Adolescents' Experiences of Isolation in Cystic Fibrosis

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Abstract

Background

Cystic Fibrosis (CF) infectious isolation guidelines and clinical recommendations exist in standards of CF care to reduce the risk of cross-infection between individuals with CF. Chronic infection is associated with deterioration in lung function and increased rates of morbidity and mortality, thus preventing and reducing cross-infection is a concern for individuals with CF. Understanding the bio-psychosocial implications of isolation is vital to developing and providing holistic approaches to CF care. This study aimed to make sense of how adolescents with CF understand and experience infectious isolation during their care.

Method

Qualitative, semi-structured interviews were conducted with nine adolescents, aged 12-19 years-old, with a diagnosis of CF who had experienced isolation. Interviews were analyzed using inductive thematic analysis.

Results

Participants experienced difficulty adjusting to living with isolation and attempted to integrate their isolation experiences. Isolation highlighted a sense of threat posed by cross-infection, a threat which participants experienced as originating from others and from themselves to others. Participants described striving to protect themselves and others from this threat. Isolation also appeared to exacerbate differences participants noticed between themselves and others without CF.

Conclusion

For adolescents with CF, isolation is not a neutral experience. Adolescents reported difficulty understanding isolation and challenges associated with this experience across settings. Given these difficulties, multi-disciplinary teams should increase awareness, understanding and discussion about the psychosocial impact of isolation amongst those with CF, their families and wider systems, to promote optimal bio-psychosocial outcomes. Future research could explore experiences of isolation from children, family and staff perspectives.

Key Words: cystic fibrosis, pediatrics, adolescents, infection control, medical isolation, chronic illness, experiences, qualitative research

Abbreviations: CF: Cystic Fibrosis; MDT: Multi-disciplinary team; Bio-psychosocial: Biological, psychological and social.

Implications for Impact Statement

This study suggests that there are psychological and social complexities associated with medical isolation experienced by adolescents with Cystic Fibrosis as part of their routine care. It highlights experiences of isolation from the perspectives of adolescents' themselves and suggests the importance of considering the possible psychological and social impact of isolation as part of a multi-disciplinary approach to practice.

In recent years, there has been increasing recognition that some chronic infections people with cystic fibrosis (CF) acquire are more difficult to treat (Márquez et al., 2017; Tunney et al., 2008). Chronic infection with mycobacterial pathogens such as *Mycobacterium abscessus* and *Pseudomonas aeruginosa* are associated with rapid deterioration in lung function and increased rates of morbidity and mortality for individuals with CF (Bar-On et al., 2015). Therefore, measures to prevent acquisition in individuals with CF are of paramount importance.

Infection control guidelines and recommendations were developed to assist in the prevention and management of cross-infection for both adults and children with CF (Floto et al., 2016; Saiman & Segal, 2003;2013). Despite debate regarding the modes of transmission of different mycobacteria (Bryant et al., 2013; Harris et al., 2014), the focus of guidelines in the United Kingdom (UK), United States of America (US) and in wider Europe (Cystic Fibrosis Trust, 2011; Floto et al., 2016; Saiman & Segal, 2003) are on the need to use cohort or individual isolation procedures. In most clinics, patient arrival times are staggered and patients/families are allocated a single separate room whilst the multi-disciplinary team (MDT) rotate rooms. The gold standard for inpatients is individually filtered rooms, but in practice patients may stay in individual side rooms, with movement around the hospital ideally restricted by the presence of others with CF. Hand hygiene, cleaning touched surfaces, the use of rooms with minimal furniture, and barrier nursing procedures are also outlined. Recommendations also state that individuals with CF avoid face-to-face contact with others with CF throughout their lifetime. Implications can occur where there are extended family members with CF, or where multiple children with CF attend the same school. Moreover, recommendations have implications for CF communities, local group activities, and cessation of events such as CF-specific meetings, summer camps or face-to-face attendance at conferences (Cystic Fibrosis Trust, 2013).

The association between disease severity and psychosocial problems in CF (Quittner et al., 2014) suggests that the emotional effect of CF may be substantial. Questionnaire studies into adult and parent perceptions of isolation in CF have indicated concerns over the potential social and emotional costs of isolation with a potential risk to patients' mental wellbeing, including loneliness, boredom, and stigma (Russo, Donnelley, and Reid, 2006; Griffiths, Armstrong, Carizino, and Robinson, 2004). Risk factors associated with adult negative psychological and social reactions to isolation include lack of understanding about isolation and uncertainty regarding consistency of implementation of isolation procedures (Ullrich et al., 2002; Russo et al. 2006). Patients' understanding of treatment in CF has also been identified as a key determinant of adherence (Bucks et al., 2009). Yet, little is known about adolescent understanding or experiences of isolation in CF and how they might adhere to isolation recommendations or procedures.

The need to better understand the potential psychosocial impact of isolation throughout adolescence and adulthood is ever-increasing. On-going improvements in medical technology and specialist care continue to raise life expectancy for individuals with CF (e.g., Reid et al., 2009). There are increasingly stringent isolation measures in place for certain infections for the foreseeable future which could also add additional challenges in adapting to CF demands through the lifetime (Shearing, Duff, and Denton, 2015).

This study aimed to provide a detailed and in-depth insight into adolescents' understandings, perspectives, and experiences of isolation across clinic, inpatient and everyday life settings for individuals with CF. The research aimed to inform ways to meet the ever-increasing medical and psychosocial demands unique to adolescents with CF, as well as to further inform delivery of patient-centered care.

Method

Participants

The inclusion criteria were adolescents, aged 12-19 years, with a diagnosis of CF who had experienced isolation as part of routine treatment at their registered clinic site. Participants were excluded if the medical team had any concern about an individual's mental state or physical health which may impact on their ability to engage in the study or if the study may negatively impact on the individual. A purposive sampling technique was used to gain an 'insider' perspective of experience, rather than seeking statistical generalizability (Rice and Ezzy, 1999). Nine adolescents participated in response to invites from clinical staff in two pediatric cystic fibrosis services in England. Table 1 shows participant demographics.

Design

A qualitative methodology enabled an in-depth exploration of adolescents' understanding and lived experience of isolation and was chosen because this is a new area of exploration (Corbin and Strauss, 2008).

Measures

Parents, or adolescents who were aged 16 years or over, completed the demographic form; where information was unknown, permission was sought for a clinic team member to access demographic data.

Procedure

Ethical approval was obtained via the National Health Service (NHS) Research Ethics Committee and the relevant Research and Development Departments. Participants were interviewed face-to-face at their homes or the CF clinic using a semi-structured interview schedule. Interviews were, on average, 45 minutes long. The interview schedule was collaboratively designed by authors in discussion with CF clinicians, an expert by experience from the UK CF Trust, and a young people's public and patient involvement panel. Topic areas were identified which broadly linked to theoretical concepts emerging from previous literature. The quality of the schedule was appraised using Kvale's recommendations (Kvale, 1996) that interviews should be: knowledgeable, structured, clear, gentle, sensitive, open, steering, and critical. The schedule was reviewed by authors and clinicians within the recruitment sites to ensure it met these criteria.

Assent /informed consent was collected from adolescents and their parents. The interview schedule began with open-ended questions about understandings of CF isolation. Questions then asked about the participants' experiences of isolation at clinic appointments, during in-patient hospitalization and day-to-day. Interview questions were open and asked flexibly to ensure that both the interviewer and participants could mutually guide the content, pace, and style of the interview, according to the participants' levels of comfort (Creswell, 2013).

Data analysis

Thematic Analysis (TA), as described by Braun and Clarke (Braun and Clarke, 2013), was used to identify, pinpoint, examine, and bring together patterns or 'themes' across the interviews. A bottom up approach was taken to data analysis as this was a novel area of research. The researcher adopted a critical realist theoretical framework for the study, acknowledging that the findings have come about via interactions and interpretations between the participants, the data and the researcher. Interviews were audio recorded, transcribed verbatim, and imported into QSR NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 11, 2015 to aid analysis. TA was conducted following a six stage approach (Braun and Clarke, 2013): familiarizing, coding, searching, reviewing, defining/naming, and production of the report. Orthographic transcripts were read multiple times. Line-by-line coding of the text enabled key concepts to be inductively derived from the data. To minimize subjectivity and to maintain the original meaning (Braun and Clarke, 2013), codes largely mirrored the participants' original words. Codes were then further refined and defined by compiling similar coded extracts into existing concepts or creating new codes for different concepts. Similar codes were grouped into broader themes. Through a recursive process, themes were then finalized and defined by the research team to ensure that they captured coherent and meaningful patterns representing the full range of experiences across the data in relation to the research questions (Braun and Clarke, 2013). A collaborative process of reviewing themes between the authors aimed to ensure that codes and nascent themes were internally coherent, consistent, and distinctive (Braun and Clarke, 2013). Reviews consisted of exploring the central organizing concept of each theme, describing the boundaries of the theme, and drawing on examples of the combination of codes and extracts which made up the theme. It is recognized that any 'knowledge' produced from research reflects, to a degree, the researchers' own values, assumptions, and experiences (Braun and Clarke, 2013). Care was taken to use an inductive analytical approach, to report semantically based themes, to stay as close to the data as possible and to ensure that concepts identified in the data stayed within their original context.

Results

Thematic analysis identified four themes and ten associated sub-themes. Themes were: (1) Adjusting to Living with Isolation, (2) Protection from a Sense of Threat, (3) Noticing Differences, and (4) Integrating the Experience.

Adjusting to Living with Isolation

All participants appeared to report difficulty adjusting to living with isolation, apparent throughout the complexity of their descriptions and experiences of isolation. Participants' accounts seemed to demonstrate how developing their own conceptualization of isolation to adjust and respond to the necessity of isolation was a challenge (Table 2).

Isolation was described as a psychologically difficult experience; isolation was linked to feelings of difference, loneliness, confinement, and sadness. These hardships of isolation appeared to lead to difficulty holding in mind the necessity of isolation, in terms of minimizing the risk of cross-infection, alongside a desire to meet their own emotional/social needs. In conjunction, participants seemed to have experienced having little choice or control over isolation, which further contributed to the difficulty of the experience. This led to a sense of obligation that perhaps implicitly forced participants to comply and adjust to the experience of isolation. This posed a dilemma of how to view and make sense of isolation. Coping mechanisms were described, from cognitive avoidance to using distraction strategies, all to try to adjust to the reality of the experience as best they could.

Protection from a Sense of Threat

A sense of threat to short-term and long-term health was understood to be posed by the risk of cross-infections. A number of worries, fears, and concerns about coming into close proximity with others with CF were reported. Adolescents described the threats to their health in the immediate short-term as catching an infection and becoming unwell, as well as concerns regarding their longer-term health and knowing the implications of repeated cross-infection for CF. This threat was perceived to originate from themselves as someone who could pose a risk of cross-infection to others, as well as from others potentially posing a risk to them (Table 3). The theme captures an apparent ultimate endeavor by participants to protect themselves and others from this threat of cross-infection by vigilance and measures taken to keep proximal distance from others with CF in clinic, inpatient settings and in day-to-day life.

Noticing Differences

Adolescents' accounts demonstrated that isolation experiences increased their perception of differences between themselves and others without CF (Table 4). This included differences in accessing social interactions, as well as hospital facilities and space. Difference was reflected in perceptions that others, although supportive, could not fully understand or empathize with the difficult experience of isolation which often led to participants feeling misunderstood. Differences were also observed within themselves, in the form of noticing contrasts in their experience whilst in isolation on the ward as compared to their day-to-day life: in other words, their accounts suggested a perceived disruption to their 'normal' sense of self.

Integrating the Experience

Adolescents described striving to integrate the experience of isolation in to their identity activities, seemingly to try to minimize the impact of isolation. Participants described perceiving differences between themselves and others who do not have CF, including feeling unable to chat with other children or adolescents at clinic and on the ward, perceiving less access to ward facilities than others without CF, and feeling that others without CF do not understand what isolation is like. Participants also described the disruption isolation had to their internal 'normal' sense of self, including changes in social contact, impact on staff interactions, and managing change and unfamiliarity in routine. For many, this presented as a dilemma between the positives and negatives of association or affiliating with others who have CF (Table 5). One way to strive to integrate the experience was to embrace their identity as someone who has CF, achieved through a curiosity and a desire to speak with others with CF and, for some, was facilitated through existing contact with CF peers via the internet, as well as with parents and family of others with CF. Conversely, other accounts suggested a distancing of themselves from others with CF, through explicitly identifying differences between themselves and others with CF and avoiding or ending existing communications with individuals with CF. Most participants spoke about drawing on the two opposing perspectives at some point, which suggests a dilemma between the positives and negatives of each strategy in terms of integrating isolation in to their identity and activities.

Discussion

As on-going improvements in medical technology and specialist care continue to result in increased longevity for individuals living with CF, exploring first-hand experiences and psychosocial implications of isolation in CF is vital to informing a holistic provision of CF care. This study explored an evident gap in the literature with regards to adolescents' understanding and experience of isolation in CF.

Several themes emerged. Findings identified that adolescents had great difficulty adjusting to living with isolation. In conjunction with previous studies (Duff, 2002; Gammon, 1998), feeling of little choice or control over its imposition were identified. Factors such as misunderstanding regarding cross-infection, and difficulty adjusting to the idea of the restrictions of isolation, appeared to compound challenges of isolation. Identified coping strategies, such as avoidance and passively adhering to isolation, are perhaps functional and accessible coping strategies. However, such strategies are not consistent with research that identifies examples of positive coping in adolescents with a chronic illness to include framing the experience optimistically, as well as gaining knowledge about their disease and its treatment (Kyngäs et al., 2001).

Similar to isolation in other conditions (Barratt, Shaban, and Moyle, 2011; Criddle and Potter, 2006), isolation in CF appeared to highlight and heighten a sense of threat of cross-infection in CF, which participants identified as originating from others and from themselves to others. Findings highlight difficulties associated with the need to manage demands of avoiding face-to-face contact with others with CF in all contexts and all of the time. These demands differ to other conditions where isolation is temporary and limited to clinic or hospital settings. Findings that medical isolation can lead to individuals noticing contrasts in their experience whilst in isolation on the ward, as compared to their day-to-day life, is not a new concept (Linder and Seitz, 2016). However, the present study highlights that isolation in CF also continually presents these challenges for adolescents with CF. Findings also add that isolation can increase perceptions of differences between adolescents and others without CF. It is likely that this is compounded by existing heightened self-consciousness in relation to sense of self and identity formation for adolescents with CF (Berntsson, Berg, Brydolf, and Hellström, 2007).

Previous literature identifies multiple ways individuals cope with chronic illness, including avoidance strategies (Frey and Troop, 2006) and seeking peer-to-peer support, which is clearly not possible for people with CF to gain from face-to-face contact amongst others with CF. Participants made attempts to integrate the experience of isolation, and therefore minimize the impact of isolation on the perceived differences between themselves and others who do not have CF, through drawing on implicit strategies of both identifying with and distancing themselves from their CF. Identifying with CF appeared to offer potential opportunities for mutual understanding, reassurance, motivation, sharing of information, as well as minimize the possible sense of segregation induced by isolation. Conversely, making comparisons between themselves and others with CF and attempting to maximize differences, as well as avoiding the difficult emotions elicited by the realities of CF which could be highlighted to them by others with CF, also appeared to be a strategy. Findings indicate a dilemma between benefits and limitations of each strategy. In reality, the opportunity to seek and benefit from these strategies is significantly limited by isolation.

The lack of available peer-to-peer support opportunities, as well as difficulties and risks of avoiding the realities of isolation, may impede coping mechanisms in the context of CF in a way that is different to other conditions. Finding safe and adaptable ways to adjust to the experience was particularly challenging for adolescents; notably, three participants voluntarily admitted to not following the isolation policies. Perhaps this is not surprising given the known challenges of adolescence as a stage of development, further compounded by additional social and psychological developmental challenges for individuals with CF in comparison to healthy peers (Taylor, Gibson, and Frank, 2008).

Clinical Implications

Findings show that developing a narrative around isolation, adjusting to living with isolation, and integrating the experience can be a difficult and ongoing process for adolescents. MDTs should be aware of this as an issue. This study suggests an apparent need to reconsider how isolation is explained, as well as how and when opportunities are provided for adolescents to speak about and explore their experiences of it. Whilst it is positive that young people are taking the information regarding risk on board and acting to implement it in their day-to-day lives, a number of apparent misconceptions were found to be held by individuals about infections and how these spread. It is important, therefore, that individuals and families have an up-to-date and accurate knowledge of cross-infection in relation to their/their family member's own condition at various developmental stages, and as their experience and awareness of isolation changes over time. As systemic factors have also been identified as key correlates to the bio-psychosocial wellbeing of young people with CF (Wood, Miller, and Lehman, 2015), increasing their own and families' confidence in their understanding alongside managing anxiety and the burden of unnecessarily acting on these anxieties could also help to continue highlighting the rationale for isolation, improve adherence to isolation recommendations and infection control procedures, and encourage communication with others who could act supportively. Therapeutic intervention, family support, working with schools, and where appropriate, communicating difficulties to the wider clinical team around concerns relating to cross-infection and isolation may be beneficial. Psychologists may be well placed to offer a consultative role with the MDT, such as supporting times where adolescents with highly infectious infections do struggle to adhere to infection control procedures. Alongside this, a more preventative approach of including discussion around isolation as part of screening adolescents regularly for psychological difficulties should be considered.

Integrating the experience of isolation into ones identity and activities, including maintaining social relationships within the context of isolation, was identified as a challenge by participants. However, interactions with others with CF has been identified in this study as a potential coping strategy for managing and integrating the experiences of isolation, including reducing feelings of 'being different' to others without CF. The absence of face-to-face group interventions or support meetings of individuals with CF further restricts options to support patients' psychosocial needs. The use of technology, the internet, social media, and facilitated online support networks for adults with CF can be a valuable source of information and interaction (Cummings et al., 2011; Kirk and Milnes, 2015). Encouragingly, research indicates the potential beneficence of innovative technologies to aid non face-to-face peer social support (e.g., Marceil et al., 2010). The Cystic Fibrosis Foundation's BreathCon virtual event provides scope for adults with CF to connect and learn from others with CF. In practice, developing and safely delivering services for children and younger adolescents pose challenges for regulation and monitoring. However, existing provisions for adults could help inform provisions for children and adolescents. Longitudinal studies are currently underway with young people to explore the use of technology for such purposes.

Limitations

As with most opt-in studies, a limitation of the study is the sampling, due to opt-in bias and conclusions being drawn from a small number of participants. Participants were recruited from two CF clinic sites in England whose application of the isolation guidelines may vary between each other and from other sites across the UK and internationally, although the analysis suggested many commonalities within their experiences. Additionally, contextual factors that were not measured in this study, such as availability of family support, visitors and utilization of psychology services, that could also have impacted adolescent experiences and their sense- making of isolation.

Recommendations for future research

Further qualitative research is needed to assess the understanding and experiences of adolescents regarding isolation practices in other clinical centers and countries to illustrate similarities or differences in experience. Isolation experience in the current adolescent population could differ from that of adults who may have accessed CF health care services prior to the implementation of isolation. Knowledge gaps exist about isolation experiences in younger children and how this may change over time as they move into adolescent stages of development and transition from pediatric to adult teams. Furthermore, future research could explore the relationship between the experience of isolation and psychosocial outcomes, including ways to try to determine psychosocial outcomes.

Conclusion

Adolescents living with CF experience benefits but also multiple psychosocial challenges associated with isolation. This study utilized a qualitative approach to give voice to the perceptions of adolescents who experience isolation as part of their routine CF care. The clinical implications of the current study could serve to better inform and develop recommendations and implementation of services supporting bio-psychosocial approaches to CF care. Isolation is not a neutral experience. Experiences of isolation need to be understood to prevent and ameliorate any potential negative psychosocial impacts, such as isolation or avoidance. Doing so could prove vital in facilitating and delivering optimal patient-centered MDT treatment and ultimately improvement in health and quality of life.

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TABLE 1 Participant Demographic Information

Pseudonym	Age	Gender	Lung Function FEV1 [a]	Attendance at planned clinic appointment	Total number of admissions in the past	Total duration of admissions in the past	Admissions in a side room on the ward

				over past 12 months (%)	12 months (%)	12 months (days)	
Emily	16	F	65	100%	3	24	All
Luke	14	M	79	100% (6)	1	3	All
Kate	16	F	49	100% (5/5)	4	65	All
James	14	M	84	100% (4)	1	13	All
Chloe	12	F	75	100% (5)	1	14	All
Anna	16	F	88	100% (5)	2	39	All
Charlotte	17	F	76	80% (4/5)	1	9	All
Josh	12	M	70	75% (3/4)	2	15	All
Sophie	12	F	62	100% (5)	1	10	All

[a] *Note.* Lung Function FEV1: Forced expiratory volume-one second, used in the calculation of obstruction and restriction in air escaping form the lungs: normal values are approximately 80%. (Swanney et al., 2008)

TABLE 2 Theme Adjusting to Living with Isolation & Associated Sub-Theme Quotes

Main Theme: Adjusting to Living with Isolation	
Sub-Theme	Participant Quotes
A restrictive necessity	"I was just stuck in one room. I had nothing but a sink." "I did step outside my room, but just like over the line, the barrier. I was like 'I'm sorry...I just wanna have air!"
An imposed obligation	"Well I didn't know anything really about it until they brought me in and said you can't do this. I was like 'Oh', it was a really big shock. They were like, right we are going to put you in your own room, you won't be able to come out, you won't be able to do this, you won't be able to do that. I was like, 'Oh ok, thanks!"
Adjusting to my reality	"I wasn't really taking in what they were saying because it's just my own little bubble, trying to get away from it all... Yeah, I don't think that I was really listening, I can't with all the stress and stuff, kind of I was just going along with it." "I've just decided that it was a matter of fact, and I just had to get over it, literally.... Freedom would be nice but isn't likely." "I guess it doesn't matter does it, I have to do it anyway."

TABLE 3 Theme Protection from a Sense of Threat & Associated Sub-Theme Quotes

Main Theme: Protection from a Sense of Threat	
Sub-Theme	Participant Quotes
Others can make me ill	"Staying away is staying safe." "Because you could have a chest infection and then you can get more ill, or sick, off getting it from somebody else." "They [staff] want to keep you safe from the other people."
Striving to stay safe day-to-day	"I just think if you sit and cover your mouth you should be alright, but it's your life you are basically risking when you go on transport, public transport." "Like in school, I asked my brother to check if that kid with CF is near because I'm not allowed to go near him. Like at the end of school where there's loads of people rushing out of the school. Don't know who's who. So, when there's a bunch of people wearing blazers or suits type of things rushing out at one time, very hard."

TABLE 4 Theme Noticing Differences and Associated Sub-Theme Quotes

Main Theme: Noticing Differences	
Sub-Theme	**Participant Quotes**
Differences to others without CF	"It felt like I was in a broken mirror, like...I don't know how to explain it. Or more like looking out at a wall, like I couldn't see them but they saw me. Well, basically, I felt like I was in a room with no doors but like just sitting there. But then people started walking past and looking at me, I just felt like I couldn't say 'Hi' or something like that. I felt very concealed…I did wonder a lot because it felt like they [other children] got out of their room more than I did…I got very jealous."
Disruption to 'normal' self	"It was quite stressful. It's quite hard because I really didn't like going to hospital. There's no comfort of home. You feel different. You feel like you're not normal... Yeah just you feel like you're not the same because, I don't know how to explain it. It just feels a lot different. I mean at home, because at home you could do your meds at the time you want, sort of see what other people you want…Yeah, all the routine is quite shaken off of it." "It's a bit sad because I want to be like friends with everyone because I'm a friendly person but I can't because of the limitations that CF has...Sometimes, it's a bit sad but like, it makes you feel like I'm different. But really, I'm not."

TABLE 5 Theme Integrating the Experience & Associated Sub-Theme Quotes

Main Theme: Integrating the Experience	
Sub-Theme	**Participant Quotes**
Connecting with CF identity	"Because obviously, you know, like to a CF, I mean like somebody who has CF, it would be like normal talk. I would ask like how they're doing and what bug they've got and I could find out information about theirs and I'll tell them about my one. It would make me a bit happy to know that I could do it [isolation] like they are and not be scared." "Cause sometimes it does feel like you're the only one, but you're not. You're not by a long-shot (laughs), so it just makes you feel better." "I don't know, it would be different from speaking to a doctor, it would be like talking to somebody who actually has experienced it. It would be reassuring."
Distancing from CF identity	"Some people with CF can be really ill and they can be like in hospital for months and stuff. And I haven't got that…I don't think I've got the really bad one." "Umm, hospital, because I met, um, another CF at hospital. Unfortunately, um, she passed away. So that was the most difficult part…Because, because you have, honestly, you can talk to them about it, but then you realize, when they go, it's a bit of a shock...because you're like 'Oh! Gosh, they had CF like me.' And, 'Oh god, when am I, I gonna go?!" "Knowing that they have got like say 90 per cent lung function and yet there supposedly like, they have to be in hospital. And I'm like, but I've

	got this much, am I worse? Like, it's the fact that if other people aren't in isolation they also do kind of say about it…it's just like yeah, stop talking now but actually don't stop!"