	
P: and I think, kinda you are going through a rough time someone might be like "oh my gosh I totally felt like that last month" and you know my family have always been like yeh we can understand and it's like " <i>you can't</i> " {participant laughs} and I know they like trying to understand and stuff but it's just having that understanding of what you are going through and the treatment every single day and it's just kinda that understanding and identifying with someone"	-frustration at non CF others not being able to understand - loss of identification & validation from others who share the experience
I: That you are in it together?	
P: Yeh ah ha	
I: Just wondering where you get most of your support from?	
P: I think mostly from my mum, my mum has basically she took on all of my treatment when I was younger and stuff like that and my mum has basically you know I can talk to all of my family by my mum is the first person I would go to which I think is understandable and I just think because she done so much for me when I was younger and she kinda knows a bit more about it, about my CF than I do	- mother as main source of support - appreciation of care from mother - perception of mother being more knowledgeable about CF
I: What do you think your mum's views are on the segregation policy, what would she say about it?	
P: I think she would kinda, I think she would maybe agree with me I think my mum thinks that I still do kinda want to talk to people and I do but I am just kinda worried in case I have the same experience and I think my mum thinks it would be good for me to talk to someone and I think she feels that she can't give me the support that I'm kinda wanting and I think that's kinda hard for her so I think if the segregation wasn't there it would take a bit of the weight off my mum's shoulders as well	- perception that mother sees benefit in contact with CF others - fear of negative experience meeting others - perception that segregation puts pressure on mother

Appendix 2.6 – Research proposal

Abstract

Segregation of patients with Cystic Fibrosis has become common practice in order to reduce cross infection and in turn prevent further lung disease. There is a sufficient amount of medical literature to support these measures as an effective method yet there has been virtually no research exploring the psycho-social impact of such a policy. The proposed study aims to explore young people's understanding and experience of segregation. In-depth interviews will be carried out to explore these aims using thematic analysis supported by an interpretative phenomenological analysis framework. Insight into young people's experiences of segregation would allow for clinical recommendations to be made.

1. Introduction

Cystic Fibrosis (CF) is a life threatening genetically inherited disease which primarily affects the lungs and digestive system (The Cystic Fibrosis Trust, 2004). Over the last decade medical research has highlighted the link between chronic infections and progression of lung disease, which is often a major predictor of survival for CF patients (Kosorok et al., 2001, Kock, 2002). These infections can be passed from one person with CF to the next. Given the health risks of these infections, the Cystic Fibrosis Trust (2004) produced guidelines in order to minimise cross infection; one of the primary recommendations was that of segregation.

Policies of segregation generally advise that patients with CF should avoid mixing with other CF patients in wards, clinics and waiting areas to avoid infections being spread. The exact policy varies between sites and is at the discretion of the individual CF service (Cystic

Fibrosis Trust, 2004). Research has shown that this is an effective method of reducing cross infection between patients (Festini et al., 2006).

Segregation at the Royal Hospital for Sick Children (RHSC) in Glasgow

In 2001, the RHSC in Glasgow, adopted a segregation policy which indicated that the type of infection held would determine the level of segregation or isolation (please note these terms are used interchangeably). For example those with infections such as B.Cepacia, are nursed in source isolation (i.e. single cubicles with en suite facilities) for their entire stay whereas those with P. Aeruginosa can be nursed in a ward, as long as there are no other children with CF. Children with CF are generally not permitted to socialise amongst each other or attend group activities in the hospital such as school teaching, unless it is non CF children only. Visitors are allowed access provided they do not have CF although it is not recommended for visitors to see more than one patient with CF at a time, within the hospital. The policy also extends outside of hospital to advise families with a CF child to avoid socialising with other CF families at all times.

Patient and carer satisfaction - segregation policies

A couple of studies have looked at patient and carer satisfaction regarding segregation policies for those with CF. Russo et al., (2006) administered questionnaires to patients and carers, using an open ended questionnaire design. The findings showed overwhelming support for the policy with 91% of parents, and 92% of children, in favour of segregated treatment. The two main themes which emerged from the data were 'a difficult balancing act' and the 'psychosocial costs of segregation' (pg.97). Despite supporting the policy, parents and patients acknowledged the potential negative implications of segregation such as; boredom, loneliness and stigma for the child, and an increased pressure on the family to visit. The validity of these findings could be questioned due to the timing of the study. For

example the study was carried out prior to the policy being introduced; meaning that participants were asked to *imagine* the experience of segregation without actually having any experience of it. This requires a certain level of abstract thinking which people can struggle to do accurately, particularly children.

An earlier study Griffiths et al., (2004), reported on satisfaction, post introduction of the policy. This study found that 85% of parents and 63% of patients (above 12yrs old) were positive about the segregation measures introduced. This study finds less patient support for segregation than Russo et al., (2006), suggesting young people's attitudes towards the policy are perhaps not as positive, after, implementation. Although providing some indication of the level of support for segregation policies; both studies fail to explain, or understand, the full experience of segregation from the patient's perspective.

Psychological impact of isolation in a hospital setting

Questions have been raised whether the benefits of segregation in a CF population outweigh the potential psychological impact (Geddes, 2001, Duff, 2001). Yet, the exact impact is actually unknown. To date there are no published prevalence figures for psychopathology in segregated CF populations, per se. Quittner (2008) reviewed the literature regarding depression in those with CF in general (i.e. not specifically those segregated) and concluded that there is a higher than average rate of depression in children, adolescents and adults living with CF. Duff (2001) suggests that segregation or isolation in hospital has the "potential to have even greater negative effects on emotional wellbeing" (pg.756). For example, Ward (2000) found that over 42% of patients that were isolated (due to infectious or tropical diseases) associated negative emotions with the experience such as confinement, loneliness and boredom. Another study found that a group of isolated patients had significantly higher levels of anxiety and depression and significantly lower levels of self esteem and control,

when compared to a control group of patients in hospital (Gammon, 1998). This can be supported by Laliotis (2003) who also found significantly higher levels of anxiety and depression in those kept in isolation compared to patients who were not. A word of caution should however be made in generalising these findings given that none of the studies were carried out specifically with CF populations and small sample sizes were used. Wilkins et al., (1988) however found that although patients reported negative emotions with isolation they often reported a preference for a single room. Overall, the limited evidence base suggests that segregation is likely to have, to some degree, a negative psychological impact. Nevertheless, there is the possibility that some patients may have positive feelings towards segregation, such as the use of a single room in hospital. Further research is imperative if we are to progress in this area and gain a clearer understanding of the emotional and psychological impact of segregation whilst having CF.

Rationale for this study

Segregation in cystic fibrosis is a relatively new policy and one which has received much backing from the medical literature. Apart from a small number of studies looking at the satisfaction of segregation, there is a significant gap in the literature investigating the impact of such an experience on those with CF. At present, there is no published literature examining the psycho-social impact of segregation on adolescents with cystic fibrosis. The purpose of this study is to develop an in-depth, thorough, understanding of the experience of segregation in order to further develop the field and make clinical recommendations. Adolescents may be a particularly pertinent age group to consider for a number of reasons. Firstly, they are likely to be spending longer periods in hospital than their younger peers (as lung functioning tends to decrease with age) therefore may have more experience of segregation. Secondly, given their developmental stage and the likelihood of the increasing importance of friendships, segregation from their CF peers could be potentially quite

distressing. Due to the rationale given above, this study aims to explore the experience of segregation from an adolescent perspective. This study will focus on the segregation policy specifically at the RHSC at Yorkhill, Glasgow.

2. Aim & Objectives:

Aim

The aim of this study is to explore the experiences of segregation in an adolescent Cystic Fibrosis population.

Objectives;

1. To explore the young people's beliefs & understanding about being segregated from their peers and what impact this has upon them
2. To contribute to the evidence base as to the psychological/psychosocial impact of the policy of segregation
3. To use the evidence generated by this study to make recommendations for professional practice

3. Plan of investigation:

Participants

All participants will have a diagnosis of Cystic Fibrosis and be between the ages of 12 and 15. The study was originally aimed at an adolescent population (12-18 years) but patients from the RHSC, Glasgow transition over to adult services at 15 years. In order to preserve a homogeneous sample it was decided to recruit only from the one service. Therefore purposive sampling will be used.

Participants will also be current in-patients at the RHSC, Glasgow, and will therefore be NHS Greater Glasgow & Clyde patients. It was thought that during hospital admissions patients would be in a well suited position to reflect on their experiences of segregation; and may welcome the opportunity to voice their thoughts and feelings on the topic. If on the other hand, patients were recruited as out-patients this may cause more disruption to their lives and interrupt their well deserved time outside of hospital.

Exclusion criteria

Individuals will be excluded if they are a non-English speaker, if there is presence of learning disabilities, or if there is any concern over their mental state (this will be decided by the CF team who will screen all possible participants before they are invited to take part in the study).

Justification of sample size

Due to the nature of qualitative research, small sample sizes are usually recommended. Smith and Eatough (2007) advise that the right sample size is one that balances having enough data to compare and contrast themes between participants, whilst also, avoiding overwhelming the researcher with the volume of data. They have suggested that six to eight is appropriate for post graduate clinical projects (Smith & Eatough, 2007; pg.40) however a larger sample size of 8-10 has been proposed for this study to allow a better chance of achieving theme saturation.

Recruitment Procedures

The CF team will be provided with the recruitment criteria and asked to identify potential participants. The researcher will phone the CF nurse specialists regularly to enquire if any potential participants have been identified, for two main reasons; to remind them about the

study, and to ensure interviews are set up as quickly as possible (some young people may only be in hospital for a couple of days). Once possible participants have been identified, a CF nurse specialist will verbally inform the patient of the study, as well as providing them with an information sheet and an 'opt in' form (see appendix). The 'opt-in' form will ask the young person if they are interested in learning more about the study and if they will allow the researcher to visit them in the hospital to do this. An information sheet for parents will also be provided at this stage, as well as an 'assent form' asking for their permission for their child to participate (see appendix).

If the patient 'opts in' this information will be passed onto the researcher and a suitable time for the researcher to visit will be arranged. This short meeting will provide the young person with the opportunity to meet with the researcher and ask any questions they may have about the study as well as ensuring they fully understand the procedures. If the young person decides they would like to take part, formal consent will then be sought at this stage as well as collecting the parent 'assent' form. The consent form will include; consent for participation in the study as well as for the interview to be digitally recorded, anonymised and transcribed. The consent form will also give permission for these interview transcripts to be read and analysed in anonymised form by the principal researcher and their supervisor, as well as one other researcher. After consent is obtained, a suitable interview time will be agreed (which will be at least 24 hours after formal consent has been received). The clinical team will be informed of all participant involvement.

Design & Procedures

Interviews will take place on an individual basis after consent is obtained. Interviews will begin by building some rapport with the young people and helping them feel at ease. Demographic information will also be gained at this point. Another brief explanation of the

process will be given as well as informing the participants that they can stop the interview at any time or if they need a break. Interviews will begin when participants appear comfortable and relaxed, clinical judgment will be used to determine this. Interviews are expected to take around an hour.

Interviews will be conducted using open questions based around the aim of the study. A topic guide will be designed in order for the following areas to be explored:

- A. Participants' beliefs about their illness. This will be informed by Mayer & Leventhal et al., (1985)'s model of cognitive illness representations. The model proposes that there are five cognitive dimensions which influence a patients understanding of their illness; identity, cause, consequence, time-line and control/cure.
- B. Participants understanding of the segregation policy, and how they, and others, view it.
- C. Impact on their lives (both inside and outside of hospital i.e. school);
 - Affect & Emotions: the questions will loosely be termed around Russo et al's., (2006) findings of negative, neutral and positive feelings (pg.96).
 - Interpersonal relationships (family members, friends, professionals etc).
 - Coping and any strategies that may be used. The importance of coping strategies has been highlighted by Folkman & Lazarus (1988) who proposed a coping paradigm. This suggests that there are two main coping processes; one that is "directed at altering the situation that is causing distress (problem-focused coping)" and/or one that "regulates distress (emotion-focused coping)" (pg.310) and will be used to guide questions in this area.

The researcher will only use the interview guide as a prompt to open up discussion in these areas. A non-directive, flexible approach will be taken, allowing the discussion to mainly be lead by the participant (Smith & Eatough, 2007). The advantages of this approach is that it is

conducive to a rich exploration of a participant's experience, allowing complex and novel themes to be followed which may otherwise be constrained by an alternative method. Probing questions such as "can you tell me more about that" will be used to encourage participants to expand fully on points of their narrative. Participant's mood will be monitored throughout the interview and if they appear uncomfortable, the researcher will respond by addressing the topic in a different way either asking the question in a more gentle fashion or leaving this area completely (Smith & Eatough, 1997). Clinical judgment will be used to decide the most appropriate course of action.

Interviews will be audio recorded using a digital recorder and will then be transcribed verbatim and anonymised. Transcription and analysis will take place as soon after the interview as possible. Three pilot interviews will be carried out initially to test out the topic guide. Following review of transcriptions by researcher and supervisor, amendments to the topic guide will be made as appropriate. Smith & Eatough (2007) suggest as a rough estimate that per hour of interview will take a minimum of around seven hours to transcribe. In total, transcribing could take between 56 and 70 hours.

Data Analysis

The analysis will be carried out using thematic analysis (TA) within an interpretative phenomenological approach (IPA) framework. The main aim of thematic analysis is to identify, analyse and report patterns (themes) within data in a simple fashion, allowing a rich and detailed account (Braun & Clark, 2006). A six phase process for analyzing data using TA, proposed by Braun & Clark (2006), will be employed.

Arguably one of the benefits of TA is its flexibility, in that it is independent of theory and epistemology, therefore it can be applied across a range of approaches and themes can be

determined in a number of ways (Braun & Clark, 2006). For this reason TA can be a useful method when carrying out studies on topics which are particularly under researched (Braun & Clark, 2006, pg.83). For example, TA can use a bottom-up approach where the data is coded without trying to fit it into a pre-determined framework, or be influenced by the researcher's preconceptions of the data. This form of thematic analysis is therefore data-driven (Braun & Clark, 2006). Despite this TA acknowledges that researchers will unavoidably have some influence on the data, due to the coding element of the approach (Braun & Clark, 2006). In this study, a bottom up approach will be used.

An Interpretative phenomenological approach (IPA) perspective will also be used. The main aim in IPA is to explore in detail individual personal experiences and the meanings participants attach to these (Smith & Eatough, 2007). IPA attempts to understand the experience from as much of the participant's perspective as possible whilst also acknowledging the role of the researcher making it a dynamic and two way process (Smith & Osborn, 2003). Smith and Osborn (2003) propose that "participants are trying to make sense of their world; and the researcher is trying to make sense of the participants trying to make sense of their world" (pg.51). It is therefore crucial that the interaction between researcher and participant is noted and reflected upon, helping reduce any bias when analysing the data. In order to aid this process the researcher will keep a record of reflections or points of interest after each interview. This 'reflexivity' is viewed as a strength of this type of approach (Reid et al., 2005). IPA has also been suggested as being particularly well suited to exploring topics within health areas (Smith & Eatough, 2007).

All identifiable information will be anonymised to ensure confidentiality is maintained. To check validity of the analysis, a sample of transcripts will be analysed independently by a

fellow researcher (who is familiar with qualitative approaches) to ensure similar themes are being identified and to allow for discussion around this.

Settings and equipment

All interviews will be conducted at the RHSC, Glasgow in a private room. A digital voice recorder will be required for each interview and a computer with transcription software. Transcribing equipment such as a foot pedal to control playing back of recording will also be required.

4. Health and Safety Issues

Researcher safety issues

The infections that some CF patients carry are not contagious for those without CF (which includes the researcher). Interviews will be conducted on hospital grounds and no home visits will be undertaken.

Participant safety issues

If patients are in isolation then the researcher will follow hospital protocols in order to prevent spreading infection. For example, wearing an apron and washing hands with alcohol gel before entering/and on leaving the patient's room. Given the interviews will take place on NHS Greater Glasgow & Clyde hospital grounds, there will be medical practitioners/clinical psychology clinicians close by should any problems arise. The researcher is also a trainee clinical psychologist therefore they are sufficiently trained in managing clients that may be distressed or managing risk issues appropriately. Local health and safety protocols will also apply. If however following the interview, the participant appears to be exhibiting signs of distress then participants will be offered the option of onward referral to the clinical psychology department at the RHSC at Yorkhill, Glasgow.

There are currently two clinical psychologists based at this hospital that are attached to the CF team.

5. Ethical Issues

Ethical approval will be gained from the local research ethics committee and ethical practice will be in keeping with The British Psychology Society (BPS) Code of Ethics & Conduct (2006). All major ethical principles will be respected:

- 1.) Informed consent - Participants will be provided with information to fully inform them of the study to help them decide if they want to take part. This will be presented in a young person friendly format. A consent sheet which they will be asked to sign will be obtained, if they decide to take part. This will be obtained prior to the interviews. This avoids any opportunity for deception with participants taking part in the study. In Scotland, participants over the age of 12 can legally consent as long as they are “capable of understanding the nature and possible consequences of the procedure or treatment” Age of Legal Capacity (Scotland) Act 1991. (c. 50). However out of courtesy, parent(s)/guardian(s) will be provided with an information sheet and an ‘assent form’ requesting their permission. In such a scenario where a young person wishes to take part, but their parent(s)/guardian(s) objects; the young person will ultimately be given the choice of whether they wish to continue or not.
- 2.) Avoidance of harm – Participants may feel distressed to some level talking about their experiences of segregation however it is hoped that the intended benefits of this study will outweigh any distress that may be caused. Their mood & fatigue level will be monitored throughout the interview and they will be told that they can terminate the interview or take a break at any point. If the participant appears significantly distressed the researcher will stay with them and monitor the situation. If this level of distress remains after a period of time, a member of the CF team will be approached.

- 3.) Privacy – all information and transcripts will be anonymised before analysis in order to ensure confidentiality and kept in a locked and secure filing cabinet. Transcripts will be allocated code numbers and patient details will be stored separately from the transcripts. All data will be kept on a NHS Greater Glasgow & Clyde computer which will be password protected. This information will be stored correctly under the Data Protection Act (2000).
- 4.) Right to withdraw - Participants will be allowed to terminate interviews at any point or if they are fatigued and would like to finish the interview at another time. Participants will also be allowed to withdraw their data at any time.

6. Financial Issues

This study will require finances to cover; paper and photocopying, travel expenses, a digital recorder and transcribing equipment. An Enhanced Disclosure Scotland form for NHS Greater Glasgow & Clyde will also be required for the researcher.

7. Timetable

Task	Planned date
Preliminary Research Proposal	25 th of January 2010
Research Proposal	26 th of April 2010
Re-drafting of final proposal	April – June 2010
Submit for Ethical Approval	July 2010
Recruitment & Interviewing	October – March 2011
Transcription	October – March 2011
Write Up	March – June 2011

8. Practical Applications

The findings from this study will add a psychological perspective to the medical literature regarding segregation and cystic fibrosis. This will offer patients, families and clinicians' greater insight and knowledge regarding the potential impact of segregation; encouraging balanced and fully informed decisions to be made regarding patient care. The findings will also allow clinical guidelines and recommendations to be made regarding minimizing, or how to compensate for, any negative psycho-social implications associated with segregation. The findings will also provide a framework for clinicians to use, or be mindful of, when working with a young person with CF where segregation is a prominent issue.

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