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Experiences of Healthcare Professionals and Patients in Paediatric Cystic Fibrosis: Making and Breaking Bonds

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Experiences of Healthcare Professionals and Patients in Paediatric Cystic Fibrosis: Making and Breaking Bonds.

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Thesis Abstract

This thesis explores the experience of Cystic Fibrosis (CF) in young people and healthcare professionals across three papers. Firstly, a systematic literature review explores the experiences of peer support for young people with CF, including peer support with CF peers, non-CF peers, impact of segregation, diagnosis disclosure, need for and purpose of peer support and parental and peer relationships. The need for social support in the lives of young people with CF was highlighted. The findings emphasised the need to continue addressing social needs of youth with CF, particularly finding ways to reduce the risk of cross-infection if youth choose to pursue friendships with CF peers. Limitations to the evidence base prevented reciprocal associations, bi-directional relationships and changes over time to be examined. Future research needs to consider the paucity of literature on peer support for young people with CF and potential avenues for future research are discussed.

The second paper presents findings from an empirical study, qualitatively exploring the lived experiences of healthcare professionals (HCPs) working with children and adolescents with CF and the transition to adult services. This study was undertaken according to the principles of interpretative phenomenological analysis (IPA), with semi-structured interviews conducted with seven participants. Three superordinate themes emerged from the data, all dynamically intertwined and represent the interplay between both professional and (inter)-personal dynamics within CF care. Implications for clinical practice and future research are discussed. The third paper discusses implications for theory and clinical practice emerging from the first two papers. Discussion emphasises how this study examined an under-represented area and expands the opportunity to bring HCPs' experiences and social needs of young people with CF to the foreground. This paper concludes with personal reflections on the research process and outcomes.

Section 1

Systematic Review

Exploring peer relations for young people with cystic fibrosis: a systematic review

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Abstract

The literature was systematically reviewed to explore peer support experiences for young people with Cystic Fibrosis (CF). The online databases PsycINFO, CINAHL and Web of Science were searched and nine studies met inclusion criteria. Participants were aged between 8-21 years to ensure studies captured the breadth of the biopsychosocial transition from dependent child to an autonomous adult. The review explored quantitative and qualitative studies published between 2004-2016 in line with local implementation of a segregation policy. Despite the paucity of literature, evidence highlighted how social support played an important role. Supportive friends were found to be a protective factor for children and adolescents. Both family and friends influenced CF management during adolescence. Parents were found to provide more tangible support whereas friends provided more relational support. Variation was found between CF peers and non-CF peers listed in friendship networks and differences were found in how adolescents disclosed their diagnosis of CF to friends. Concerns arose around the potential impact of segregation; however health benefits seemed to far outweigh any negative impact. Interactive resources and increased one-to-one time with staff were suggestions made to compensate for the impact of segregation. Online discussion groups provided parents and young people an opportunity to share experiences with a relatable audience. A significant decrease in perceived loneliness was also found following a focus group life skills intervention. These results are considered alongside an appraisal of research methods used to explore peer support and CF, with recommendations made for future research design. Clinical implications are informed by developmental theory, highlighting the need to consider the wider social context and develop innovative solutions to meet the psychosocial needs of young people, without jeopardising their physical health.

Keywords: cystic fibrosis, peer, social, support, friendship

1.0 Introduction

"The road travelled with cystic fibrosis is often deserted, devoid of like minded companions."
— Wicks (2007, p. 1270)

Cystic Fibrosis (CF) is a hereditary life limiting disease, which primarily affects the lungs, pancreas and digestive systems (Williams, Corlett, Dowell, Coyle & Mukhopadhyay, 2009). The objective of treatment for CF is to relieve discomfort and delay the effects of the disease; however treatment can be burdensome, and it can last up to 8 hours per day (Williams, Mukhopadhyay, Dowell & Coyle, 2007). The experience and management of CF can have a psychosocial impact for both the young person and wider family (Bluebond-Langer, Lask & Angst, 2001), particularly since treatment regimes are often completed at home (Williams et al., 2007). Furthermore, the severity of CF progresses from mild to moderate during childhood and adolescence, and this can increase during adulthood (Quittner, Modi & Roux, 2003).

To effectively manage CF requires flexibility and support from family and friends (De Civitka & Dobkin, 2004; Gallant, 2003; Kakak, Rourke, Navsaria, 2009). Peer support or friendships play a key role in the lives of children and adolescents and can impact future adjustment (Bagwell & Schmidt, 2011). Relationships with peers foster the development of appropriate social skills, the acquisition of a healthy self-concept, and lower levels of loneliness (Demir & Urberg, 2004; Gaertner, Fite, Colder, 2010; Harrop, 2007; Thomas & Daubman, 2001). However, a chronic condition such as CF can increase vulnerability in peer interactions (Harrop, 2007), particularly during adolescence.

Adolescence signifies a developmental period characterised by the importance of peer relationships (Helms, Dellon & Prinstein, 2015; Way & Silverman, 2011). Epidemiological data highlights the variation in lower and upper age limits and failing to consider adolescence as a developmental stage when conceptualising a definition (Sawyer, Drew & Britto, 2007). However, middle childhood (6-12 years) is also considered a crucial turning point for children,

particularly with chronic illness (Christian & D'Auria, 2006), and children and adolescents with CF have identified middle childhood as the most vulnerable period for growing up with chronic condition (Christian & D'Auria, 1997). Children begin to develop a comparative sense of self in relation to others during middle childhood (Damon & Hart, 1992). A subsequent milestone in cognitive ability and self-understanding occurs when children reach the age of 8 (Scroufe, Cooper & DeHart, 1996), when children start to define themselves by groups to which they belong and through peer comparisons (Christian & D'Auria, 2006).

As children transition into adolescence, they enter a period of sudden social, cognitive and physiological changes (Kostakou et al., 2014). Peers become influential and adolescents with CF in particular are desperate to fit in with their peers, be normal and not stand out (Segal, 2008). Adolescence also signifies a time when young people with CF begin to have greater realization over the severity of their illness and when responsibility for treatment adherence shifts gradually from parents to themselves (Modi, Marciel, Slater, Drotar & Quittner, 2008; Sawicki, Heller, Demars & Robinson, 2015). Parents can however hinder the development of peer relationships by attempting to limit activities to reduce exposure to infection (Bolyard, 2001). Thus, despite the normal developmental tendency and need for autonomy (Reis, Collins & Berscheid, 2000), adolescents with CF are to some extent kept dependent on their parents and members of their medical team (Yeo & Sawyer, 2005).

Although adolescents acknowledge the need for continuous treatment, the social reorientation towards peer groups and moving away from the family may decrease motivation to complete treatment (Ernst, Johnson & Stark, 2014). Adherence to treatment has also been found to decrease during adolescence, thus symptoms can worsen and this increases the illness burden (Hegarty, Macdonald, Watter & Wilson, 2009). Therefore, it is important to understand the influence that peer relations have on adherence during adolescence (La Greca, Bearman & Moore, 2002).

Good peer relationships have been found to be an important source of support for children with CF (Christian & D'Auria, 1997), however intensive treatment regimes, restrictions on physical activity and interruption of daily activities can limit peer relations (La Greca, Bearman & Moore, 2002). CF along with its extensive treatment burden, and potential decline in health, may impact on normative developmental experiences (Modi & Quittner, 2006). Independence can be interrupted due to treatment demands and hospital admissions, and this can lead to a sense of being 'different' to their peers (Ernst et al., 2010; Towns & Bell, 2011 p.66). Thus, children and adolescents with CF can have difficulty adjusting socially in comparison to healthy peers (Kostakou et al., 2014), with regular hospitalisation and absences of school placing them at risk of social isolation or feeling alienated (Kostakou et al., 2014; Macdonald & Greggans, 2010). Adolescents can therefore become increasingly vulnerable to interruptions in peer relationships and in their ability to establish supportive peer networks as CF progresses (D'Auria, Christian, Henderson & Haynes, 2000).

Being in the company of peers with CF, particularly during hospitalisation allows them to begin to integrate their CF-related life experiences with their respective personal identities (D'Auria et al., 2000). D'Auria et al., (2000) found that adolescents viewed meeting peers with CF at special camps or during hospitalisations as a significant event in their life history. Peer support with others who share similar experiences has been found to be important to individuals with chronic illnesses (Thorne, 1993). The context of peer relationships can therefore influence how children with CF come to perceive their chronic illness experience (Christian & D'Auria, 2006).

However, individuals with CF may have different friendship experiences compared to those with other chronic illnesses. For example, there are three main bacteria that can cause infections in people with CF these include; *Staphylococcus Aureus*, *Pseudomonas Aeruginosa* and *Burkholderia Cepacia (*The Cystic Fibrosis Trust, 2004). Lung disease is often a key

predictor of survival for CF patients; however medical research has highlighted a link between chronic infections and progression of lung disease (Koch, 2002). Therefore, minimizing the number of infections is a priority in order to maximise life expectancy for CF patients.

Unfortunately, cross infection, (the transfer of bacteria from one person to another) can occur amongst individuals diagnosed with CF, resulting in the spread of infection (Cystic Fibrosis, 2004). Following such serious health implications associated with cross infections, guidelines have been introduced to minimise this risk. One fundamental recommendation from the Cystic Fibrosis Trust guidelines (2004) is segregation, namely keeping CF patients apart both inside and outside of the hospital. The guidelines contrast with clinical practice for other chronic illnesses such as diabetes or cancer, where summer camps or peer support groups can offer unique opportunities for social support from peer who are experiencing similar health difficulties (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012).

In light of the literature, it seemed pertinent to provide a systematic review exploring peer support for young people with CF. Both quantitative and qualitative studies will be considered to capture the breadth of research undertaken in this area. Therefore the current review aims to answer the following question:

What are the peer support experiences of young people with CF?

This systematic review of current research in this area aims to generate clinical and empirical implications for the care of young people diagnosed with CF.

2.0 Method

2.1 Search Strategy

Systematic Reviews need to target the most relevant research, whilst simultaneously avoiding being too specific as this reduces the risk of potentially excluding pertinent articles (Wilczynski, Haynes, & Hedges, 2007). A systematic search of three electronic databases

containing abstracts of literature (Psycinfo, Web of Science and CINAHL) was conducted in February and March 2016. Three areas were identified as being key to the research question: 'cystic fibrosis', 'adolescents' and 'peer support'. These terms were expanded into a list of synonymous search terms and were inputted as search strings in the three databases:

1. "Cystic Fibrosis"
2. "Peer support" OR "friend*" OR "social"
3. "Adoles*" or "teen*" OR "young"
4. 1 AND 2 AND 3

2.2 Eligibility Criteria

Using the SPICE system (Booth, 2004) for defining inclusion criteria for systematic reviews (setting, perspective, intervention/interest, comparison/control and evaluation), the studies had to fulfil the following inclusion criteria:

1. Published in a peer-reviewed journal.
2. Participants must be aged between 8-21 years old to ensure studies captured the breadth of the biopsychosocial transition from dependent child to an autonomous/independent adult (Segal, 2008).
3. The sample must, at least in part, comprise adolescents with a diagnosis of cystic fibrosis (CF).
4. In line with a strict cohort based segregation policy to control for cross infection implemented in 2003 for all CF patients in the UK (Ashish, Shaw, Winstanley, Humphreys & Walshaw, 2013), only studies published between 2004-2016 could be included.
5. Be an English publication.

6. Quantitative outcome data was clearly reported relating to peer support for an adolescent with CF.
7. A qualitative exploration of adolescents' experiences of any peer support related intervention.
8. Any qualitative methodology was accepted.

2.3 Data Extraction and Quality Assessment

Data extraction forms were devised to facilitate systematic summation of key findings and quality assessment (Appendix A). The Qualitative Critical Appraisal Skills Programme (CASP, 2013) checklist and the Quality Assessment Tool for Quantitative Studies (Cochrane Public Health) were used to assess quality of qualitative and quantitative studies respectively. Original quality assessments are available from the authors on request.

2.4 Selection process

A total of 473 records were identified and transferred from the abstract databases to RefWorks (a bibliography and database manager). Each article was screened, in line with PRISMA guidelines (Preferred Reporting Items for Systematic Reviews (Moher, Liberati, Tetlzaff & Altman, 2009); this process is illustrated in Figure 1. Screening involved examining titles, key words and abstracts to ensure that each article met the inclusion criteria and answered the research question. 395 papers were excluded because the articles were duplicates, did not relate to CF, were conference posters or abstracts, and that they did not meet the inclusion criteria. The remaining 78 articles were then scrutinised for relevance, and 72 were excluded for the following reasons: (a) no access to full text (n=1), (b) duplicate study (n = 6), and (c) did not meet inclusion criteria (n = 65). Therefore 6 studies met the inclusion criteria, and electronic citation searches and examination of their reference lists was then undertaken to identify further

relevant studies. These secondary searches generated a further 5 papers, which were accessed and the full papers were screened for relevance. Of these five studies, two were excluded as they did not meeting the inclusion criteria. Consensus regarding the suitability of studies was reached through discussion with the research team. In conclusion, nine papers, describing an aspect of peer support for young people with cystic fibrosis, met criteria and were included in the review.

[INSERT FIGURE 1]

2.5 Process of Analysis

Thematic analysis (Braun & Clarke, 2006), a common method for synthesis, was adopted. Although thematic analysis is typically associated with qualitative data, it can also be applied to quantitative data by extracting themes and findings from quantitative evidence for an interpretive synthesis (Pope, Mays & Popay, 2007). This approach enabled us to stay 'close' to the results of the primary studies; ensuring synthesising was transparent and facilitated the production of new concepts for further research.

3.0 Results

Due to the variety of methods, measures and outcomes employed, it was considered appropriate to present the results in a narrative form rather than as a meta-analysis. Thus, a narrative account of nine studies that examined peer support for young people with cystic fibrosis was undertaken. The findings are organised according to the following categories, design and methods, sample characteristics, outcome measures, and findings per outcome variable. Extracted data is presented in chronological order in Table 1.

3.1 Design and methods

There were five qualitative studies, and each used different methods of data collection. Focus group interviews were used by Berge, Patterson, Goetz & Milla, (2007); semi-structured interviews by Barker, Driscoll, Modi & Quittner (2011), and semi-structured questionnaire for parents and young people were used by Russo, Donnelly & Reid (2006). The study by Ravert and Crowell, (2008) examined disclosures of CF on the World Wide Web made by adolescents (13-18 years), emerging adults (19-25 years) and adults (25 years and older). This study employed a mixed method analysis, and quantitative methods were used to examine age related differences in the distribution of online disclosure statements (NB only the adolescent data is synthesised in this current review). The study by Kirk and Milnes, (2015) explored online peer support using ethnography, an emerging approach adapted from ethnographic methods to explore social interactions in online communities (Kozinets, 2010).

Four studies were quantitative, one of which included a mixed sample of participants with CF, type 1 diabetes and chronic asthma (Herzer, Umfress, Aljadeff, Ghai & Zakowski, 2009); however there were no statistically significant relations/differences between medical variables therefore this study was included in the review. Two studies included both parent and patient responses (Griffiths, Armstrong, Carzino & Robinson, 2004; Helms et al, 2015) and one included children with CF being randomly assigned to a basic life skills intervention and usual care groups at baseline and at 3, 6, and 9 months (Christian & D'Auria, 2006).

3.2 Sample characteristics

Six studies were conducted in the USA, two were conducted in the UK and one in Australia. The sample size of the studies (including all young people and/or caregivers who participated) ranged from 22-293. The age range of the children and adolescents who participated ranged from 10-21 years. Three studies reported the ethnicities of their participants. Of these, three

studies included white or Caucasian participants (81.8-92.9% of samples), two studies included Hispanic participants (1.7-9.1% of samples), two studies included mixed race/other (4.8-9.1% of samples), two studies included African Americans (2.4-2.6% of the samples), one study included Native American participants (6.9% of the sample), and one study included an Asian participant (0.9% of the sample). Six studies did not describe the ethnicity of their participants (Griffiths et al 2004; Russo et al, 2006; Berge et al, 2007; Ravert & Crowell, 2008; Barker et al, 2011; Kirk & Milnes, 2015;). Potential participants were recruited from outpatient clinics, university based CF centres, World Wide Web and a CF charity website.

3.3 Outcome measures

Three quantitative studies used numerous outcome measures. Overall, one study examined whether high levels of perceived support from parents could buffer the adverse effects of negative social interactions with peers and vice versa (Herzer, et al., 2009); one examined the effectiveness of an intervention to improve psychosocial adjustment functioning health in children with CF (Christian & D'Auria, 2006); and one examined friendships among adolescents with CF and explored associations between friendship quality, treatment adherence and health-related quality of life (Helms et al., 2015).

Helms et al., (2015) used three measures including The Network of Relationships Inventory (Furman & Buhrmester, 1985) to assess friendship quality, with excellent internal consistency being reported for both positive and negative composite scores across CF and non-CF friendships (α= .95 to .99). The Treatment Adherence Questionnaire- CF (TAQ-CF; Quittner, Espelage, Ievers-Landis, & Drotar, 2000) was also used with adequate 1-year test-retest reliability and teen parent concordance. The Health Related Quality of Life was assessed using the Cystic Fibrosis Questionnaire Revised (CFQ-R; Quittner, Buu, Watrous & Davis,

2000), a widely used measure with CF populations and excellent reliability reported in the current sample (α= =.95).

Christian and D'Auria (2006) used four instruments to measure psychosocial adjustment. These included The Perceived Illness Experience Scale (Eiser, Havermans, Craft & Kernahan, 1995), The Children's Loneliness Scale (Asher, Hymel & Renshaw, 1984), the Social Support Scale for Children (Harter, 1986) and The Self-Perception Profile for Children (Harter, 1985). Authors reported the reliability of these measure, which ranged from good to excellent (α= =.69-.96). The Functional Disability Inventory was also used to assess impact of illness on physical and psychosocial functioning (Walker & Greene, 1991) with good reliability (α= =.77-.84).

Herzer et al (2009) used six outcome measures including, The Social Support Scale for Children (Harter, 1986) with good reliability for parents and close friends (α=.87 and α= .85 respectively). The Living with a Chronic Illness (Adams, Streisand, Zawacki & Joseph, 2002) was used to assess general social functioning, the Child Report of Parent Behavior Inventory (Schludermann & Schludermann, 1988) was used to assess children's perceptions of parent behaviours and the Pediatric Quality of Life Inventory (Varni, Seld, & Rode, 1999) was used to assess health-related quality of life, self-concept was assessed using the Piers-Harris Children's Self Concept Scale Second Edition (Piers & Herzberg, 2002) and Youth Self Report assessed overall emotional and behavioural functioning (Achenbach & Edelbrock, 2001). Authors reported on the reliability of these measures, which ranged from good to excellent (α= =.79-.96).

3.4 CF peers and non-CF peers

Barker et al., (2011) reported that the size of family networks ranged from 4 to 10, and friendship networks for adolescents (aged 11-18 years) ranged in size from 1 to 13. Adolescents

(aged 12-18 years) in the Helms et al., (2015) study reported having significantly more friendships with non-CF peers than with CF-peers, (t (41) = 10.57, p < .001, d = 2.00, 95% CI [5.37, 7.91]). Eighteen participants endorsed having friends with CF, 7 of these reported they spent face-to-face time with their best friend with CF, whereas 5 reported spending at least some time (range 1-60hr per week). When total time (inclusive of all face-to-face and electronic time) spent with friends was summed into a composite, young people reported time with non-CF best friends per week significantly greater than their report of total time spent with CF best friends (t (13) = 3.01, p = .01, d =0.81, 95% CI [5.33, 32.49]). No significant differences were found in negative friendship quality across best friendships with CF and non-CF peers. In contrast, adolescents reported significantly higher levels of positive friendship quality with their non-CF peers than a CF peer, (t (14) = 3.45, p = .004, d=0.89, 95% CI [0.53, 2.28]). A further study suggested that an online community had in some cases led to offline relationships through face-to-face meeting or interaction via social networking sites, email and text messaging (Kirk et al., 2015).

3.5 Segregation: "A necessary evil" (Russo et al., 2006, p.95)

The perceived impact of implementing the segregation policy was explored in two studies (Griffiths et al., 2004; Russo et al., 2006). Griffiths et al., (2004) found that parents' overall response to segregation measures was positive (85%). However, parents who were negative about segregation also had concerns about the emotional impact of segregation. Concerns included the emotional impact of their children not socialising with other CF children, inconclusive evidence about person-person spread of infection, and feelings of alienation created in clinics due to the separation. The majority of children who responded to the questionnaire were positive about segregation (62%); however, many did not give explanations for their answers but those who did commented on missing their CF friends.

Similarly, Russo et al., (2006) found that most parents (91%) and children (92%) agreed with the segregation policy. It is important to note that this study was carried out prior to the policy being introduced at this particular paediatric CF centre. Participants were therefore asked to imagine what segregation would be like, before actually experiencing it. In comparison with Griffiths et al., (2004), findings suggest that acceptance of segregation may decrease after implementation. Although participants were supportive of the policy, they did also acknowledge that segregation would inevitably bring social and emotional costs.

Parents perceived the impact of segregation, and negative connotations were identified. Parents in the Russo et al. (2006) study described segregation as "a necessary evil" and listed negative factors such as boredom, loneliness, increased worry and frustration during hospital admission and felt that segregation would likely impact older children more due to the greater need for peer contact. Parents also perceived that other children with CF played a positive role in helping their child adjust and adapt to the challenges of CF: "It is sad that [segregation] has to happen because it removes the opportunity for children to offload worries about their condition to others who are similarly affected". Few parents reported that any positive benefits that might ensure from social contact with CF were not worth the risk of cross infection "His health is more important than socializing at this time of life" (Russo et al., 2006).

Russo et al., (2006) further found that children were aware of the positive impact of segregation on their health: "it will stop any other infections within the hospital form harming me" and "the hospital must think this is needed so I would agree". However, children also took into account the perceived negative aspects of segregation: "I understand why we are all being segregated but I think it is unfair as some of us have built up very good friendships with other patients". Children also felt that segregation would result in boredom during hospital admissions, however some felt that segregation would not impact upon their feelings at all: "I've never really interacted with other patients so in a way segregation is not new to me".

Segregation was also perceived to be unfair, as friendships had been formed, particularly as inpatients. One adolescent described the feeling of independence that they had experienced during previous admissions and how this would be missed after segregation was implemented: "you can't replace the freedom you enjoy in [the adolescent unit] as it doesn't feel like hospital".

Parents and young people suggested way to compensate for the introduction of segregation on the ward (Russo et al., 2006). Suggestions included resources for individual rooms to decrease boredom; use of mobile phones, email and intercoms as alternatives to communicate with family at home and to maintain contact with friends both in and out of hospital. Parents also suggested that segregation would involve staff needing to spend more one-to-one time with children during admissions. Play therapy was suggested for younger children and additional psychosocial support was also perceived as helpful. Parents felt as though increased contact with staff would be needed to prevent feelings of isolation. Interactive resources were also suggested by children who felt as though web cams and linked game boxes might help communication between peers who were admitted onto the ward at the same time.

Kirk et al., (2015) found that an online discussion group enabled both parents and young people an opportunity to discuss their feelings of isolation, sadness, difference and frustration. Such opportunity to express their feelings was 'cathartic' given that they were able to share with an audience who could understand and relate to their experience. Normalisation of feelings was apparent, as participants felt as though were not alone.

3.6 Disclosure

Three studies discussed disclosure of CF (Ravert & Crowell, 2008; Barker et al., 2011; Kirk & Milnes, 2015). Ravert et al., (2008) analysed web-based disclosures of CF and found that the most common disclosure statement type involved the discussion of medical complications ("I

have CF and must go to the hospital often"). The second most common was in the context of expressing psychosocial concern associated with CF, these statements included "I have CF and miss out on activities my friend can do". Psychosocial concern disclosure statements were more frequent among adolescents (13-18 years) than other age groups (χ^2 (1, n=186) = 6.32, p = 0.012), which accounted for 36.7% of disclosures. The third type of disclosure was conceptualised as 'supportive connection' when an individual disclosed his/her illness to connect with or offer support to others with CF or other life-threatening illnesses, "I have CF too, and know what you mean". Adolescents (13-18 years) were more likely to disclose their illness at supportive web pages compared with other age groups (χ^2 (1, n=186) = 5.83, p = 0.016).

Barker et al., (2011) found that 78% of friendship networks had some knowledge of the adolescent's diagnosis. The majority of adolescents (58%) informed everyone they listed in their network about their CF and 25% of participants shared their diagnosis, with some, but not all, of their friends. However, 17% reported that only a few of their friends knew about their CF and stated that either a parent or family member had informed their friends of their diagnosis without their permission, and that they would have preferred that this disclosure had not occurred. This study also found a commonality between unwanted behaviours from both family and friends was related to privacy and how adolescents did not like being asked unwanted questions about their illness or their health information being shared without their permission. Barker et al., (2011) therefore suggested that adolescents' concerns about disclosure of their diagnosis to friends might be a key barrier to accessing support from their peer networks.

Kirk et al., (2015) found that adolescent online disclosures on an online discussion group (via a CF charity website) demonstrated a number of psychosocial challenges, including the need for support from peers and concerns in how to disclose CF to peers. Kirk et al., (2015)

suggested that adolescents might benefit from supportive interventions that aimed to develop and share coping strategies between peers for psychosocial issues related to CF.

A longitudinal study looked at the effectiveness of the Building Life Skills (BLS) Intervention, which was delivered in two sequenced phases a) an individual home visit and b) a structured, small group intervention session (Christian and D'Auria, 2006). To prevent the risk of cross-infection, four children with a particular strand of bacteria or drug resistant infection participated in the group in a separate room connected by real time video camera link. Children who attended the BLS intervention demonstrated significant decreases in perceived impact of illness ($p < .0001$) and this intervention effect was sustained over 9 months ($p = .24$). Significant differences between children in the intervention and control groups were found for loneliness ($p < .0001$), again sustained over 9 months ($p = .019$). Significant differences were found over time for social support from peers ($p = .009$).

3.7 A Need for, and Purpose of, Peer Support

Berge et al., (2007) used focus groups to explore the transition into adulthood for young adults with CF, and focused on how these young adults managed the shift in treatment responsibility. A gender difference was found in the experience of peer acceptance. Females reported feeling different from their peers due to treatment compliance: "I wouldn't go to sleepovers... like birthday parties, because I'd have to take my machine" whereas males reported acceptance: "If they are going to be your friends, they will accept you". Another unique gender difference was females' desire for a CF support group. Females reported that attending national CF conferences and meeting people like themselves and hearing ways to manage their CF was helpful. Although several females had previously participated in formal mental health services, they requested a support group with other young adult females with CF in addition to the services they had previously received.

Helms et al., (2015) also found a mixed picture in terms of potential benefits of friendships for treatment adherence goals. Lower levels of negative friendship qualities were associated with higher levels of treatment adherence. Results also suggested that higher levels of positive friendship qualities might be associated with lower levels of treatment adherence. Positive friendship qualities were suggested to be associated with spending greater time with peers and therefore less time completing treatments, however further research is needed to explore these relations.

3.8 Parental and Peer Relationships

Herzer et al., (2009) found that parental overprotection was associated with lower child health related quality of life, lower child self-concept and greater child emotional/behavioural difficulties for children with low levels of friend support. Parental overprotection had little or no effect when children perceived having high levels of friend support. In addition, support from parents did not compensate for the negative effects of feeling left out by friends. Moreover, Barker et al, (2011) found that both family and friends influenced CF management during adolescence. Similarities and differences were found in the treatment related support they received from family and friends. Although both provided treatment reminders and monitoring, family tended to provide tangible support of treatment (e.g. preparing medication) whereas friends tended to provide relational support (e.g. accompanied young people when doing physical activities, helped managed their social network). Adolescents were however reluctant to call family and friends unsupportive when they engaged in some treatment related behaviours such as nagging, because they recognised the need for treatment reminders and recognised that their 'nagging' came from good intentions. Yet, parents reportedly allowed adolescents to occasionally 'slack off' their treatments and such lack of monitoring was considered unsupportive. One adolescent reported that her friends' reminders as supportive

because they were encouraging and not demanding. Tone, manner and timing of the treatment reminder also influenced adolescents' perception on the supportiveness of the behaviour.

4.0 Discussion

The aim of this systematic review was to explore peer relations for young people with CF. Nine studies were identified which were published between 2004-2016. Of these, the majority of studies examined young people with CF, with only one study including young people with other chronic illnesses (however no significant differences were found between all conditions) and four studies included both young people and parents. Despite the paucity of literature, the evidence highlights how social support plays an important role in the lives of young people with CF. Findings are discussed alongside methodological limitations that may have contributed to the pattern of results identified.

Overall, the evidence highlights the need to consider young peoples' wider social context, whilst acknowledging the need for further research. Peer support may not be accessible to all young people with CF given the variation of CF peers and non-CF peer listed in friendship networks. This may be associated with differences in how adolescents inform their friends of their diagnosis. CF has been considered to be an invisible illness (Kundrat & Nussbaum, 2003) since individuals have some degree of control over when and to whom they decide to disclosure their illness. Little is known however about why adolescents with CF choose not to disclosure their diagnosis with friends.

The majority of parents and young people expressed support for the implementation of the segregation policy; however, they also acknowledged the negative impact. Despite the clinical recommendation of avoiding others with CF (Saiman & Siegel, 2003), it was apparent that young people engaged in face-to-face contact with other CF patients in addition to using electronic interactions (Helms et al., 2015; Kirk et al., 2015). Further research has found that

70% of young people would like to have contact with someone with CF (Masterson et al., 2008). However, overall young people in the Helms' et al, (2015) study reported fewer friendships and less frequent interactions with friends with CF than with non-CF peers (Helms et al., 2015). Nevertheless, there appears to be a concern around the potential impact of segregation, namely limiting opportunity for support that would otherwise be there.

Findings also highlighted significant decreases, sustained over time, for perceived impact of illness on quality of life and loneliness following a focus group life skills intervention (Christian & D'Auria, 2006). Loneliness in children is often influenced by peer acceptance (Asher & Paquette, 2003) and CF can elicit feelings of being different from peers at a crucial time of development (Sroufe et al., 1996). This emphasises the importance of peer support, particularly for young people with CF, due to the recommended isolation from other CF patients. It is important to note that participants infected with a particular strand of bacteria (*b.cepacia*) were isolated however still remained a part of the CF group via video camera link (Christian & D'Auria, 2006).

In a further study, supportive friends were also found to be a protective factor for children and adolescents, with strained parental relationships having little or no effect on their health-related quality of life, self-concept or emotional/behaviour difficulties (Herzer et al., 2009). Although parental relationships remained integral in young people's wellbeing, parents did not compensate for the negative effects of feeling left out by friends. Collectively, findings emphasise the need to continue addressing social needs of youth with CF, particularly finding ways to reduce the risk of cross-infection if youth choose to pursue friendships with CF peers.

4.1 Theoretical and Clinical Implications

Although causality could not be inferred from this review, the findings can be viewed using developmental theory as a framework, indicating how human development occurs within a

psychosocial context where individuals encounter crisis stages on eight distinct dimensions across the lifespan (Erikson, 1982). Developmental theory can facilitate understanding on the psychosocial development of adolescents with chronic illness, particularly with regard to autonomy, social maturation and identity development, with particular emphasis on peer relationships. Findings have implications for how health professionals might use developmental psychosocial theories to recognise existing needs and opportunities for interventions for children and young people. Adolescents with CF may therefore benefit when treatment management is broadened to include their social context.

Helping families verbalise their mixed feelings and beliefs around segregation may help to alleviate its negative psychosocial consequences. It is crucial that segregated peer support programmes that enhance emotional wellbeing by increasing connections between chronically ill young people with CF, continue to be encouraged (Olsson, Sawyer & Boyce, 2000). Traditionally, medical treatments have focused on physical function and health; however there is growing acceptance to foster psychosocial function in order to enhance long-term outcomes (Aldiss, Baggott, Gibson, Mobbs & Taylor, 2015).

It is essential that innovative solutions are developed to meet the psychosocial needs of young people with CF without jeopardising their physical health. Technology and social media continue to advance and have become key sources of communication and information sharing for people (Baruah, 2012). However, concerns around patient confidentiality have contributed to the low uptake of integrating social media in clinical medicine (George, Rovniak & Kraschnewski, 2013). Nevertheless, social media is often being held as a useful platform for promoting patient engagement, facilitating access to information and disseminating and discussing research (Campbell, Lambright & Wells, 2014; Hopkinson, Hart, Jenkins & Smyth, 2015). Infection control restrictions placed on young people with CF could mean that online communication is particularly well suited to this clinical population, as illustrated by two

studies reviewed in this study. Young people are ‘digital natives’ and are also experiencing a developmental period shaped by a need for autonomy and peer identity (Aldiss et al., 2015, p. 99). Health professionals are therefore recommended to attempt to provide more innovative ways of supporting CF patients, particularly during hospital admissions.

A recent review of children’s experiences of CF also suggested that social media and facilitate online support networks for paediatric patients with CF may be particularly useful, but would need to be closely monitored to ensure accurate exchange of information (Jamieson et al., 2014). Creating supportive technology in isolation increases the likelihood of young people not using it or lack of sustained use over time (Drotar et al., 2006). Thus, user involvement is an integral part of service development, policy and research in the UK (Staniszewska & Ahmed, 2000) and children and young people should be encouraged to engage in research and consultation (Beddoes, Hedges, Sloman, Smith & Smith, 2010) with the aim of ensuring the technological support is acceptable and works in practice (Aldiss et al., 2011).

4.2 Limitations

In summary, some studies offered a snapshot of relationships between variables, therefore potential reciprocal associations and bi-directional relationships between young people and peers could not be examined. Similarly, exploring changes over time and examining whether electronic contact served as a precursor to face-to-face contact could not be explored. It is possible that perceptions of peer support and the effect that the presence or absence of peer relationships has on other variables such as adherence may evolve or interact with different variables in different ways over time. Two of the studies involved the World Wide Web therefore authors acknowledged the difficulty in ascertaining authenticity of online information, and lack of demographic information available as limitations. Overall, the

review is also limited to some extent due to the paucity of literature on peer support for young people with CF.

4.3 Research Implications

Detailed future research employing thoughtful and robust study designs is needed to extend the emerging evidence base and further explore the promising findings reported in the current review. Future research needs to explore the complex dynamic between the treatment demands of CF and the development within the social context of family and peers. Internet based support and educational groups may provide a viable alternative for CF patients (Johnson et al., 2010), however further research is required. Moreover, there is a need to establish whether online illness disclosure generalises to disclosures in other contexts of young people's lives, and whether disclosures enhance understanding to improve treatment adherence in adolescents.

Exploring clinical interventions that target children's peer groups and focus on friendship building, social skills and problem solving in peer situations may be beneficial. Although some studies included in this review had multiple informants (young people and parent), future work could expand on this and include friends' reports of friendship qualities or other outcome measures. In light of parental overprotectiveness, clinical interventions should address the behaviours and work with the entire family system rather than just the ill child. Qualitative studies exploring adults' experiences of segregation and peer support whilst growing up with CF may also be a worthy avenue for future research. Additionally, future research is needed to expand on how peer relationships influence health, psychological and behavioural functioning over time.

5.0. Conclusion

Peer support appears to play an important role in the lives of youth with CF, confirming the importance of considering patients within a wider social context; however existing research does not provide sufficient evidence to clearly define this role. A variety of fruitful avenues for future research and valuable clinical implications were outlined; including incorporating a developmental perspective to recognise existing needs for young people with CF and more longitudinal studies to expand on changes and influence over time. Exploring the impact of segregation and creating innovative solutions, such as interactive and electronic resources to address the social needs of youth with CF, without jeopardising their physical health is also encouraged.

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Table 1:

Summary of studies included in the review

Author	Country	Research Question/ Focus	Study Design	Sample	Data Collection	Measures	Summary of Findings	Limitations
Barker, Driscoll, Modi, Light & Quittner (2011)	USA	Interview to explore support adolescents receive from family and friends	Qualitative: Thematic Analysis	24 Adolescents Mean age 15	Semi structured interviews divided into four sections addressing both supportive and non-supportive behaviours from family and friends and frequency of specific supportive behaviours. Frequencies coded to indicate number of times a behaviour occurred per week.	N/A	Both family and friends provided treatment related support to adolescents with CF. Family provided more tangible support and friends provided more relational support. Subset of adolescents (17%) chose not to disclose their diagnosis with their friends.	Small sample size; only adolescent perspective; did not focus on specifics around each component of treatment. Some behaviours may therefore be more helpful for certain aspects of CF treatment regime. Did not include measure of disease management limiting ability to examine how social support is related to health outcomes.
Berge, Patterson, Goetz & Milla (2007)	USA	Exploring transition into adulthood for females and male young adults with CF. How they manage	Qualitative: Grounded hermeneutic approach	11 females 6 males aged between 16-21 years.	Focus group with other young adults with CF to talk about their experience living with CF. Total of 4 focus groups conducted, two	N/A	Gender differences in treatment; males did fewer treatments than females. Females reported mental health problems (depression, body image problems); Females identified that treatment compliance had made them feel 'different' from	Small sample size thus generalisability is limited to the characteristics of the sample.

		treatment responsibility, view their quality of life and how they perceived their future.			for each gender. Genders separated intentionally in order to learn more about gender differences. Group interview questions were open ended designed to elicit the personal thoughts, feelings and perceptions of young adults.		peers and family members. Males felt more accepted by their peers. Females requested support group with other young adult females in addition to mental health services they had already been involved in.	
Christian & D'Auria (2006)	USA	To test effectiveness of an intervention to improve psychosocial adjustment in children.	Quantitative Two group experimental repeated measure design Longitudinal	116 children aged 8-12 years	116 children randomly assigned to intervention and usual care groups at baseline and at 3,6, 9 months post intervention. The Building CF Life Skills (BLS) was an educational, problem solving and social skills intervention designed to help children with CF deal with specific problems including finding out about their diagnosis, explaining their	1. The Perceived Illness Experience Scale 2. The Children's Loneliness Scale 3. The Social Support Scale for Children 4. The Self Perception Profile for Children	Significant decreases in perceived impact of illness on quality of life, and this intervention was sustained over 9 months. Significant decreases in loneliness sustained over times after BLS intervention. Provided opportunities for children with CF to improve social skills and peer relationship and create a CF peer group.	Mild CF severity intervention therefore intervention could have been more sensitive to children with more severe disease and greater functional disability Dosage of intervention could be improved by increasing number of intervention sessions and by including a booster session. 9-month interval may have been insufficient to capture developmental change and changes in the chronic illness trajectory.

					CF related difficulties, peer relation difficulties. BLS intervention was delivered in two sequenced phases by a) individual home visit and b) structured small group intervention session. Four children with drug resistant infections or particular bacteria participated in the group from a separate room connected via video camera link to prevent cross infection.			
Griffiths, Armstrong, Carzino & Robinson (2004)	Australia	Assess CF parent and patient responses to segregation measures to determine overall support	Quantitative: Questionnaire	291 families 65% response rate (n=190). 40% completed questionnaire with a child.	A questionnaire devised of eight questions: 2 questions allowed written comments Contained item on the overall response of parents and patients ≥ 12 years.	N/A	Overall parental response to segregation measures was positive (85%), negative in 4% and unsure in 11%. Overall children with CF ≥ 12 years were positive (63%), 12% negative and 25% unsure. Many did not elaborate on their answers. Unsure might felt ambivalence, poor understanding of the issues and lack of opinion. Negative group were largely adolescents who had been separated from other CF peers, particularly during inpatient stays.	Not a validated questionnaire.

Helms, Dello & Prinstein (2015)	USA	Describe friendships among adolescents with CF and to explore associations between friendship quality, treatment adherence and health related quality of life.	Quantitative Questionnaire Cross sectional	42 adolescents with CF aged 12-18 years.	Participants were asked to list all of their friends without CF and all of their friends with CF, including duration of each friendship. Encouraged to list friendships with similar-aged peers (i.e. not siblings, adult family friends etc). Asked to select their closest friend from each list and children who provided a best friend with and without CF, were asked to select their overall best friend between those two individuals.	1. The Network of Relationships Inventory 2. Treatment Adherence Questionnaire (TAQ-CF) 3. Cystic Fibrosis Questionnaire Revised (CFQ-R)	All endorsed the non-CF friend as being their overall best friend. Fewer friendships and less frequent interactions with friends with CF than with non-CF peers. 25% engaged in weekly face-to-face contact with CF peers despite recommendation not to. Frequent electronic interactions also reported. With non-CF peers, significantly higher levels of friendship qualities relative to their best friendships with CF peers. Positive and negative friendship qualities associated with parent reported treatment adherence and positive friendship associated with parent reported health related quality of life. Lower levels of negative friendship qualities are associated with higher levels of treatment adherence. Higher levels of positive friendship qualities may be associated with lower levels of treatment adherence despite being associated with higher levels of health related quality of life.	Cross-sectional precludes ability to determine whether electronic contact served as a precursor for face-to-face interaction. Relatively small sample size and drawn from a single CF centre.
Herzer, Umfress, Aljadeff, Ghai & Zakowski (2009)	USA	Examined cross-domain buffering effects; assessed whether high levels of perceived	Quantitative: Questionnaire Cross-sectional	Children aged between 11-18 years of age (n=127) with 3 types of chronic illness (diabetes, asthma and CF),	One assessment, packet of questionnaires that each child completed independently	1. Social Support for Children 2. Living with Chronic Illness 3. Child Report of Parent Inventory	No significant difference between medical variables. Parental overprotectiveness was associated with lower child health quality of life, lower child self-concept and greater child emotional/behavioural	Cross sectional prevented examination of change over time in addition to establishing bidirectional relationships between variables.

		support from parents can buffer the adverse effects of negative social interactions with peers and vice versa.		17 of which had CF. Caregivers also completed face-valid questionnaires on demographics as well as the child's medical history.	during a clinic visit.	4. Pediatric Quality of Life Inventory 5. Piers-Harris Children's Self Concept Scale 6. Youth Self-Report	difficulties among children with low levels of friend support. High-perceived support from friends, parental overprotectiveness had little or not effect on children's health related quality of life, self-concept or emotional/behavioural difficulties. Having supportive friends is a protective factor. Parents did not compensate for the negative effect of feeling left out by friends.	
Kirk & Milnes (2015)	UK	To explore how online peer support is used by young people and parents to support self-care in relation to CF.	Qualitative: Online Ethnographic Grounded theory.	182 participants on the parent's discussion group and 97 participants in the young people's discussion group.	Virtual observations of all postings made to a young people and parent discussion group/online forum based on a CF charity website over a random 4 month period. Discussion threads were downloaded and data was coded using grounded theory approach to identify themes.	N/A	Parental postings related to CF management. Young people's posts also related to treatment but also on how to live with CF diagnosis. Both discussion groups provided an opportunity to discuss feelings and relationships. For young people, this related mainly to peers. Strong relationships developed and led to some offline relationships through face-to-face meetings and interaction via social networking sites.	Unavailability of demographic information (i.e. age) due to methodology. Results relate to one particular online community support.
Ravert & Crowell (2008)	USA	Examine instances of CF diagnosis disclosure on	Qualitative: Content analysis	Total sample n=277 comprising of children (<13), adolescents aged	Sampling approach involved a web search conducted using terms 'I have CF'	N/A	Adolescents 13-18 years old were more likely than other age groups to be found disclosing their illness at supportive web pages compared with other age	Web pages were limited to those including the specific terms used in the search. Authors

		the World Wide web.		13-18 years old (n=37), emerging adults (19-25 years) and adult ≥ 25)	and 'I have cystic fibrosis' using the Google search engine.		groups. 43% of adolescents' disclosures took place in web pages designed for sharing support and made up the largest proportion (36%) of disclosures at those web pages. Disclosure that took place in the context of expressing psychosocial concern (e.g. telling friends about CF) more frequent among adolescents.	acknowledged that authenticity on the Internet is not guaranteed.
Russo et al., (2006)	UK	To elicit patient and carers' views and to involve them in the process of introducing segregation in a paediatric CF centre.	Quantitative: Questionnaire	192 parents and 101 patients (10-17 years) sent questionnaire. 43% of parents and 23% of children returned questionnaires	Semi structured questionnaire (a child friendly) and parent/carer version devised to elicit views, opinions and suggestions.	N/A	92% of children and 91% of parents reported support for policy. Some negative aspect related to social impact and isolation. Health benefits seemingly outweighed negative impact. Suggestions to help with segregation included more contact with staff and interactive resources	Small sample size and cannot be taken to be representative of all young adults with CF. Questionnaire methods are prone to positive response bias and this may account for high levels of satisfaction. Key limitation was low response rate particularly from patients.

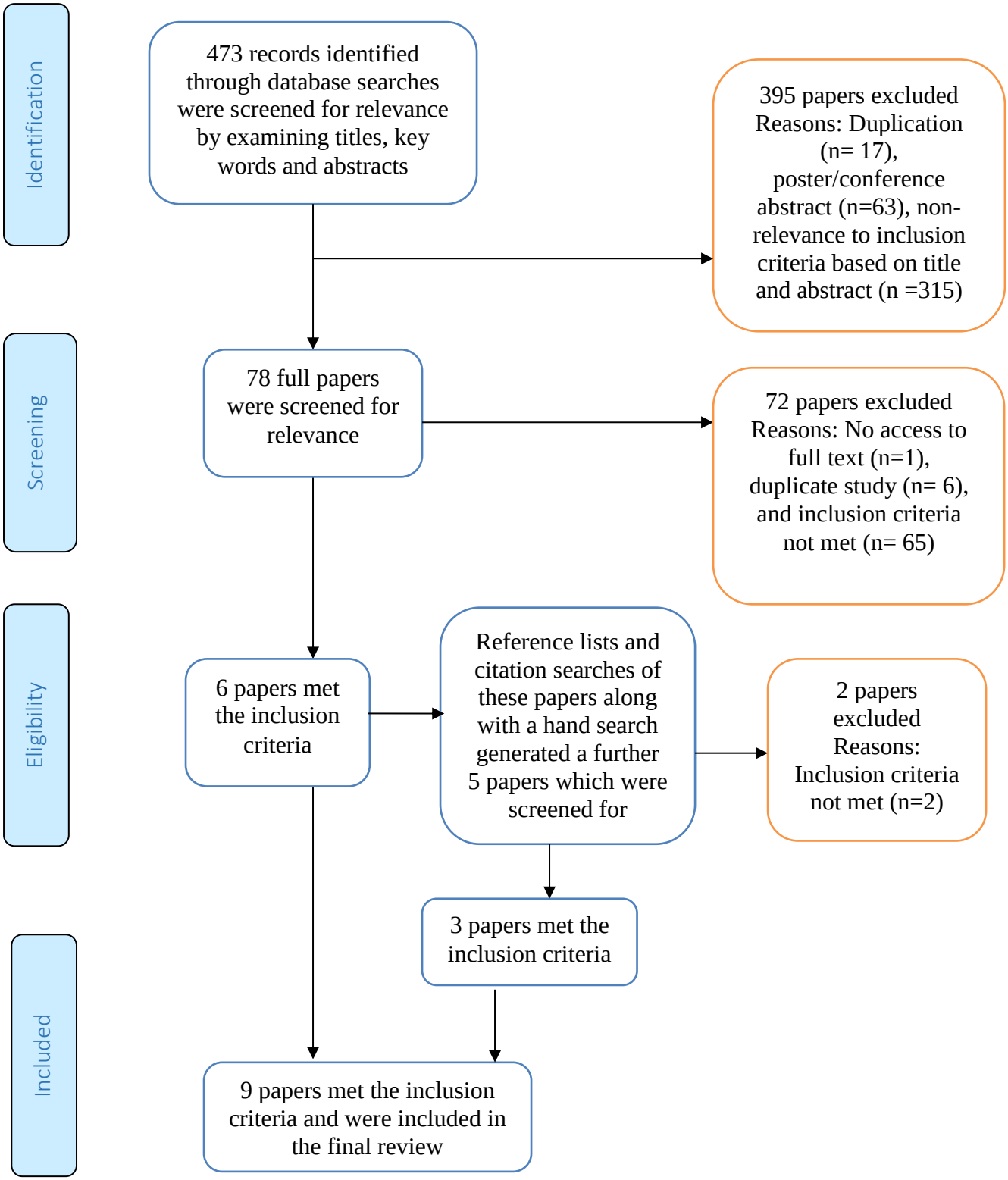

Figure 1: Flow diagram of study selection process in line with PRISMA

Section 2

Empirical Study

"Blurred Boundaries": Health Care Professionals' Experiences of Working with Children and Adolescents with Cystic Fibrosis and the Transition to Adult Services.

SHORT TITLE: Working within Cystic Fibrosis Care and Transitioning Adolescents to Adult Services

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Abstract

The aim of the study was to explore Health Care Professionals' (HCPs) experiences of working with and transitioning children and adolescents with Cystic Fibrosis (CF) from paediatric to adult services. Seven HCPs working in paediatric services participated in an Interpretative Phenomenological Analysis study where they engaged in individual semi-structured interviews. Three superordinate themes emerged from the data: trajectories of care and therapeutic investment; professional parent(ing); and, coping culture. The longevity of CF care and the emotional investment elicited an attachment dynamic. Coping strategies were described to counteract rupture in attachment prompted by transition and the interconnectedness of HCPs' professional and personal selves. Findings provide insight into a currently under-studied area, highlighting worthy areas of further research and suggesting valuable clinical implications.

Key words cystic fibrosis, healthcare professionals, adolescent, transition, qualitative

Introduction

Cystic Fibrosis (CF) is the most common inherited childhood disease, affecting approximately 1 in 2500 births (Nazareth & Walshaw, 2013). This multi-organ progressive and life-limiting disease is caused by a gene defect that affects the transport of salt and water across cells (Ernst, Johnson & Stark, 2013; Rogers, 2013), leading to abnormal thick and sticky secretions in the lungs and digestive system (Cystic Fibrosis Trust, 2013). Multisystem damage can include respiratory failure, pancreatic dysfunction and liver disease (Flume 2009; Kobelska-Dubiel, Klincewicz & Cichy, 2014). Additional complications include bone disease (Stalvey & Clines, 2013), CF related diabetes (CFRD, Brennan & Beynon, 2015), and renal disease (Nazareth & Walshaw, 2013).

Early and accurate diagnosis avoids delays in the onset of treatments for the effects of CF (Wallis, 2007). Initiatives such as newborn screening in the UK since 2007 (Public Health England, 2016), and advances in management and treatment, have contributed to the improved life expectancy of individuals diagnosed with CF (Dodge, Lewis, Stanton & Wilsher, 2007; Barr, Britton, Smyth & Fogarty, 2011; Nazareth & Walshaw, 2013). Indeed, when the condition was first identified in 1938, more than 70% of children died within the first year (Parkins, Parkins & Rendall & Elborn, 2011; Simmonds, 2013); however, over the past five decades, the predicted median survival for individuals with CF has increased to over 40 years, and the CF population now comprises 59% adults (Cystic Fibrosis, 2014). Moreover, the prevalence of CF is predicted to increase by 50% by 2025 (an increase of 20% and 75% in children and adults respectively) (Burgel et al., 2015). CF is therefore no longer considered to be a disease affecting children (Nazareth & Walshaw 2013), and this has had implications for the development of adult CF services.

Particular interest in the transition period that children with chronic illness face when

moving to adult orientated health care has been propelled by the increased survival of children into adolescence and adult life (Viner, 2001). This is a timely reminder of the "obligation to respect the developmental level" of the young person with CF and the need to bridge the gap between the different philosophies of care between child and adult healthcare services (Madge & Bryon, 2001 p.6). Transition is the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centered to adult-orientated health-care systems" (Blum et al., 1993, p. 570). Transitional care focuses on the medical, psychosocial, educational and vocational needs of young people, is multidisciplinary, and incorporates the involvement of the young person and their family (McDonagh & Viner, 2006; Dugueperoux, et al., 2008; Nazareth & Walshaw, 2013).

Transitioning to adult services occurs around the time of the young person's 17th to 19th birthday, and in concordance with European Cystic Fibrosis Society standards, the topic is introduced when the diagnosis of CF is made, and reintroduced at appropriate intervals thereafter (Conway et al., 2014). Child and adult care teams work closely together, even before transition, to ensure collaborative working. This is because children with CF and their families develop longstanding relationships with HCPs within children's services (Dupuis, Duhamel & Gendron, 2011), and transitioning to unfamiliar adult care can pose challenges (Por et al., 2004). Developments in service provision, training and research in transitional care are therefore needed to ensure that all young people meet their full adult potential (McDonagh & Viner, 2006). However, the process of transition has been shown to be affected by HCPs reluctance to 'let go' of the young person and the management of their care, ambivalence in adolescents' independence, and a lack of confidence in the ability of adult services to provide appropriate CF care (David, 2001).

Exploring HCPs' accounts of working within children's CF care, and focusing on transition in particular, may offer valuable perspectives - particularly as care experiences

have been shown to be affected by HCPs' well-being (Maben et al., 2012); however, there is a paucity of literature focusing on such perspectives during this period (Kreindler & Miller, 2013). A qualitative exploration of such experiences was therefore conducted with HCPs working in these settings. To the authors' knowledge, this is the first qualitative study to address a two-fold research objective, the experiences of HCPs of working with children and young people with CF and their families, more generally and on transition specifically, particularly within child CF care teams in Wales and England.

Method

Study design

The study aimed to explore HCPs' experiences of working with children and adolescents with CF, and their experiences of transitioning young people from child to adult services. Interpretative Phenomenological Analysis (IPA, Smith & Osborn, 2008) was selected as an appropriate qualitative methodology to explore how HCPs make sense of such experiences (Smith, Flowers & Larkin, 2009). IPA is informed by phenomenology (the study of what an experience is like), thus it focuses on personal or subjective accounts rather than on objective truths (Smith & Osborn, 2008). IPA is also informed by hermeneutics (the theory of interpretation) and enables researchers to acknowledge that the exploration of participants' experiences is dependent on the researcher's interpretation (NB this is expanded upon in the Third Chapter). Indeed, within IPA, the researcher is engaged in a 'double hermeneutic' as "participants are trying to make sense of the world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2008, p.53).

Another key influence upon IPA is idiography, that is, the detailed analysis of the phenomenology of a homogenous group (Smith et al., 2009). The intention of this study is therefore not to produce a definitive description of 'the experience' of all HCPs; instead it

highlights the nature and context of possible responses to working within child CF services, and the effect of transitioning children to adult services. Thus, IPA allows for the "detailed, nuanced analyses of particular instances of lived experience" (Smith et al., 2009, p.37). These detailed idiographic analyses have potential for theoretical transferability, and contribute a rich understanding to knowledge; the findings of such studies have implications for clinical work (Smith et al., 2009).

Participants

A small purposive, homogenous group of CF HCPs was recruited from both a regional and specialist CF centre in the UK. The model of MDT and shared care between regional centres and local hospitals is considered a "gold standard" in the health management of children with CF and their families in the UK (Cystic Fibrosis, 2011; National Institute of Clinical Excellence [NICE], 2014; Smyth et al., 2014). This allows treatment and advice to be provided from a local hospital near an individual's home, with additional input being supplemented by specialist CF centres (Cystic Fibrosis Trust, 2011).

Participants represented a range of professional backgrounds, and all had experience of working with a minimum of one young person with CF who had transitioned to adult services. Seven HCPs working in children's services across two NHS organisations were recruited between November 2015 and December 2015. Recruitment targeted all professionals within the CF MDTs studied, and the final sample comprised Paediatricians, Dietician, Clinical Psychologists and a CF Specialist Nurse. To uphold anonymity, pseudonyms have been given and demographic data includes years of experience within CF services as a range (i.e. 0-5 years), rather than specifying years of experience for each individual participant (Table 1).

[INSERT TABLE 1]

Ethical Considerations and Recruitment

Ethical approval was granted by Bangor University School of Psychology Ethics Committee (see Appendix B) and NHS Research and Development approval was provided by the relevant organisations (see Appendix C, Appendix D; Appendix E). The primary researcher (SJ) made email contact with one member of each CF MDT and was invited to attend a team meeting. Eligible HCPs received study information, and they were provided with a 'Participant Information Sheet' (Appendix F, Appendix G) outlining the study rationale, details of the inclusion criteria, and an 'Opt-In form' (see Appendix H, Appendix I). If HCPs were interested in participating in the study, they were required to complete the opt-in form and return via the self-addressed envelope to the primary researcher. On receipt of the 'Opt-in form', HCPs were contacted by email, and interviews were arranged to take place at a convenient time at their place of work. Prior to the interview, all participants provided written consent (see Appendix J, Appendix K).

Semi-Structured Interviews

Individual face-to-face semi-structured interviews were conducted by the primary researcher. As recommended by Smith and Osbourne (2015), the interviews were guided by an interview schedule (see Appendix L, Appendix M), which had been developed in collaboration with the research team (JH, GG and LW). The interview schedule focused on HCPs' experiences of working within CF care, and on their experience of transitioning young people from children's to adult services. The interviews, lasting between 35 and 56 minutes were audio-recorded, transcribed and analysed consecutively. To uphold anonymity, participant transcripts were assigned a pseudonym and potential identifiers were removed. In accordance with IPA, all

spoken words, false starts, pauses, laughs and other notable features of speech were recorded in transcription to facilitate analysis (Smith, 2003). As suggested by Fade (2004), field notes were made to record observations including non-verbal communication, eye-contact, fluidity of speech, tone and general impressions of participants/interviews. These were used to inform initial coding. Six participants chose to conduct the interview in English and one participant chose to conduct the interview in Welsh.

Data Analysis

The transcription, translation and analysis of the interviews were completed consecutively. As recommended by Smith et al., (2009), line-by-line analysis of the interviews was undertaken and descriptive, linguistic and conceptual comments were made; these enabled more abstract and interpretative concepts to be identified. Identification of these concepts provided insight into the way in which participants spoke of, and thought, about their experiences. The concepts were then compared, and these were used to develop emergent themes that captured each participant's experience. This process was repeated with each transcript, and a summary description was created containing emergent themes, illustrative verbatim extracts and researcher's interpretative notes (see Appendix N for example of annotated transcript). This was a cyclical process and themes that emerged in later transcripts were reviewed in earlier ones. Through a subsequent process of abstraction, the final stage involved identifying patterns of commonality and divergence both within and between transcripts, and the subsequent creation of super-ordinate and sub-ordinate themes. The translation of the Welsh transcript into English was undertaken by the primary researcher, however consideration was given to the impact of translation on analysis (expanded upon in Chapter 3).

Quality

Evaluative frameworks outlined by Yardley (2000; 2015) were used to guide quality and validity of the research. The researcher engaged in reflexivity and issues were addressed and discussed within research team meetings and peer supervision. These issues are discussed further in Chapter 3.

Results

Three superordinate themes (and underlying themes) emerged from the data: 1) Trajectories of care and therapeutic investment; 2) Professional parent(ing); and 3) Coping culture. These are summarised descriptively in Table 2.

[INSERT TABLE 2 HERE]

The superordinate themes are dynamically intertwined and represent the interplay between both professional and (inter)-personal dynamics within CF care. The themes within 'trajectories of care and therapeutic investment' and 'professional parent(ing)' represent the experiences of all HCPs; however, HCPs employed a variety of different strategies within the 'coping culture' superordinate theme. The themes are evidenced by the inclusion of verbatim extracts from the interviews (see Appendix O theme summary for each participant), and the following transcription conventions are used:

(…) Words omitted to shorten quote

[text] Explanatory information included by author

… Short pause

Superordinate theme 1: Trajectories of care and therapeutic investment

This superordinate theme represents the co-existence between HCPs commitment to working within CF care, and the sense of responsibility that they feel in the fight against the natural

progression of CF. All HCPs described the relentlessness of CF when acknowledging how it permeated through every aspect of children's lives; it was a "part of everything".

Theme 1: "That's my role and my responsibility": Sense of responsibility. HCPs realised the extent to which their involvement in the care of individuals with CF was essentially an attempt to fight against CF's natural trajectory. William (Consultant Paediatrician) noted:

> One of the early presentations, teaching presentations I did when I started looking after children with cystic fibrosis (…) was entitled foiling nature's plan (...). Nature has designed cystic fibrosis to be, that there is a relentless progression of disease, and there is a relentless deterioration (...) where death is inevitable. So actually everything that we do is purely designed to interfere with that plan and prevent that progression.

This 'fight' elicited a sense of responsibility, and HCPs expressed 'frustration' when young people experienced declines in health because of concordance issues, such as the non-adherence to treatment. Charlotte (Clinical Psychologist) spoke about internalising this sense of responsibility, and she talked about how unsuccessful outcomes made her feel as though it was she who had failed. This was further impacted upon by her belief that psychology had become 'second class sort of service':

> I don't think they ever would allow dietetics and physio to have as little time as psychology does, and I get that because you know, I get that those sort of things are actually really essential and you know they have a more direct role than I do in clinic.

Thus, although Charlotte felt as though she could do more, the lack of provision for psychology impacted upon her perceived sense of efficacy.

Theme 2: Lifespan commitment. HCPs emphasised that they had chosen to work in the CF specialty, and they used phrases such as "felt that it was right for me", "I love working in CF I don't think I'd do anything else", and "I think working in a team where people really want to be in that specialty makes you want to stay". HCPs valued the commitment and enthusiasm about CF that existed within the MDT and stated "it isn't something you could train or pick up in an interview, so we are lucky". Chelsea (Dietician) had previously worked in an adult CF service and she acknowledged her preference of working within children's services, because "you actually watch them grow and develop, which is actually nice". Working in this settings contrasted to Chelsea's experience of working in adult CF services, and she provided an emotional account of the death of a young adult who was of a similar age to her, stating it "took such a long time to get over" his death. Working in children's CF services now enabled Chelsea to intervene at the beginning of the illness's trajectory: "You're seeing them from early on and you can actually feel like you do actually get to know them and do a bit more".

William also shared his commitment to working within children's CF services, and expressed how the lifespan approach allowed him to go beyond typical "conveyer belt medicine":

> (…) Whilst I can practice um conveyer belt medicine you know, you give me a line of patients and a list of jobs to do and I'll work through them and I'll make quick decisions and you know provide hopefully what the patients need. I like the idea that I can develop a longer-term relationship with my patients and with their families and I like that part of CF care.

Theme 3: "You don't have a magic wand': No cure. HCPs were aware of CF's trajectory (no cure) and how there were many 'hurdles' ahead for young people with CF (i.e. burden of treatment). HCPs empathised with families about the systemic impact of a CF diagnosis, and they tried to help families integrate CF into their daily lives; this is outlined by Heather (Specialist Nurse):

> I think we just um we realize how difficult it is for families and it's really hard cos you don't have a magic wand to say we want to make this right…I think it's very different um with CF because it's a lifelong illness (…) I think what's most difficult is you still know it's going to be really hard you know for the them.

There was an emphasis on the permanency of CF and helping families see the bigger 'picture', and fighting against the natural progression of CF as illustrated by Charlotte:

> I guess it's helping them understand that longer picture so I think a mixture maybe of seeing their point of view and understanding how frustrating and difficult it can be, but also trying to help them understand the sort of longer term implications of that.

HCPs commitment to working within CF services is prominent, and they support families to understand the reality of CF. They are not the bearers of a cure, which is contrary to how HCPs are often viewed within the medical profession. Families likely hope to evade the progression of the disease, whereas HCPs attempt to carry the families along the CF trajectory, despite the rigours of the condition and provide a more realistic outlook.

Superordinate Theme 2: Professional parent(ing)

Professional parent(ing) describes both a role (parent) and process (parenting) taken on by HCPs. This essentially captures the way in which HCPs become caregivers, and how attachment dynamics play out as a result of the strong emotional investment and longevity of care. Consequently, boundaries can become blurred. Upon transition the attachment is ruptured and HCPs are left longing.

Theme 1: Attachment: Emotional investment. The longevity of CF care led participants to express their emotional investment using terms such as "we've invested an awful lot emotionally in these patients for a long time" and "we become a massive part of their life". HCPs valued the unique opportunity to go beyond clinical treatment and to develop a longstanding rapport with young people and families. Patricia (Consultant Paediatrician) explained:

> I like the fact that we get a long-term relationship with families (…) we know the illness in the children, but we also get to know the children (…). You get to know the child and the family slightly better and there aren't a lot of things in paediatrics where you can do that. There is something nice about that and different to the rest of paediatrics.

William also shared the personal nature of his work, and emphasised that his work for children and families was not purely disease focused. Bi-directional trust also seemed to be a key component of his emotional investment, and reassured him that he could make the best decisions regarding care:

> I look after families I don't look after diseases (…). I like the opportunity afforded by cystic fibrosis care to actually develop a relationship with a family and to build up um extra layers of knowledge and trust um that work in all directions (…). I have to have a belief that I have trust in the family that they will engage with me and tell me the information I need to be able to make sensible decisions.

It seems that the long emotional investment in CF care can elicit an attachment dynamic. It is possible the familiarity of hospital and the CF team, who have been present from very early, provides a secure base for children with CF. Charlotte described it as "feeling safe and secure here, and same for us" implying it applied to both the young people and HCPs. Rachel (Clinical Psychologist) also explained:

> I think the CF children you probably are because you've been there from day one, the children are very familiar, you know. I guess that's one of the striking things you know, the children with CF are very, very comfortable around their hospital staff and the hospital team.

Theme 2: Blurred Boundaries. A notable feature of professional parent(ing) was the way in which attachments elicited blurred boundaries and evoked emotive reactions in HCPs. Their experiences of working in CF afforded them a unique position of building long-term relationships with families, thus gaining insight into families' lives. Some viewed themselves as part of "an extended family" and used terms such as "proprietorial" and emphasised "my", when referring to young people they have "cared for" up until adolescence. This attachment dynamic seemingly fostered a conflict between HCPs' professional and personal self and

blurred boundaries. Charlotte initially struggled with this conflict and noticed how CF work elicited this parental reaction:

> I think my boundaries are very different in terms of I probably do give more of myself away (…). I can sort of feel a bit parental almost in a sense (…). Yeah … doesn't feel very boundaried does it [laughs] (…)! I think maybe sometimes there is that sense of having seen somebody grow up and then moving on, it feels a little bit like uh you know like your child like, you might feel if your child was leaving home or if a child was moving on.

Parallels with parenting appeared significant when approaching the end of care in children's CF settings, as illustrated by William:

> Yeah it's sometimes it's a challenge to, to kind of say 'okay we're done, my job is done, now I have to let them go' um. It's, it's fascinating isn't that the kind of, the older my own children get the more you can see um you know the, the parent in you kicks in more than the doctor or, or you know, begins to kick in as well as the doctor in you kicks in.

In light of this frequent involvement and emotional investment, Chelsea explained how it is difficult to disentangle her professional and personal self given that "you see them more, and interact with them more than you would with your own close family and close friends". This was exacerbated for Chelsea by grief and loss experienced on the 'other side' (i.e. adult services). Chelsea stated that "it took such a long time to get over that" and how attending a funeral seemed "wrong" as she felt that she was "intruding" despite having had a

"big involvement". This loss had remained with Chelsea and had seemingly shaped cautiousness relating to personal and professional boundaries:

> There's been a few deaths since I've been here, but I haven't actually been to any of the funerals cos I think that's quite a, that is where I think your professional boundary is, I don't know, it's quite blurred isn't it, 'cos I know it's quite common especially in paediatrics from all of the kind of care team to go to the funeral and the family want them to. So I think that's like a difficult one.

The multifaceted nature of blurred boundaries was also highlighted by Susan (Specialist Nurse), who in contrast to Chelsea, captures a humbling experience of being asked by a young person with CF to be present at the birth of her child:

> She came to tell me that she was pregnant (…), and then she asked, I'm shivering thinking about it, she asked me would I be present for the birth (…). It was absolutely just lovely to be part of that, and to be asked to be part of that was just it was an honour to be honest. I might cry thinking about it.

Theme 3: "Unfinished business": Left longing. For HCPs, transitioning young people on to adult services seemed to catch them off guard. They used terms such as "you're with us and then you've gone" and "you don't know what's going to happen to them". Chelsea described feeling a sense of "unfinished business". She elaborated on how writing the last entry in the notes captured the poignancy of ending the relationship:

> You won't see them again, and it is quite interesting like you've got this big wad of notes, and then you kind of write the last entry in the notes and then (…) they're gonna like disappear off.

The onset of transition seemed to elicit uncertainty relating to an unknown future for young people facing transition, and the perceived discrepancies between child and adult CF care. This is illustrated by Patricia:

> For us I find it horrible, it's really horrible because we have fussed over them in paediatrics, we are terrible you know we see them every two months. If they can't come to clinics we will see them as extras on the ward, we go after them. The parents often phone us too, so then it feels completely wrong and it feels as though we are pushing them off some cliff and we aren't sure where they'll land!

Although HCPs acknowledged that transition into adult services was typically a positive part of development, emotionally, the finality of transition and lack of connection thereafter led to feelings of discomfort. Rachel explained:

> Um it's strange knowing that (pause…) he won't come into clinic again (…) there's no sort of um…compulsion for him to come back and let us know how he's getting on (…). You know it's natural, it's like when your kids leave home (…) but then when your kids leave home, you sort of got that contact with them (…).

Superordinate Theme 3: Coping culture

HCPs employed a variety of different coping strategies to help manage the interconnectedness between the professional and personal impact of working with young people with CF and their families.

Theme 1: Disconnect and distancing. HCPs all expressed good working relationships within CF MDTs and used words such as 'close', 'functional' and 'respectful' to describe the teams' ethos. However, Charlotte and Heather who both worked within the same team illustrated how a culture of unspoken needs existed. Charlotte seemed surprised that the team did not talk about the emotional impact of transition, and she questioned whether it was 'an avoidance thing': "We don't really talk. I've never heard any members of the team sort of say 'oh I'm really upset they're going or I'll really miss them".

Heather referred to relationship building as "nice stuff", but explained she had little times for this due to work demands; this consequently made her feel "overwhelmed". Charlotte acknowledged that "it would be nice to have somebody just to you know discuss ideas with or just offload to". Rachel, who worked in a different team acknowledged that her team allowed some space to discuss the impact of loss, although it seemed brief and lacked depth: "When the young man left yesterday, we can all have a hug and a bit of a cry, and then just get on with the MDT".

Therefore, despite acknowledging the emotional investment that they make with patients, the emotional needs of some HCPs are seemingly neglected. However, in an attempt to protect herself, Charlotte implemented a "process of distancing" from the young person and their family, which occurred "subconsciously without kind of planning it". Distancing was also reflected in William's narrative, but this was conceptualised as a "professional disconnect" from the adult services. This disconnect seemed to protect him from the "discomfiture" that he felt relating to uncertainties about the quality of care in adult service:

> Um so of course if there's a professional disconnect, if I don't know that I'm sending them into; an environment where they will be receiving care provided in a different manner than the way I would chose to do it, then that protects me from professional discomfiture.

Not having to directly deal with the adult team 'taking over' care of patients, William's 'professional discomfiture' may signify the bittersweet nature of helping a young person transition to adult services.

Theme 2: Whose needs? HCPs seemed to highlight that there was no way to 'formally' know how young people were coping, following transition to adult services. They used phrases such as: "that strikes me as quite odd you know, you could have cared for families for a long time, then you don't really know what happens to them". HCPs acknowledged their sense of curiosity in knowing how young people were after transitioning, and used terms such as "out of interest" and "reassurance" to justify why. Susan expressed a hope that they were "living life" despite their condition. Charlotte however began to question whether this sense of curiosity, and urge to ask adult services how the young person was, reflected more about her own needs:

> I've found it hard to sort of say 'oh how is such a body doing' without that sort of sense of who am I asking that for? That's about my own needs, not necessarily about theirs, and not like there's anything wrong with that, but just sort of being aware.

Although facilitating a healthy transition was "satisfying" for Rachel, she indicated that she would "keep them all until they were twenty-five anyway". She expressed her discomfort in not knowing what young people had accomplished in later life, yet

acknowledged that it was “right” not to know, but felt that this was also “tough” and had parallels with “when your children leave home”. This illustrates the intertwined nature of professional and personal self in CF care.

Theme 3: Evolution of CF: Optimism. Despite the emotive nature of CF work, participants shared optimism about how much CF treatment had evolved over the years, using phrases such as “evolved”, “drastically improved”, and “fantastic”. Focusing on the positives and progression of CF treatment instilled confidence in “making a difference”. Patricia explained:

> Perhaps it’s a coping mechanism, but I choose to think about the fact that the life expectancy now, children who are born today with CF, um their life expectancy is 42. Twenty years ago the life expectancy was 18-20, that’s incredible isn’t it. We have doubled it, and that’s without really seeing the full impact/effect of screening yet (…)

Optimism was also captured by Heather who conveyed “hope” about there being “light at the end of the tunnel” for families, given the promise of new drugs. HCPs also expressed pride that young people were healthy enough to transition, and were not being held back by CF. Rachel explained how it felt like “the end of an era but actually it’s also the new beginnings”. The improvements in CF care and the need for transition was viewed as a celebration, as captured by Patricia:

> I think we forget that it’s somewhat of a privilege and honour to look after the children and send them forwards (…). So even though they are sad to move on (…) it’s positive in the fact that there is a need for an adult service (…). I think that’s not something to complain or moan about, it’s something to celebrate isn’t it?

Discussion

The three superordinate themes elaborated on the conflict HCPs experience between their professional role and personal self. HCPs were committed to expanding the lives of young people and help families see the "bigger" picture but the longevity of CF work afforded an emotional investment. This created blurred boundaries, and parallels were being made to that of the role of parenting. However, transition to adult care ruptured the attachment relationship and no opportunities for emotional closure were afforded. Individual idiosyncrasies of conceptualising the complex nature of CF work provided some insight into the coping mechanisms adopted by HCPs. This subsequently provoked the question as to whether HCPs' emotional needs were being addressed when working within a complex emotionally demanding specialty. The present study advances what is currently known about HCPs' experiences of working within children's CF services more generally and on transition, and this provides valuable new information about this multifaceted and understudied area.

Some themes were consistent with existing literature. For example, it has been acknowledged that the longstanding and trusting relationships developed by children with CF with paediatric staff can hinder willingness to separate and transition to adult services (Landau, 1995; Rosen, 1995). Families have been found to be reluctant to leave the security of paediatric teams, particularly when children have essentially 'grown up with them' (Madge & Bryon, 2001; McDonagh, 2005 p.365). Craig, Phty, Towns and Bibby (2007) suggested that parental concern regarding transition was related to parental tendency towards overprotectiveness, often seen in chronic illness, which can be exacerbated by the paediatric team's reluctance to let go (Craig et al., 2007).

Similarly, it has been suggested that the prescriptive, protective and systemic philosophy of paediatric CF work can result in HCPs adopting parental type relationships with patients (Madge & Bryon, 2001 p.5). The strongly developed relationship, beliefs that

transitioning to adult care signifies a step closer to death; loss of control that the adult services would not be as good coupled with a more generally fear of the unknown, are all potential contributing factors of transition reluctance in HCPs (Madge & Bryon, 2001). Flume, Anderson, Hardy and Gray (2001) hypothesised that although HCPs' uncertainty about transition could be valid in light of change, HCPs could also be projecting their own concerns to others or that concerns were related to perceived loss. The reciprocal relationships and presence of mutual trust between HCPs and families has also been emphasised in the literature (Reiss, Gibson & Walker, 2005). Thus, findings from the present research highlight that appropriate termination of relationships needs to be integrated into the transition process.

Since the existing literature seems sporadic and dated, the findings of the present study primarily compliment and extended existing research. The current study also explored the overlap between HCPs professional and personal self. The attachment dynamic and blurring of boundaries was shown to lead to discomfort regarding transition; however, HCPs coping mechanisms included avoidance, being optimistic about young people's increased life expectancy, and the hope afforded by advancements in CF care. Importantly, this current study also raises an important question as to whether HCPs own needs are being met. The HCPs' experiences therefore provide another layer of understanding and allow a timely rich glimpse into their world of working within CF more generally *and* specifically on transition.

Close attachment with families is essentially inevitable given the longstanding nature of CF care. HCPs acknowledged that sharing aspects of their personal self was an essential part of engaging with and building rapport with families. HCPs may identify with families thus leading them to employ conscious or unconscious coping strategies such as avoidance (i.e. distancing) or task centeredness (i.e. I can only do what I can do; role responsibility) (Speck, 1994). Coping culture highlights the need to utilise certain self-care strategies to

manage the attachment and blurred boundaries and to create a physical and emotional distance. This is of particular interest when nursing specialities suggest that the idea of countertransference[1] impacts on personal and professional relationships throughout nursing (O'Brien, 2001). Jones (2004) suggested that discussing difficult issues might not only foster effective team working but also enhance knowledge of personal attachment styles and how they influence the care-giving process.

Lack of awareness of the attachment dynamic and neglecting HCPs own needs is unlikely to be sustainable over time. Meadors and Lamson (2004) suggested emotional attachment to a sick child, despite not being the 'provider's own' (p.25) and emotional identification (i.e. similar temperament to own child) may result in higher probability of compassion fatigue[2] in HCPs caring for children in paediatric settings. This suggests a need to review how multidisciplinary team (MDT) response and resourcing can be optimized in CF services. With the ageing CF population, HCPs need to be supported to find a more systematic way of acknowledging and managing their own needs.

One suggestion may be acknowledging Clinical Psychologists' breadth and depth of training and experience across the lifespan, and their competence in offering consultation, supervision and reflective practice (British Psychological Society [BPS], 2009; 2011), to increase team communication and cohesion (Jacobs, Titman & Edwards, 2012). Training and or consultation could be provided on psychological theory (e.g. attachment) to aid other members of the MDT to become more self-aware of processes that arise in the clinical

[1] Conscious and unconscious emotions, attitudes, feelings experienced by the therapist about a client relating to his/ her own needs (Gelso and Hayes, 2007).

[2] ''A state of exhaustion and dysfunction biologically, psychologically, and socially as a result of prolonged exposure to compassion stress and all it evokes" (Figley, 1995 p. 253).

context of CF.

Within mental health services, different supportive staff groups exist to encourage staff to talk about emotional experiences encountered in the workplace, however, reflective sessions are seen as a 'luxury rather than a necessity', particularly within the medical world (Yakeley, Hale, Johnston, Kirtchuk & Schoenberg, 2014). Having clinical psychologists integrated in teams has also been suggested to offer a 'helpful counter-balance to the medical model' (Onyett, 2007). In this study, Charlotte's narrative reflected that psychology felt like a 'second class sort of service' and 'unequal', thus adopting more of a biopsychosocial focus to clinical practice and within teams may facilitate bridging the gap between the medical and psychological model.

"Unfinished business" highlighted the way in which transition seemingly ruptured attachment and caught the HCPs off guard. This finding suggests the need for more consistent practice in relation to transition. It also raises the question as to whether HCPs prepare for endings, both from a service and emotional level. With increasing life expectancy for CF, transition planning and most importantly preparation are vitally important (Gravelle, Paone, Davidson & Chilver, 2015). Most importantly, the findings suggest that transition is not a single one off event but instead a complex process that occurs over time during which healthcare is transferred from one service to another (Nobili et al., 2001).

Emphasis should therefore be on gradual preparation earlier on in adolescence and could serve the basis for a transition clinic to address the planning, preparation and transfer with health needs (Kennedy & Sawyer, 2008) such as CF. Families should be given ample opportunity to meet the adult team prior to transition to prevent higher levels of concern (Boyle, Farukhi & Nosky, 2001), which in turn may better prepare HCPs for transition and prevent the sense of unfinished business. Overall, the role of transition continues to evolve

and should remain a key priority for CF teams.

It is acknowledged that the study's findings are representative of a small sample of HCPs, however rather than generalisability, IPA is more focused on 'transferability', whereby findings can be applied to persons in contexts, which are more, or less, similar (Smith et al., 2009). This study respected the idiographic traditions of IPA. Key themes were described by several participants, which indicate that the findings may have wider applicability. The findings warrant further exploration in future research. Social desirability bias and contextual cues may have also resulted in participants withholding or downplaying beliefs. The researcher adopted an open, empathic and non-judgemental approach in an attempt to counteract this as much as possible. The richness of the data suggests that participants were able to meaningfully articulate experiences. Cross-validation of initial coding, a thorough audit trail of analysis and reflective sessions with the research team attempted to minimise the researcher's subjective bias.

The experience of HCPs working within CF remains an under-researched phenomenon. Further research is required to determine whether the findings have wider applicability. As an extension of the professional parent(ing) theme, one fruitful avenue of research would be to explore HCPs' attachment styles and the impact on alliance and outcomes. With supervision or training, HCPs may become more self-aware about their own attachment style, which in turn could help guide intervention, pace of sessions and deal with ruptures in attachment/ therapeutic relationship (Wallin, 2009) as well as transitions. In light of parallels being made to parenting and HCPs being caught off guard by transition, qualitative studies examining HCPs' perception of therapeutic endings are also of particular importance.

Considering the 'disconnect' described between paediatric HCPs and the adult team, future research should explore experiences of HCPs from adult services. This could include

exploring their experiences of working within adult CF care more generally and on their working relationships with the paediatric CF team. This study did not distinguish whether HCPs' experiences changed over time, indeed differences in the 'coping culture' noted in the sample may reflect a process of acceptance or adjustment. Longitudinal research, perhaps across both paediatric and adult service should be undertaken to explore this possibility.

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Table 1:

Demographic Information

Participant Number	Pseudonym	Profession	Years of experience (range)
P1	Patricia	Consultant Paediatrician	5-10 years
P2	Charlotte	Clinical Psychologist	5-10 years
P3	Chelsea	Specialist Dietician	5-10 years
P4	Heather	Specialist Nurse	0-5 years
P5	Williams	Consultant Paediatrican	5-10 years
P6	Susan	Specialist Nurse	10-15 years
P7	Rachel	Clinical Psychologist	5-10 years

Table 2: *Summary of superordinate and underlying themes*

Superordinate theme	Underlying Themes	Descriptive Summary
1 Trajectories of care and therapeutic investment *Captures the professional impact of working within CF*	"My role and my responsibility"; Sense of responsibility	HCPs expressed the all-encompassing nature of CF and acknowledged their involvement in CF care, particularly their attempts to fight against CF's natural trajectory. This elicited a sense of responsibility and frustration when young people experienced declines in health and HCPs occasionally internalised this sense of responsibility and felt as though they had failed on occasion and needed to do a good enough job.
	Lifespan commitment	Captures the dedication to working within the field of CF; that HCPs choose to work in CF and that this is the right fit for them; HCPs valued the longevity of input and having the opportunity to see young people grow and develop.
	"You don't have a magic wand"; No cure	HCPs were aware of CF's trajectory and the reality that there is no cure and death is inevitable. HCPs empathised with families about the systemic impact of CF and acknowledged the many 'hurdles' facing them. Emphasis is on the permanency of CF and HCPs attempted to help families see the 'bigger picture'.
2. Professional parent(ing) *Captures the personal impact of working within CF*	Attachment; Emotional investment	Captures the strong emotional investment/ bond across the lifespan, the longevity of the therapeutic relationship and bidirectional trust between HCPs, young people and families. An attachment dynamic emerged as HCPs described CF care/team as a secure base.
	Blurred boundaries	Boundaries are blurred in light of the attachment/emotional investment and fostered a conflict between HCPs' professional and personal self. Such struggle elicited a parental reaction for HCPs and further parallels were made to parenting.
	"Unfinished business"; Left longing	Outlines the disruption in attachment with the sudden finality of transition. HCPs seem to be caught off guard by transition and expressed uncertainty relating to an unknown future for young people facing transition and perceived discrepancies between child and adult CF care. The lack of connection following transition led to feelings of discomfort.
3. Coping culture *Captures coping strategies of HCPs in light of the interplay between the professional and personal impact of working within CF*	Disconnect and distancing	Captures the process by which HCPs appeared to subconsciously distance themselves from the young people who are transitioning; The emotional impact of CF care and transition seemed to be avoided as a culture of unspoken needs emerged. A protective disconnect existed between paediatric and adult CF care team, emphasising the bittersweet nature of transition for HCPs.
	Whose needs?	HCPs acknowledged their curiosity in knowing how young people were after transitioning and their desire in keeping the young people within paediatrics until they were a little older. This theme captures HCPs' own needs and a potential by-product of professional parent(ing).
	Evolution of CF; Optimism	HCPs had optimism relating to how much CF treatment and life expectancy had advanced. Optimism instilled confidence and hope for HCPs. Improvements in CF care and the need for transition were viewed as a new beginning and a celebration.

Section 3

Contributions to Theory and Clinical Practice

Contributions to Theory and Clinical Practice

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This final paper combines findings from the literature review and empirical study to consider their mutual impact. Integration of findings is presented in three sections: 1) contributions to theory and recommendations for future research 2) clinical implications 3) personal reflections on the research process.

Theoretical Implications and Future Research

Both the literature review and empirical study highlighted the scarcity of research on Cystic Fibrosis (CF). Further recommendations emerging from this present study include on-going research about HCPs' experiences and young people's experiences of other aspects of transition within CF care, (e.g. transplantation, palliative care). The research examines an under-represented area and expands the opportunity to bring HCPs' experiences and needs of young people with CF to the forefront.

The literature review highlighted the need for peer support for young people with CF. Social ecological theory (Bronfenbrenner, 1994) can be of relevance here as it conceptualises the child at the centre of what can be visualised as concentric circles (environments) of context, each with increasingly more distal relationships to the child (Darling, 2007). For example, the most innermost circle (microsystem) encompasses the relationships and interactions that a child has in their immediate surroundings, and those who the child is inherently dependent upon, family. The family interact closely with the healthcare team at the next less proximal level and subsequent distal levels include extended families, schools, culture and values as interacting subsystems (Kazak, Simms & Rourke, 2002). Illness-specific microsystemic influences include the nature of the illness, impact on the child and impact on parents and siblings (Brown & Sammons, 2002).

The shift in importance of particular microsystems for adolescents is that parents become less influential and their innermost circle consists of a social network of interpersonal

relationships with peers (De Goede, Branje, Delsing & Meeus, 2009). Peer relationships can also be impacted by CF as illustrated in the literature review with focus on reluctance to disclosing CF. Peers do however represent a key source of social support for children with chronic conditions. Being able to share an identity and having supportive friends can increase adaptation to illness and improve illness management behaviours (La Greca, Bearman & Moore, 2002). Further qualitative research is however needed to explore the psychological impact of segregation on young people and adults with CF.

Bronfenbrenner (1994) highlights the most influential reciprocal interactions that occur in the individual's immediate environment and over an extended period of time. It emphasises the reciprocal nature of human relationships and attention must be drawn to the structure, function and resources of each of the systems (Kazak, 1992). Thus, consideration of the social context is vitally important when children learn to cope with a chronic condition, such as CF. Research is needed to further utilize Bronfenbrenner's ecological model to understanding the multiple systems impacting and impacted by day-to-day living with CF.

Attachment is a developmental theory with a multitude of clinical implications (Bowlby, 1988) and allows exploration into relational patterns and processes within the family. Attachment theory proposes that internal working models of attachment are formed in early life and determine interpersonal expectations and behaviours later in life (Bowlby, 1988). Attachment types can be seen as an outcome of early caregiver relationships within a specific social environment (Schore & Schore, 2008). The professional parent(ing) theme emerged from the empirical paper, illustrating how HCPs attempted to maintain professional boundaries but recognised the inevitable emotional impact and personal connections formed with young people with CF and their families. There is consensus among attachment researchers of viewing the therapist and client relationship as an attachment. Bowlby (1988) believed that therapists should assume the role of a temporary attachment figure and act as a

secure base. Ainsworth (1989) also argued that clients can and do form an attachment to their therapist (Amini et al., 1996; Holmes, 2001). Attachment theory is particularly pertinent with regards to therapeutic endings as illustrated by HCPs feeling as though transition signified unfinished business and left them longing. Therapeutic endings appear to be underexplored within the healthcare literature. There is a need for research to explore factors that can facilitate increased dialogue regarding therapeutic endings to increase HCPs' self-awareness. Future research is also needed to explore HCPs' ending behaviours and experiences alongside their attachment styles. Research could attempt to inform best practice relating to endings through gaining greater understanding of the influence of attachment.

Transition from childhood to adulthood spans physical, social, psychological and emotional domains, for example establishing identity, positive self-image, sexuality, employment and family planning (Arnett, 2000). Further longitudinal research is needed to accurately define and measure such key developmental concepts and explore interactional relationships between these concepts and specific illness experiences (e.g. treatment burden), particularly since a CF diagnosis is made at a very early stage. Medical treatment routines can affect one's identity and alter perception of self (Charmaz, 2002), thus acceptance of CF across the lifespan may be temporal (Badlan, 2006). Acceptance-based skills may therefore be relevant to the adolescent with CF for whom "fitting in" with peers is paramount yet escaping the turmoil associated with adolescence is not possible due to the demand of daily treatment.

Moreover, the systematic review primarily focused on young people and adolescents, however it is important to consider that the type of social support may vary across the CF life trajectory. Future research is recommended to explore family dynamics, particularly sibling relationships when both children are diagnosed with CF. Does this compensate for the lack of relationship with CF peers? Also, life expectancy for CF now spans into adulthood, therefore

attention needs to be drawn to important issues such as establishing and sustaining intimate relationships and family planning. Is segregation as strict within adult services? What are the experiences of relationships for adults with CF?

Research could be complemented by employing a more critical, discursive approach such as Foucauldian discourse analysis, with the aim of describing and critiquing the discourses held within the healthcare field for CF. In the UK, children needing palliative care services typically fall into one of four categories (ACT/Royal College of Paediatrics and Child Health, RCPCH, 2003). Category two includes CF, an incurable disease, involving long intensive treatment targeted at prolonging and enhancing life. Importantly, children and young people represent a heterogenous group encompassing a wide range of conditions. An arbitrary distinction exists between life-threatening and life limiting conditions that echoes clinical practice, namely the uncertainty around the life-death trajectory, as children fluctuate between critical illness and managing chronic illness before reaching the final stage (Clarke & Quin, 2007). Thus, are terms such as palliative, life limiting used interchangeably within CF? How does this impact HCPs' experience? What are the implications for practice?

One further avenue for research is with respect to language. One interview in the empirical study was conducted through the medium of Welsh. In line with the Welsh Language Act (1993), provision of information was made readily available both in English and Welsh and participants were supported to converse in their preferred language. In an attempt to uphold the sensitivity to context, transparency commitment and rigour quality principles, the Welsh transcript was analysed in Welsh and the researcher's interpretation was translated to reduce losing the participant's meaning. Two authors who were fluent in Welsh checked interpretations were consistent with Welsh verbatim quotations. Discussion of epistemological and methodological issues on translation across languages appears to have been neglected within research (Nikander, 2008; Temple & Young, 2004). IPA however is a

linguistically based approach and has a theoretical commitment to the participant as a cognitive, linguistic, affective and physical being and assumes a chain of connection between each state (Smith & Osborn, 2008). Thus, language "constitutes our sense of self" and is potentially value laden (Temple & Young, 2004, p. 174). Language also potentially reflects meaning of experiences and the researcher fully immersed herself with the data. Nikander (2008) suggested that providing space and access to both original and translated materials favors transparency and students of different ethic backgrounds should be supported in conducting research (and analysis) in their mother tongue. Future research should acknowledge the complexity yet importance of conducting qualitative research with bilinguals and multi-linguals.

Clinical Implications

A number of clinical implications arise from the work presented within this thesis. First, as outlined in the review paper, clinicians need to be aware of the psychosocial needs of young people with CF. Furthermore, results from the empirical study suggest that HCPs are torn between the interconnectedness of their professional and personal self, and how the impact of working within young people with CF and transitioning them onto adult services is being neglected.

The need for social support for young people with CF is paramount. All HCPs should consult with the young person regarding the impact and personal meaning of segregation. It is important to consider whether key developmental concepts (e.g. peer relationships, sexuality, identity, body image) are being overlooked by HCPs and to ensure they are on the clinical agenda, particularly in preparation for transition into adult service. The concept of 'good' medical outcomes (e.g. adherence) needs to take a broader stance of adopting a holistic view of the young person with CF, with greater emphasis on psychosocial aspects of

their illness experience. For example, the health belief model could be implemented to explore underlying beliefs and barriers for non-adherent behaviour.

Resilience is an important quality in order for HCPs to work in the face of managing complex and emotive situations (Stephens, 2013). Establishing and maintaining appropriate boundaries are one aspect of developing resilience, thus 'gradually increase the ability to differentiate client and practitioner responsibilities and to relate in functional ways' (Skovholt & Ronnestad, 2003, p.48). HCPs' emotional boundaries can however affect their vulnerability to stress and burnout (Rodolfa, Kroft & Reilly, 1988). HCPs must function in complex and evolving health care systems and are faced with emotional strain by the very nature of their profession (May & O'Donovan, 2007), and as discussed in the empirical study HCPs may experience compassion fatigue. A quarter to a half of NHS staff report distress, which may be a higher rate compared to the wider working population (Harvey, Laird, Henderson, & Hotopft, 2009), all impacting on the health and wellbeing of employees and the productivity of organisations (Kieselbach et al., 2009). Taking into account the needs of HCPs given the emotional consequences of professional caregiving is therefore vital.

Reflection and reflective practice are terms often used in the literature to described the essential attributes of competent HCPs who are willing to address these challenges (Epstein & Hundert, 2002). Reflection has been defined as ''a generic term for those intellectual and affective activities, in which individuals engage to explore their experiences in order to lead to a new understanding and appreciation'' (Boud, Keogh & Walker, 1985, p. 19). It allows HCPs to make meaning of complex situations and allows learning from experience (Mann, Gordon & MacLeod, 2009). Reflection has been acknowledged as a worthy investment of time and effort resulting in more effective care (Girot, 1995; Paget 2001). Two methods promoting staff wellbeing and reflection have been suggested. Firstly, Balint groups are aimed at encouraging HCPs to 'focus in a discipline way on the emotional dimensions of

their work' (Launer, 2016 p.245), including the therapeutic relationship (Balint, Courtenay, Elder, Hull & Julian, 1993). Secondly, Schwartz rounds®[3] have been implemented as a practical way of supporting staff wellbeing, by allowing them to come together to discuss and reflect on the emotional and social challenges related to clinical work (Goodrich, 2012). Supportive avenues to facilitate reflection and to help HCP express emotion, share experiences, build resilience and balance work responsibilities are encouraged.

Acceptance based approaches could also be implemented to help staff manage discomfort and anxieties that arise, for example discomfort raised by rupture in attachment signified by transition. Acceptance and Commitment Therapy (ACT; Hayes, Strosahl & Wilson, 1999) has the potential to increase acceptance of difficult thoughts and feelings (e.g. managing the interconnectedness of their professional and personal self) and enable HCPs to work in accordance with their values.

A further clinical implication arises from the narrative of Charlotte and how she felt as though psychology was a second rate substandard service. This raises the question of ensuring a biopsychosocial framework is implemented in an attempt to bridge the gap between medical and psychological perspectives to ensure optimal care. Clinical Psychologists have both theoretical and working knowledge of psychosocial development and experience of formulation and intervention that incorporates multiple system perspectives (BPS, 2011). Clinical Psychologists also have the ability to expand their direct work with young people and families to work indirectly in services by supporting other HCPs by providing peer supervision, reflective sessions or case consultation (BPS, 2009). Thus, they are well suited to help healthcare teams plan and provide developmentally and psychologically informed care.

[3]Developed by the Boston-based Schwartz Center for Compassionate Healthcare www.theschwartzcenter.org

In addition, the empirical study emphasises the need for more attachment informed practice to inform planning and management of transition more effectively. The professional parent(ing) theme illustrated the longevity of relationship between the paediatric team and young person with CF and their families. HCPs therefore observe development and life stages from birth to young adulthood (Nobili et al., 2011). This investment needs to be more explicitly acknowledged to facilitate more open dialogue about the coping culture of paediatric CF teams following transition, with the aim of better preparation and adaptation thereafter.

Large geographical distance between two services can limit opportunities for health care teams to participate actively in transition too (Towns & Bell, 2011). Moreover, this also raises cultural implications when young people have to transition out of area to access adult CF services and are unable to receive their care in their first language. The disconnect between HCPs and adult CF team along with the need for adult services, given the increase in life expectancy, emphasises the need for more local adult provision.

Reflective Commentary

"Art is never finished, only abandoned".

— Leonardo da Vinci (as cited in Landi, 2014)

The reflective commentary provides insight of extracts that arose from my written reflective notes. Interpretative Phenomenological Analysis (IPA) facilitated this process with its emphasis on reflectivity throughout the entire thesis process. Reflection allowed me to become self-aware of my own preconceptions and best attempt to bracket them in order to focus on the lived experience of participants.

Throughout my time as an Assistant Psychologist and a Trainee Clinical Psychologist I have developed a growing interest in bridging the gap between physical and mental health and also on the concept of transition. I have worked with individuals across the life trajectory from very young children; adolescents, adults and older adults and I feel that I have observed how both physical and mental health can affect individuals at different transitions in life. Clinical training has also further enhanced my curiosity of HCPs' experiences of clinical work and I felt as though they were the forgotten yet worthy population within research. Following discussions with my research supervisors, it became apparent that CF care was a fruitful avenue to explore HCPs' experiences and transition.

Prior to undertaking this research, I had no previous personal or clinical experience of CF and had no specific teaching regarding the condition as part of my clinical training. However, I acknowledged having personal experiences of other respiratory and chronic health conditions. During data collection, I commenced a specialist Child Health Psychology placement and although aware of other HCPs working with the condition, I did not have any young people with CF on my caseload. Prior to data collection, I reflected on and acknowledged my beliefs relating to CF. Lacking any clinical or personal experience, my beliefs were largely rooted in the literature and venturing further afield looking at blogs and YouTube videos relating to CF, which I had completed in preparation for the research. From this, I became aware of the lack of literature available and a sense from local clinicians that further research was needed. I felt my lack of experience of CF limited my personal understanding, however my perception that CF work was likely to be emotive and stressful for HCPs and transition would likely trigger a sense of loss were acknowledged.

An interesting reflection was my personal experience of working with uncertainty. Personally, I felt that this process encapsulated the constructivist viewpoint, in that there was not one objective truth to discover through the data, but a much richer understanding to be

gained by taking into account the multiple perspectives and experiences of participants. The qualitative methodology elicited an inherent sense of uncertainty, which contrasted with my previous experience of conducting quantitative research. I noticed how I potentially had a personal preference for structure, which was initially challenged by being restricted to predict the course of the emerging data. Yet, interestingly such uncertainty evolved into excitement as the narrative developed and I was glad I had persevered with the qualitative approach.

This was my first experience of undertaking a full qualitative research project and I found the process both challenging and rewarding. I embraced the challenge of learning a new methodology given that I was a novice to IPA. I was committed to the research and valued an opportunity to attend a two-day IPA training workshop to familiarise myself with its theoretical and practical underpinnings. Co-establishing a monthly IPA peer supervision group with fellow trainees further developed my commitment to IPA. Both peer supervision and guidance from my research team provided moments of clarity, particularly when I felt overwhelmed whilst immersing myself in the data. I had underestimated the intensity and time commitment of qualitative research and analysis was extremely effortful and painstakingly slow. However, as a visual learner incorporating some creativity compensated for this. My walls became filled with an array of colour all depicting paper accounts of themes and quotations; this artistic side of analysis facilitated flexible story telling and brought the participants' subjective accounts to life.

An interesting observation was how strongly I felt in wanting the paper to be a true reflection of each participant's story. I noticed how protective I became of the participants' accounts and protective of my own interpretation of the data, both of which made it difficult to rearrange or delete extracts. I was concerned about losing the individual narrative and felt that everything I had heard was important and that this should be incorporated in some way. I felt quite uncomfortable deleting extracts yet accepted that this was a key aspect of

qualitative analysis. I hoped that the write up would reflect a level of detail that participants would approve of and I wondered what they would think about the quotations chosen to illustrate themes.

Throughout analysis I gained an increasing appreciation of my active role within the analysis itself. Although I made attempt to remain relatively objective, I was mindful that my own values and experiences might influence decisions that I made about the data. This drew parallels to my clinical work and how therapists were once viewed as blank canvases. Personally, I disagree with this historic claim, because attempts are made to effectively manage our own set of assumptions, beliefs and values within therapy, for example through clinical supervision. I valued the time to reflect on my assumptions and experiences and the impact they had on analysis. The research was a timely reminder of how important it is to provide a space for individuals to tell their story and to develop their own narrative. Interestingly, the coping culture theme reminded me how passionate I have become about staff wellbeing and how reflective practice is a necessity and should not be considered a luxury.

Initially, I found interviewing participants quite daunting because I felt pressure to ensure that the interview would elicit 'rich enough data'. I occasionally felt discouraged when listening to interview recordings, particularly when I had missed an opportunity to explore something in more depth. Acknowledgement of these feelings along with taking some time away from the thesis to refocus was beneficial and later the depth of engagement and meaningful narrative surprised me. I valued embracing the subjective accounts and the reflective diary aided me to document emotions or thoughts that occurred following an interview and supported my learning from each interaction. The interview was piloted on a member of the research team who provided feedback on my style and process. I became

aware of the importance of familiarising myself with the interview schedule in order to improve eye contact and ensure a natural flow of exploration.

I also acknowledged the potential bias of perceiving and interpreting findings from a Clinical Psychology viewpoint. Discussions with the research team, who comprised of Nursing and Clinical Psychology, were fundamental in helping me identify occasions where I had interpreted findings using psychological principles and a reminder to stay true to the dataset. I was also apprehensive about whether my findings would resonate with my supervisors' experiences and appear clinically valuable. However, I was relieved to know that many points raised were familiar yet new perspectives had also emerged.

It is interesting and important to reflect on the way in which young people with CF were referred to as patients. This was the term I used given that it echoed terminology used within the interviews, healthcare services and literature. However, I recall questioning the emotional and psychological impact this label may have for young people with CF. My fear was that the person behind the patient label could be forgotten. Such fear resonated with me given that similar reflections had arisen in my clinical work, questioning the interchangeable terminology of patients, clients and service users within my clinical practice. I seek to empower as a clinician and I believe there is a need to reflect on how we construct those who use our heath care services.

Towards the end of the thesis process it dawned on me that I am about to embark on my own transition from Clinical Training into qualified life. This prospect is daunting, exciting and a privilege all at once, mirroring how I felt before embarking on this research. The thesis provided insight into the juggle of the multifaceted role of Trainee Clinical Psychologist by balancing the clinical, academic and research demands. I began to wonder how qualified Clinical Psychologists incorporate research into their professional life given the stretched nature of clinical work. As I anticipate my next steps into qualified life, I will

undoubtedly continue to reflect and think about how I will intertwine both clinical and research components. I hope I do not lose sight on how both clinical practice and research can complement each other and the enjoyment associated with both.

Lastly, anxiety and self-doubt are familiar territories to me and both sporadically appeared whilst completing this thesis. In particular, the great emphasis placed on 'your' research was initially anxiety provoking, however I converted thoughts of doubt into productivity. I demonstrated ability in undertaking research independently and over time had confidence and self-belief in *my* own work. I also gained a sense of acceptance that I had reached a point where I had completed a piece of work that reflected the best of my ability and that this was 'enough'. I once read that 'progress takes place outside of your comfort zone' and I hope I will continue to fulfill my ambition of doing just that. This thesis therefore symbolises my perseverance, my commitment to lifelong learning and ultimately my professional and personal growth.

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Appendix A: Data Extraction Form

Appendix B:
Bangor University School of Psychology Ethics Approval

Appendix C:
Research and Development (R&D) Approval Letter

Appendix D:
Research and Development (R&D) Approval Letter

Appendix E:
Integrated Research Application System (IRAS) Research Form

Appendix F: Participant Information Sheet [English]

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

PRIFYSGOL BANGOR UNIVERSITY 1884

Participant Information Sheet

Research Project Title

A Qualitative Exploration of the experiences of Paediatric Health Care Professionals working in Cystic Fibrosis Care and on the transition between Paediatric and Adult Services

Information about the research
You are invited to take part in a research study. It is important you have all the information to understand why you are doing the research and what it will involve if you choose to take part.

Please take some time to read this information sheet and if anything is unclear please feel free to contact us

Research Team
Samantha Jones, Trainee Clinical Psychologist
Dr Liz Whitehead, Clinical Psychologist
Dr Jaci Huws, Research Tutor
Dr Gemma Griffith, Research Tutor

What is the purpose of the study?
You are invited to take part in a research study examining the perspectives/experiences of Health Care Professionals (HCPs) working with children and adolescents with Cystic Fibrosis. Given the significant improvements in CF survival, there is now every expectation that children with CF will enter adulthood. Research highlights there is no 'one size fits all' approach in transitional care and each region will develop a different model that suits the needs of the young people.

This study aims to explore the attitudes, perceptions and experiences of HCPs working with this client group and their perspectives on the transition between paediatric and adult services. The study hopes to elicit themes on cystic fibrosis care and the transition process to extend upon previous research and further our understanding of working with this population and to help inform service development.

Why am I being asked to take part?
You have been asked to take part because the study is inviting HCPs who are currently working with children and adolescents within paediatric services in North Wales and HCPs currently working within the CF team at Alder Hey Children's Hospital.

What does the study involve?
The study will require you to participate in a semi-structured interview, exploring your experiences of working with CF and on the transition process between paediatric and adult services. The interview will last between 30 – 60 minutes and will take place at a time, and in a location, which is most convenient for you.

The interview questions have been approved by Bangor University and Betsi Cadwaladr University Health Board as acceptable for this research. However, Samantha may ask further questions based on the answers you have given throughout the interview. All interviews will be recorded on a digital audio recorder and transcribed for analysis purposes. All identifiers will be removed to ensure that all transcribed data is anonymous.

Are there any benefits or risks?
There are no risks anticipated in participating in the study. However if you do feel distressed by any of the questions asked, you do not have to answer them and you can end the interview if you choose. It is important you mention to the researcher if you are becoming distressed. The researcher will also check in with you throughout the interview.

In contributing to the knowledge base of CF there is potential benefit for young people with this condition and professionals working in the field, in furthering our understanding of CF and how it can be treated. Participation may also be of potential personal benefit by providing you with an opportunity to reflect on your professional practice in this area.

What will happen to my data?
At the start of the interview Samantha will discuss with you confidentiality and its limits. Essentially, everything you discuss with the Samantha is confidential between you and her. However, if you disclose information that makes Samantha worried about your safety or the safety of another person she will discuss this with you and make a decision with you if she needs to break confidentiality. Samantha may discuss this with the other research team members.

All data collected will be confidential, and you will not be identifiable in any report, thesis or publication, which arises from this study. All identifiable data will be destroyed when the project has been completed and marked by the University; non-identifiable data from this study will be stored securely for 5 years (to allow for scrutiny following publication). If you would like to receive feedback upon completion of the study your contact details will be stored on a separate database and will be destroyed once feedback has been given. If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

What if I don't want to take part?
It is up to you to decide whether or not you would like to participate in this study. Deciding not to take part will not impact any aspect of your employment, or relationship with the University.

Who do I contact with any concerns about this study?
If you have any concerns or complaints about this study, or the conduct of individuals conducting this study, then please contact Mr. Hefin Francis, School Manager, School of Psychology, Adeilad Brigantia, Penrallt Road, Bangor, Gwynedd LL57 2AS or e-mail h.francis@bangor.ac.uk.

Welsh Language
All information about the study will be provided bilingually. The researcher, Samantha, is a Welsh speaker and interviews can be conducted through the medium of Welsh if preferred.

Who do I contact about the study?
For further information you can contact the Principal Investigator:
Samantha Jones Trainee Clinical Psychologist, NWCPP, School of Psychology, Bangor University, Bangor, Gwynedd LL57 2AS or email psp2c6@bangor.ac.uk

Alternatively you can contact the project supervisor:
Dr. Liz Whitehead, Clinical Psychologist, Paediatric Psychology Service, Ysbyty Gwynedd, Penrhosgarnedd, Bangor, Gwynedd, LL57 2PW or email liz.whitehead@wales.nhs.uk.

Appendix G: Participant Information Sheet [Welsh]

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

PRIFYSGOL BANGOR UNIVERSITY 1884

Taflen Wybodaeth i Gyfranogwyr

Teitl y Project Ymchwil

A Qualitative Exploration of the experiences of Paediatric Health Care Professionals working in Cystic Fibrosis Care and on the transition between Paediatric and Adult Services

Gwybodaeth am yr ymchwil
Gwahoddir chi i gymryd rhan mewn astudiaeth ymchwil. Mae'n bwysig bod gennych yr holl wybodaeth i ddeall pam rydych yn gwneud yr ymchwil a beth fydd yn digwydd os byddwch yn penderfynu cymryd rhan.

Cymerwch amser i ddarllen y daflen wybodaeth hon, ac os oes rhywbeth yn aneglur, mae croeso i chi gysylltu â ni.

Y Tîm Ymchwil
Samantha Jones, Seicolegydd Clinigol dan Hyfforddiant
Dr Liz Whitehead, Seicolegydd Clinigol
Dr Jaci Huws, Tiwtor Ymchwil
Dr Gemma Griffith, Tiwtor Ymchwil

Beth yw pwrpas yr astudiaeth?
Rydym yn eich gwahodd i gymryd rhan mewn astudiaeth ymchwil sy'n edrych ar safbwyntiau/profiadau Gweithwyr Proffesiynol Gofal Iechyd(GPGI) sy'n gweithio gyda phlant a phobl ifanc gyda Ffibrosis Cystig (FC). O ystyried y gwelliannau sylweddol o ran byw'n hirach gyda FC, mae pob disgwyliad yn awr y bydd plant gyda FC yn byw i fod yn oedolion. Mae ymchwil yn dangos nad oes unrhyw un dull pendant i'w ddefnyddio o ran darparu gofal trosiannol a bydd pob rhanbarth yn datblygu model gwahanol sy'n addas i anghenion pobl ifanc.

Felly, nod yr astudiaeth hon yw edrych ar agweddau, canfyddiadau a phrofiadau GPGI sy'n gweithio â'r grŵp cleientiaid hwn a'u safbwyntiau ar y trawsnewid rhwng gwasanaethau plant ac oedolion. Gobeithia'r astudiaeth amlygu themâu'n ymwneud â gofalu am gleifion ffibrosis cystig er mwyn helaethu ymchwil flaenorol a hyrwyddo ein dealltwriaeth o weithio gyda'r bobl hyn a thrwy hynny helpu i ddatblygu gwasanaethau.

Pam rydych yn gofyn i mi gymryd rhan?
Gofynnwyd i chi gymryd rhan gan fod yr astudiaeth yn gwahodd GPGI sy'n gweithio ar hyn o bryd gyda phlant a rhai'n eu harddegau o fewn y gwasanaethau pediatrig yng Ngogledd Cymru a GPGI sy'n gweithio ar hyn o bryd o fewn y tîm FC yn Ysbyty Plant Alder Hey.

Beth mae'r astudiaeth yn ei olygu?
Fel rhan o'r astudiaeth, bydd gofyn i chi gymryd rhan mewn cyfweliad lled strwythuredig, yn archwilio eich profiadau o weithio gyda FC a'r broses drosiannol rhwng gwasanaethau pediatrig ac oedolion. Bydd y cyfweliad yn para 30-60 munud a chynhelir ef ar adeg ac mewn lle sydd fwyaf cyfleus i chi.

Mae cwestiynau'r cyfweliad wedi cael eu cymeradwyo gan Brifysgol Bangor a Bwrdd Iechyd Prifysgol Betsi Cadwaladr fel rhai derbyniol ar gyfer yr ymchwil hon. Fodd bynnag, fe all Samantha ofyn cwestiynau pellach i chi wedi eu seilio ar yr atebion rydych wedi eu rhoi drwy gydol y cyfweliad. Caiff yr holl gyfweliadau eu cofnodi ar beiriant recordio digidol a'u trawsgrifio i ddibenion dadansoddi. Bydd pob enw yn cael ei ddileu er mwyn sicrhau bod yr holl ddata a drawsgrifir yn ddienw.

Oes yna unrhyw fanteision neu risgiau?
Ni ragwelir bod unrhyw beryglon yn gysylltiedig â chymryd rhan yn yr astudiaeth hon. Fodd bynnag, os ydych yn teimlo bod unrhyw rai o'r cwestiynau a ofynnir yn achosi gofid i chi, nid oes raid i chi eu hateb a gellwch ddod â'r cyfweliad i ben os dymunwch. Mae'n bwysig eich bod yn sôn wrth yr ymchwilydd os ydych yn dechrau teimlo'n ofidus. Bydd yr ymchwilydd hefyd gofyn i chi a ydy popeth yn iawn ar adegau drwy gydol y cyfweliad.

Wrth gyfrannu at y sail wybodaeth am FC, mae manteision posibl i bobl ifanc sydd â'r cyflwr hwn ac i'r gweithwyr proffesiynol sy'n gweithio yn y maes, o ran ehangu ein dealltwriaeth o FC a sut y gellir ei drin. Gall cymryd rhan hefyd fod o werth personol posibl gan roi cyfle i chi fyfyrio ar eich ymarfer proffesiynol yn y maes hwn.

Beth fydd yn digwydd i'm data?
Ar ddechrau'r cyfweliad bydd Samantha'n trafod cyfrinachedd a chyfyngiadau cyfrinachedd gyda chi. Mewn gwirionedd, bydd popeth y byddwch yn ei drafod â Samantha yn gyfrinachol rhyngoch chi a hi. Fodd bynnag, os byddwch yn dweud rhywbeth wrth Samantha a fydd yn gwneud iddi bryderu am eich diogelwch chi neu ddiogelwch rhywun arall, bydd hi'n trafod hyn gyda chi ac yn gwneud penderfyniad gyda chi a oes angen iddi drafod hyn gyda rhywun arall. Gall Samantha drafod hyn gydag aelodau eraill y tîm ymchwil.

Bydd yr holl ddata a gesglir yn gyfrinachol ac ni ddefnyddir eich enw mewn unrhyw adroddiad, thesis na chyhoeddiad sy'n deillio o'r astudiaeth hon. Caiff yr holl ddata y gellir adnabod pobl ohonynt eu dinistrio pan fydd y project wedi ei gwblhau a'i farcio gan y Brifysgol; bydd data arall o'r astudiaeth hon lle na ellir adnabod pobl ohonynt yn cael eu cadw'n ddiogel am 5 mlynedd (i ganiatáu archwilio yn dilyn cyhoeddi). Os hoffech gael adborth ar ôl i'r astudiaeth gael ei gorffen, bydd eich manylion cyswllt yn cael eu storio ar gronfa ddata ar wahân ac yn cael eu dinistrio unwaith bod yr adborth wedi ei roi. Os dewiswch dynnu'n ôl o'r astudiaeth a bod eich data eisoes gan y tîm ymchwil, yna mae gennych hawl i ofyn am i'r data beidio â chael eu defnyddio.

Beth os nad wyf yn awyddus i gymryd rhan?
Chi sy'n penderfynu a ydych am gymryd rhan yn yr astudiaeth ai peidio. Ni fydd penderfynu peidio â chymryd rhan yn cael effaith ar unrhyw agwedd ar eich cyflogaeth, nac ar eich cysylltiad â'r Brifysgol.

Â phwy rydw i'n cysylltu os ydw i'n bryderus o gwbl am yr astudiaeth hon?
Os oes gennych unrhyw bryderon neu gwynion ynglŷn â'r astudiaeth hon, neu ynglŷn ag ymddygiad unigolion sy'n cynnal yr astudiaeth hon, cysylltwch â Hefin Francis, Rheolwr yr Ysgol, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd LL57 2AS, neu anfonwch e-bost at h.francis@bangor.ac.uk. h.francis@bangor.ac.uk.

Yr Iaith Gymraeg
Bydd yr holl wybodaeth am yr astudiaeth yn cael ei darparu'n ddwyieithog. Mae'r ymchwilydd, Samantha, yn siarad Cymraeg a gellir cynnal cyfweliadau yn Gymraeg os dymunwch.

Â phwy y dylwn gysylltu ynglŷn â'r astudiaeth?
Am wybodaeth bellach gellwch gysylltu â'r prif ymchwilydd:
Samantha Jones, Seicolegydd Clinigol dan Hyfforddiant, NWCPP, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd LL57 2AS neu anfon e-bost at psp2c6@bangor.ac.uk

Fel arall, gellwch gysylltu â goruchwyliwr y project:
Dr Liz Whitehead, Seicolegydd Clinigol, Gwasanaeth Seicoleg Pediatrig, Ysbyty Gwynedd, Penrhosgarnedd, Bangor, Gwynedd, LL57 2PW neu anfon e-bost at liz.whitehaed@wales.mhs.uk mailto:liz.whitehead@wales.nhs.uk.

Appendix H: Participant Opt-in Form [English]

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

Research ID No:

Opt-In Form

Title of project: A Qualitative Exploration of Paediatric Health Care Professionals' experiences of working in cystic fibrosis care and on the transition between paediatric and adult services.

Name of Researcher: Samantha Jones
Name of Supervisors: Dr Liz Whitehead, Dr. Jaci Huws and Dr Gemma Griffith

Thank you for considering to take part in this research project. Please read the items below and tick the boxes if you agree to be contacted. Please leave your contact details and signature at the bottom and use the stamped addressed envelope to send this form back to Samantha Jones. Alternatively, you can scan and email the form to psp2c6@bangor.ac.uk. Once received, Samantha will contact you to discuss the next stage of the research.

1. I have read and understood the participant information form. ☐
2. I am happy for Samantha to contact me via the contact details I have provided below. ☐
3. I understand I can contact Samantha to discuss the research further. ☐
4. I understand that I can opt-out of the project at any time. ☐

Contact Details:

Name:

Telephone (work):

Email (work):

Preferred method of contact (Please circle): Telephone / Email

Signature…….

Date……

Further information about the study
If you have any further questions or require more information about this study please contact: Samantha Jones via e-mail psp2c6@bangor.ac.uk

Complaints: Any complaints concerning the conduct of this research should be addressed to: Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Gwynedd, LL57 2AS.

Appendix I: Participant Opt-In Form [Welsh]

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

PRIFYSGOL BANGOR UNIVERSITY 1884

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

Rhif Adnabod Ymchwil:

Ffurflen Ymuno

Teitl y project: A Qualitative Exploration of the experiences of Paediatric Health Care Professionals working in Cystic Fibrosis Care and on the transition between Paediatric and Adult Services
Enw'r Ymchwilydd: : Samantha Jones
Enw'r Goruchwylwyr: Dr Liz Whitehead, Dr Jaci Huws a Dr Gemma Griffith

Diolch am ystyried cymryd rhan yn y project ymchwil hwn. Darllenwch yr eitemau isod a thiciwch y blychau os cytunwch i rywun gysylltu â chi. Rhowch eich manylion cyswllt a'ch llofnod ar y gwaelod, a defnyddiwch yr amlen barod i anfon y ffurflen hon yn ôl at Samantha Jones. Fel arall, gellwch sganio'r ffurflen hon a'i hanfon trwy e-bost at: psp2c6@bangor.ac.uk Unwaith y bydd yn ei chael, bydd Samantha'n cysylltu â chi i drafod cam nesaf yr ymchwil.

1. Rwyf wedi darllen a deall y daflen wybodaeth i gyfranogwyr. ☐
2. Rwy'n fodlon i Samantha gysylltu â mi trwy'r manylion cyswllt isod ☐
3. Deallaf y caf gysylltu â Samantha i gael mwy o drafodaeth ar yr ymchwil. ☐
4. Deallaf y caf roi'r gorau i'r project ar unrhyw adeg. ☐

Manylion Cyswllt:

Enw:

Rhif ffôn (gwaith):

E-bost (gwaith):

Dull cysylltu dewisol (rhowch gylch): Ffôn/ E-bost

Llofnod……..…… Dyddiad:……

Mwy o wybodaeth am yr astudiaeth
Os oes gennych unrhyw gwestiynau eraill, neu os hoffech gael rhagor o wybodaeth am yr astudiaeth hon, cysylltwch â: Samantha Jones trwy e-bost psp2c6@bangor.ac.uk

Cwynion: Dylech anfon unrhyw gwynion ynglŷn â'r modd y cynhaliwyd yr astudiaeth hon at: Mr Hefin Francis, Rheolwr yr Ysgol, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2AS.

Appendix J: Participant Consent Form [English]

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

PRIFYSGOL BANGOR UNIVERSITY 1884

Participant Consent Form

Title of project: A Qualitative Exploration of Paediatric Health Care Professionals' experiences of working in cystic fibrosis care and on the transition between paediatric and adult services.

Name of Researcher: Samantha Jones
Name of Supervisors: Dr. Liz Whitehead, Dr. Jaci Huws and Dr. Gemma Griffith

	Please initial
1. I confirm that I have read and understood the Participant Information Sheet (Version 3 dated 22.09.15) for the above study.	
2. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any of my legal rights being affected.	
4. I confirm that I consent to the interview being audio recorded by the researcher as part of the study.	
5. I give permission for the researcher to use anonymised quotes from the interview and for the anonymised interviews to be shared with any other researchers, or stored as data archives.	
6. I agree to take part in the above study.	
7. If I indicate that I would like to receive a summary of the study's findings upon completion, I agree to the researcher contacting me again in due course to provide this information.	
8. I am aware that all identifiable data will be destroyed when the project has been completed and marked by the University and that non-identifiable data from this study will be stored securely for 5 years.	

Participant:

Signature: …… Name: ……..…

Date:……

Researcher:

Signature: …… Name: ……..……

Date:…….

Should you have any questions or require further information regarding the study and/or your rights as a participant please contact: Samantha Jones psp2c6@bangor.ac.uk

Complaints: Any complaints concerning the conduct of this research should be address to: Mr Hefin Francis, School Manager, School of Psychology, Bangor University, Gwynedd, LL57 2AS

Appendix K: Participant Consent Form [Welsh]

Ffurflen Gydsynio i Gyfranogwyr

Teitl y project: A Qualitative Exploration of the experiences of Paediatric Health Care Professionals working in Cystic Fibrosis Care and on the transition between Paediatric and Adult Services

Enw'r Ymchwilydd: Samantha Jones
Enw'r Goruchwylwyr: Dr. Liz Whitehead, Dr. Jaci Huws a Dr. Gemma Griffith

	Llofnodwch
1. Cadarnhaf fy mod wedi darllen a deall y Daflen Wybodaeth i Gyfranogwyr (Fersiwn 3, dyddiedig 22/09/15) ar gyfer yr astudiaeth uchod.	
2. Rwyf wedi cael cyfle i ystyried y wybodaeth a gofyn cwestiynau, ac wedi cael atebion boddhaol.	
3. Deallaf fy mod yn cymryd rhan o'm gwirfodd, a bod gennyf hawl i dynnu'n ôl ar unrhyw adeg, heb roi unrhyw reswm, a heb i hynny effeithio o gwbl ar fy hawliau cyfreithiol.	
4. Rwy'n cadarnhau fy mod yn cytuno i'r cyfweliad gael ei recordio ar dâp sain gan yr ymchwilydd fel rhan o'r astudiaeth.	
5. Rhoddaf ganiatâd i'r ymchwilydd ddefnyddio dyfyniadau dienw o'r cyfweliad ac i'r cyfweliadau dienw gael eu rhannu gydag unrhyw ymchwilwyr eraill, neu eu storio fel archifau data.	
6. Rwy'n cytuno i gymryd rhan yn yr astudiaeth uchod.	
7. Os rwyf yn nodi yr hoffwn gael crynodeb o ganlyniadau'r astudiaeth pan fydd yr astudiaeth wedi'i gorffen, cytunaf i'r ymchwilydd gysylltu â mi eto i roi'r wybodaeth hon.	
8. Rwy'n deall y caiff yr holl ddata y gellir adnabod pobl ohonynt eu dinistrio pan fydd y project wedi ei gwblhau a'i farcio gan y Brifysgol ac y bydd data arall o'r astudiaeth hon lle na ellir adnabod pobl ohonynt yn cael eu cadw'n ddiogel am 5 mlynedd.	

Cyfranogwr:

Llofnod: …… Enw: ……

Dyddiad ……....

Ymchwilydd:

Llofnod: …… Enw: ….....……

Dyddiad:……....

Os oes gennych unrhyw gwestiynau neu os oes angen rhagor o wybodaeth arnoch am yr astudiaeth ac/neu eich hawliau fel cyfrannwr cysylltwch â: Samantha Jones psp2c6@bangor.ac.uk

Cwynion: Dylid anfon unrhyw gwynion ynglŷn â'r ffordd y cynhaliwyd yr astudiaeth hon at: Mr Hefin Francis, Rheolwr yr Ysgol, Ysgol Seicoleg, Prifysgol Bangor, Bangor, Gwynedd, LL57 2AS.

Appendix L: Interview Protocol/Schedule [English]

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PRIFYSGOL BANGOR UNIVERSITY 1884

Interview Protocol

Title of Project: A Qualitative Exploration of Paediatric Health Care Professionals' experiences of working in cystic fibrosis care and on the transition between paediatric and adult services.

Name of Researcher: Samantha Jones
Name of Supervisors: Dr Liz Whitehead, Dr. Jaci Huws and Dr Gemma Griffith

Prior to commencing interview:
Research will explain that the interview will be audio recorded and will anticipate the interview will last between 30 minutes to one hour. Participants will be reminded that anonymised information will be used in the analysis and reporting of the study and transcribed data will be anonymised so that individuals will not be identifiable. Limits of confidentiality will also be outlined regarding the specific case of a participant disclosing information that indicated that themselves or someone else they talk about may be a risk.
Participants to be reminded that they can withdraw and stop the interview, or request a break from the interview at any time. Participants will also be told that there are no right or wrong answers to the questions I am going to ask and it is really important that they talk to me honesty so that I can learn about their experience of working with CF care and their experiences of transitioning a young person between paediatric and adult services.
Clarify whether the healthcare professional is currently a member of the CF multidisciplinary team and has some experience of transition within CF.
Following this written informed consent will be gained.

Demographic Info

- What is your job role?
- How long have you worked in this current role?

Warm up questions

- I am interested in your experiences of working within cystic fibrosis care and also on your experiences of transitioning a young person between paediatric and adult services.

Cystic Fibrosis Care

- If we begin with your experiences of working in cystic fibrosis care more generally - how would you describe your role in relation to cystic fibrosis care?

Follow up on information shared by the respondent and proceed to the following structured questions, omitting any aspects already covered. The questions can be adapted according to respondent's responses.

- What are your thoughts on cystic fibrosis care?

- How does working within cystic fibrosis make you feel?
- Could you share some of your experiences of working within cystic fibrosis care? (What happened? What did you do? How did you feel?)
- Could you tell me about your working relationships with other professionals within the team? (Describe/share examples of working together)

Transition

- Can you tell me what you think of transition within cystic fibrosis care?
- Can you give me any examples of this?
- How do you see your role within transition?
- How does transitioning a young person from your service onto adult services make you feel?
- What are your thoughts/experiences on your working relationships with respect to transitioning a young person?

Is there anything else that you think I should know and that could help me understand your experiences?

Thank you for taking your time to participate in this interview and sharing your experiences, it is greatly appreciated.

Appendix M: Interview Protocol/Schedule [Welsh]

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

PRIFYSGOL BANGOR UNIVERSITY 1884

Trefn y cyfweliad

Teitl y Project: A Qualitative Exploration of the experiences of Paediatric Health Care Professionals working in Cystic Fibrosis Care and on the transition between Paediatric and Adult Services

Enw'r Ymchwilydd: : Samantha Jones
Enw'r Goruchwylwyr: Dr Liz Whitehead, Dr Jaci Huws a Dr Gemma Griffith

Cyn dechrau'r cyfweliad:
Bydd yr ymchwilydd yn egluro y caiff y cyfweliad ei recordio ar dâp sain ac y rhagwelir y bydd y cyfweliad yn para rhwng 30 munud ac awr. Caiff cyfranogwyr eu hatgoffa y defnyddir gwybodaeth ddienw wrth ddadansoddi ac adrodd ar yr astudiaethau ac y bydd data a gaiff eu trawsgrifio yn ddienw fel na fydd modd adnabod unigolion. Hefyd nodir beth yw terfynau cyfrinachedd pe bai cyfranogwr yn datgelu gwybodaeth y gallent hwy eu hunain neu rywun y maent yn siarad amdanynt fod mewn perygl.
Dylid atgoffa cyfranogwyr y gallant dynnu'n ôl o'r cyfweliad a'i stopio, neu ofyn am seibiant yn ystod y cyfweliad ar unrhyw adeg. Dywedir wrth gyfranogwyr hefyd nad oes yna atebion cywir neu anghywir i'r cwestiynau y byddaf yn eu gofyn a'i bod yn wirioneddol bwysig eu bod yn siarad â mi'n onest fel y gallaf ddysgu am eu profiad o weithio gyda gofal FC a'u profiadau o symud pobl ifanc rhwng gwasanaethau pediatrig ac oedolion.
Er mwyn bod yn glir gofynnir a yw'r gweithiwr proffesiynol gofal iechyd yn aelod o'r tîm FC amlddisgyblaethol ac a oes ganddo beth profiad o'r cyfnod o newid o un gwasanaeth CF i'r llall.
Yn dilyn hyn gofynnir am gydsyniad gwybodus ysgrifenedig.

Gwybodaeth ddemograffig

Beth yw eich swydd?
Ers pryd ydych chi'n gweithio yn y swydd yma?

Cwestiynau rhagarweiniol

- Mae gen i ddiddordeb yn eich profiadau o weithio ym maes gofalu am rai gyda ffibrosis cystig a hefyd eich profiadau o symud pobl ifanc rhwng gwasanaethau pediatrig ac oedolion.

<u>Gofal Ffibrosis Cystig</u>

- Os gallwn ddechrau gyda'ch profiadau o weithio ym maes gofal ffibrosis cystig yn fwy cyffredinol - sut fyddech chi'n disgrifio eich swydd mewn perthynas â gofal ffibrosis cystig?

Ewch ar ôl y wybodaeth a rannwyd gan y cyfranogwr gan fynd ymlaen at y cwestiynau strwythuredig a ganlyn, gan hepgor unrhyw agweddau yr ymdriniwyd â hwy eisoes. Gellir addasu'r cwestiynau'n ôl ymatebion y cyfranogwr.

Beth yw eich barn am ofal ffibrosis cystig?

Sut mae gweithio ym maes ffibrosis cystig yn gwneud i chi deimlo?

Ellwch chi rannu rhai o'ch profiadau o weithio ym maes gofal ffibrosis cystig? (Beth ddigwyddodd? Beth wnaethoch chi? Sut roeddech chi'n teimlo?)

Ellwch chi ddweud rhywbeth wrtha i am eich perthynas waith gyda gweithwyr proffesiynol eraill yn y tîm? (Disgrifio/rhannu enghreifftiau o gydweithio)

Cyfnod trawsnewid

- Fedrwch chi ddweud wrthyf beth ydych chi'n ei feddwl o'r trawsnewid o ofal pediatrig i ofal oedolion ym maes ffibrosis cystig?
- Fedrwch chi roi enghreifftiau o hyn?
- Sut ydych chi'n gweld eich swydd o fewn y trawsnewid hwn?
- Sut mae symud rhywun ifanc o'ch gwasanaeth chi i'r gwasanaethau i oedolion yn gwneud i chi deimlo?
- Beth yw eich meddyliau/profiadau ynghylch eich cysylltiadau gwaith o ran symud pobl ifanc o un gwasanaeth i'r llall?

Oes yna unrhyw beth arall yr ydych yn meddwl y dylwn ei wybod a allai fy helpu i ddeall eich profiadau?

Diolch am roi eich amser i gymryd rhan yn y cyfweliad yma a rhannu eich profiadau. Fe'i gwerthfawrogir yn fawr.

Appendix N: Segment of annotated transcript

Emergent Themes	**Original Transcript** I = Interviewer P = Participant	**Exploratory Comments*** **(in line with Smith et al., (2009)**
*Exploratory Comments Key Descriptive Comments: Focus on describing the content of what the participant has said, the subject of the talk within the transcript (normal text). *Linguistic Comments*: Focus on exploring the specific use of language by the participant (*italic*) Conceptual Comments: Focus on engaging at a more interrogative and conceptual level (underlined)		
Longevity of input Lifespan perspective Personal transition Change Enrichment/growth Improvement Finality Death in adulthood.	I: What are your thoughts on CF care generally? P: Well I I previously worked in the adult um I previously worked in adult CF in (England) so this is the first time I've ever done pediatrics when I came here so I did paediatrics generally aswell ... but now I just mainly do CF. Um so I find that...I find paediatrics I enjoy more than adults. I don't know I think I feel like from the fact that we see them from newborn and they also are newborn screened so a lot of them are better that you can actually see more of an improvement and obviously you actually watching them grow and develop, which is actually nice just to get to know them. You actually do see things improve whereas as suppose before when I worked in adults um a lot of the inpatients, it was inpatients you see, I didn't really do a lot of outpatients work then so as an adult dietician in an inpatient unit... um I was also a young person myself and I was looking after people my age that were essentially palliative so although we did obviously support them and help them nutritionally and keep as well as they could be, ultimately there were lots of deaths... and here in I think with the way they are and our care at the moment we do actually .. you're seeing them from early on and you can actually feel like you do actually get to know them and do a bit more	Did not know what to expect when starting in paediatric CF. Mainly worked in adult CF prior to this. Unconfident at first? Lack of experience initially. Self-reflection on why she prefers paediatrics to adult CF work. Early input – sees a sense of growth and development. Does this take her away from the reality of CF Contrast between paediatric and adult care – both ends of life trajectory – life and death. Improvements seem more noticeable in paediatrics. What is the impact of culture [England]? What impact has her experience in adult services had on her role within paediatrics? Her own transition/change. Our care – team aspect

		Closeness to self – her own age; relatable wonder about her role and how effective she felts 'Better' - what does better signify? Improvements in health? Awareness of no cure in CF. Could not prevent death in adulthood but paediatrics has better outcomes due to seeing them grow up and develop? Get to build a relationship and are functional in their development as opposed to support them towards death? Did it make her face her own mortality did she feel guilty? 'Actually' used on numerous occasions; didn't expect to like it? Jumbled over words – difficult to get a coherent sense at times
Lifespan Emotional/impact sadness Attachment/Emotional Bond Family/parental? Humanity Therapeutic Investment Personal self	I: What types of emotions come up in your paediatric work? P: Um yeah I mean I think when I think back to the adult side and suppose now with the adolescents now and um we have some very sick older inpatients like even now ... so you do think some of them but not often may not actually even reach transition, um which is unusual and very sad. In adults I think a lot of the time yeah it's actually really emotional cos you actually see I mean I suppose the same here really like I think you actually see these children patients more than you see like most of your own family, so you know if you see especially like if they're an inpatient you'll see them pretty much everyday um when they're in. You know obviously you have your own family you're not at home but your actual general family and your friends you see them more and interact with them more than you would with your own close family and close friends so ultimately yeah you do actually get very involved with them not just in the clinical sense. It's easy to so yeah so you know and you you can't actually just [sigh] I don't think you can become completely separate and you can be professional and we obviously are but I don't think you can't help but not get	Reflecting back to her experiences in adult experiences. Adult side – dark side? Understanding of CF trajectory – conflict? Which is 'better' dying younger or older? Children and patients – terminology used interchangeably Investment in paediatric CF care – relationship with families and young people. Parallels being made to family- extension of the family. Personally invested? Shaped by longevity of CF care? Attachment – being human; difficult to separate professional and personal self?

	involved in their personal life. So as in not just their nutritional care, because actually it's relevant whatever is happening to them you know, you know and and I think you just yeah so it's quite I don't know the word	Difficult in articulating the emotional impact for her – does this reflect the struggle associated with the attachment and conflict between professional and personal self?
	I: Do you have any examples of experiences of when that has happened in paediatrics?	
Professional role/leadership Empathy Compassion Responsibility Bond Trust Therapeutic rapport/investment Loss/Grief	P: So I suppose like I as well things like … with I I I'm like the lead for CF diabetes as well so with that you've obviously got another whole diagnosis for them um I think with those patients you kind of go through it with them really (...) so you do feel you know you feel bad for them ultimately you feel you know but you have to try and make them do something that ultimately you know they don't want to do and you don't and you actually just think well I don't blame you. Um yeah and also when I worked in adults there was um a boy who was like my age at the time, was he was my age no he wasn't much different to me. He was probably like three or four years younger than me and he and I think he had just started uni so yeah he must have been about not that much different to me, so yeah he started at uni and he was doing teacher training and he was actually and um that's quite interesting co we both liked all the same kind of music and stuff so obviously as you're talking to people you've got to and if you're trying to like persuade somebody to do something and he was another one that had diabetes and he was struggling so ultimately to try to get to know them and for them to like trust you and want to actually take your advice. You can't just go in there and be um dictatorial you've got to be um a bit more you know same here really. So we got to know each other quite well and he was and um he died um ... like when I was there and I went to his funeral and actually it was awful and actually I haven't been to another funeral since then.... Actually it was interesting because actually the whole team did go and I always think that's an interesting thing cos I think here there's been a few deaths since I've been here but I haven't actually been to any of the funerals cos I think that's quite, that's	Additional role in CF care - dual diagnosis Go through it with the young people – empathise burden of (dual) diagnosis and treatment demand. Jumbled language Influence of experience in adult care. Emphasis on closeness in age and life stage; did she feel guilty because she was embarking on her career? Appreciation for her own health? Interesting used on a number of occasions – what does this signify? Therapeutic relationship – core of her care Trust – bidirectional trust between her and young adult Could reflect her values as a clinician. Grief response – has not attended a funeral since. Interesting – is this used to mask the true emotional impact? What did this funeral mean to her? Did it help her grief process?

Professional and personal conflict Responsibility Blurring of boundaries Life stage Guilt Investment/ Involvement Emotional impact Change in care Preparation Fostering independence Development	where I think your professional boundary is is I don't know it's quite blurred isn't it, cos I know it's quite common especially in paediatrics from all of the kind of care team to go to the funeral and the family want them to so I think that's like a difficult one isn't it especially with the older ones that you've looked after I mean I've only been here six years but then six years is a long time to have been seeing somebody very regularly so and now here I just think, I think that I don't know I just think it took me such a long time to get over that...I think you I almost felt as well like it was a bit wrong I don't know. I just felt like I shouldn't maybe have been there cos obviously it was really upsetting cos it's upsetting when any young person passes away and when they've and it almost makes me like worse not worse but you know when somebody has got like when they're already they're kind of embarking on their career as a young person so you can put yourself in their position so I thought it was it just felt like you were intruding in their own lives. Although you do have a big involvement in them um so I don't know I found that quite interesting and I almost think like that there is an expectation with a lot of families that you would go you know (...). So he was twenty two no he would have been twenty one yeah and I was probably like twenty five or something or maybe twenty four actually yeah maybe twenty four so I don't know so yeah, it is hard when the and I suppose here we've got a lot of children now who are going over to adults and they are like um you do kind of think you feel sad when they go [laughs] cos you almost feel like you've had you've look after them for so long and then you almost feel like someone else has gotta take over and I don't know it's interesting I: How do you see your role now in terms of transition? P: Um when they go into transition we almost prepare them for that process because there the there is a different change in the way they're managed I think. Although they are still like kind of supported they are seen as adults but I think the thing in paediatrics is I think they are more supported than adults and I think children that have got a long term condition like CF or anything their parents do	Death also pertinent to paediatric CF care. Expectation that staff will attend funerals. Torn between her professional and personal role – uncertain whether it is 'okay' to attend a funeral. Longevity of input -takes it toll professionally and personally? Sadness Guilt? Professional and personal involvement Intruder – what does this mean to her? Does this signify that she felt as though she overstepped the boundary in attending the funeral? Hard Sadness following transition – shaped by longevity and emotional impact? Interesting – repeated use of word Mixed feelings Prepare young people for adult life/adult services. Differences in paediatric and adult care

Service contrast Treatment Life stages Burden	a lot of the treatment and things for them and I think more than children without a chronic disease they're probably babied you know. I think so we try to prepare them so you have you gotta do things for yourself you can't have your mum counting out like your enzymes for you when you're nineteen; you can't have your mum coming and doing your insulin for you or doing or reminding you to take your whatever especially if you're going off to uni or something like that you know. So I think there's a lot of like and then there's also wanting them to um be able like demonstrate to the adult team that they understand what their creon is for, what their enzymes are for how many they're suppose to take and why you know actually why they are taking insulin and all that. So like often you find like when you ask them those questions they'll you ask that those questions coming up cos we had a few in clinic this week that are going to adults in March um that they can't answer you still they still don't know. I wonder if that's cos they don't even bother to listen because they think well my mum's going to do it for me anyway or when it's coming up to the adults you're saying to them you're going to the adult clinic you know can you tell me like what you're suppose to do with your enzymes, why you take your enzymes or whatever and some of them are like well I dunno.	Babied – reflection of paediatric CF and differences between services Helping young people Developmental stages and life experiences & impact of CF Expectation – do demonstrate understanding to adult team? Anxiety? Does she question her efficacy as a professional here? Pressure? Her own needs?
	I: How does that make you feel?	
Responsibility Systemic impact Competence	P: Yeah I think yea I know I think it's hard cos I think it would be hard as a parent to let go and let them have responsibility because the teenager probably just wouldn't do it and they know that. I think as well that you also think about um how the adult team see you and your care and think that maybe when they go over there and say I don't know what that's for, well then the adult dietician will think well clearly they've not encouraged much independence or done much teaching with them which in actual fact you've been hammering it home for like for fifteen years so (laughs) so yeah.	Hard, frustration She was also a parent – what impact does this have? Letting them go – sense of responsibility that she has done a good enough job. Anxiety? How will adult team see her and her work? Will the young person's adherence/knowledgeable be a good reflection of her input. Hammering – frustration related to her commitment? Mirrors relentless nature of CF.
	I: Can you share some examples of transition?	

Uncertainty Investment Curiosity No closure Own needs Boundaries Reassurance (own needs) Therapeutic investment Out of the blue	P: There's been a few like where I think you feel like you don't know what's going to happen to them. I mean there was one chap for example who we had loads and loads and loads of input, and he kind of would run off and things and escape on the ward and go to parties and things like that and he didn't really do his feeds and he fostered I think and um then adopted and um he wouldn't do things really.... and I kind of felt like when he went off to the adults I wondered whether they would just cos he wasn't necessarily pleasant with people unless um you knew him whereas I think what would probably happen is he'd just behave badly and then just be discharged or something so you kinda thing about him. You think I wonder what's happened I wonder what, cos you don't really hear and you don't really I suppose you shouldn't you don't get updates on them officially you might hear things what people have done but you don't really hear so you wonder what they're up to and things so yeah. I: How does that make you feel? P: I dunno, I suppose, I suppose if you if you knew like a year down the line where they were and what they were doing that would be quite nice, but only out of kind of interest or reassurance that they were doing well or not or whatever. But yeah I suppose it's it is strange that you know they kind of just go and that's it really cos somebody asked me actually this week about a patient that we were starting on insulin and I was actually off sick for two months this year August and September so that last time I saw them was in clinic and she needed to start insulin and she wouldn't so I did lots of work with them. I got a meeting with the diabetes consultant and nurse um basically to say like you know she should be on insulin and she needs it and she should start but they declined cos she was doing her exams um and it must have been like the end of June and she was doing her GCSEs and um and then I was off and then the diabetes nurse asked me this week how she got on and when she was next coming to clinic... And um I'd forgot that she's actually transitioned now so we won't see her again so I just went down to the diabetes nurse this morning um to say she's gone so dunno, like we've obviously handed her over to them, so	Uncertain about what's going to happen Trajectory of paediatric to adult life/CF care Relentless input Impact of chronic illness for a adolescent Get to know patients' personalities Anxiety – how young person will be in adult services? Curiosity <u>The unknown – acceptance to that? Or is there a reluctance to accept not knowing? Sadness due to the lack of closure and finality of transition. Raises the question as to whether she is professionally and personally prepared for transition.</u> *Repetition* <u>Does this reflect her own needs – need for reassurance or to know how young people are out of interest following transition? Is this a personal or professional need?</u> Off sick from work – <u>consider concept of being unwell and not in work if she views young people as extended member of family.</u> Transition seems to catch her off guard Professional investment

Unfinished business	that's it we've done that well somebody has because I wasn't here, um it's almost kind of like that unfinished business almost you know.	*Forgot* – is transition avoided emotionally? Transition comes by abruptly? Familiarity of seeing young people and longevity of input- does this make accepting and preparing for transition harder?
	I: So quite recent	Young person had transitioned – caught off guard. Lack of preparation?
Curiosity Regret Frustration	P: Yeah, yeah cos I feel like I just saw her but then obviously I was then off so somebody will have seen her in the interim but she's just gone over to the adults...And in my head I keep thinking she won't be on insulin even though she needs it she's probably refused with them whereas we almost had it do you know what I mean so it's like, so yeah it's interesting.	Abrupt nature of transition Thinking about her care – value base as clinician? *Almost had it* –does this signify that her? Linked with unfinished business?
	I: What are your thoughts on your working relationships with other professionals in terms of transitioning?	*Interesting – repeated use*
Dedication Commitment Frustration Disconnect	P: Um, so I've been over a few times to the [adult hospital] and the [other dietician] is more like senior who I work so she's been here for like I dunno like thirty years I think, so she would normally go over to meet them. So and we would go through all the transition patients and we send them a summary so [other dietician] and I had sent a big detailed summary of all our patients who were going in November and in March um but we didn't hear anything back, we haven't even had acknowledgement of like our email or anything so	Counterpart in team – longer investment (30 years) consider impact on perceived competence
	I: How do you feel about that?	Disconnect between paediatric and adult teams
Disconnect Disappointment	P: Well yeah it is quite disappointing cos I remember I suppose the other side as well when I was in adults we would get we might have, that was [England] that wasn't here. So I remember getting eighteen year olds that had transitioned from paeds to adults with like little or no information about them from some centres and them being really annoyed um and wanting to have like a detailed conversation but I suppose you just get like very little information. You basically just would get the transition information from the paeds from some places and	Disappointment due to the disconnect between paediatric and adult services. Reflecting on when she worked in adult services – reminiscing?

Need for improvement Maternal/parental influence?	just almost not disregard it but just start from scratch you know with your own kind of assessment of what's actually gone on, cos you think well there's nothing on this that's helpful to us, so you know. I think face to face is better I think because we're so busy and so under staffed here [other dietician] and I haven't been over, well we haven't been over together since probably before I was on maternity leave so that was you know two years ago um so I haven't been over to the adults to do a transition meeting with them in person and an email isn't really I think enough. The [other dietician] went over to do the transition clinic um but when you send over information and you don't even get like a thank you or whatever back or even an acknowledgement it is quite poor really.	*'Other side' – dark side? Feels very separate and sense of unknown* Did she want to do a better job in paediatrics? Does she feel betrayed by adult team? Importance of face-to-face contact Maternity leave – consider impact of this in relation to CF work? Maternal influence?

Appendix O: Summary of Superordinate and Subthemes for Each Participant

	Trajectory of Care: Therapeutic Investment			**Professional Parent(ing)**			**Coping Culture**		
	"My role and my responsibility"	**"Lifespan commitment"**	**"You don't have a magic wand": No cure**	**Attachment: Emotional Investment**	**Blurred Boundaries**	**"Unfinished Business": Left Longing**	**Disconnect and distancing**	**Whose needs?**	**Evolution of CF: Optimism**
"Patricia"	√	√		√	√		√	√	√
"Charlotte"	√	√	√	√	√	√	√	√	
"Chelsea"	√	√	√	√	√	√	√	√	√
"Heather"	√		√	√			√		√
"William"	√	√		√	√	√	√		√
"Susan"	√		√	√	√	√		√	
"Rachel		√		√	√	√	√	√	√