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Article:

An Exploration of How Young People and Parents Use Online Support in the Context of Living with Cystic Fibrosis

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ABSTRACT

Background: There is increasing recognition of the Internet's potential role in providing information and support for people living with long-term conditions. However, how young people and parents use online forms of self-care support in the context of living with childhood chronic illness has been under-researched.

Objective: To explore how online peer support is used by young people and parents to support self-care in relation to cystic fibrosis (CF).

Setting and Participants: Online forum for young people and parents based on a CF charity website. 279 individuals participated in the forum during the study.

Design: An online ethnographical approach; involving observing, downloading and analysing discussion-group postings. All postings made over a random four-month period were included (151 discussion threads).

Results: The online setting enabled a physically-disconnected group to connect and create a safe space to collectively share experiences and receive support to manage and live with cystic fibrosis. Participants exchanged experientially-derived advice and views on how to manage treatments, emotions, relationships, identity and support from services. While parents sought information and support on managing specific therapies/services and ways of maintaining their child's health, the information and support young people desired appeared to be more directed at how to 'fit' CF into their everyday lives.

Discussion and conclusions: Online support groups appear to supplement professional support in relation to self-management. They enable young people and parents to share experiences, feelings and strategies for living with long-term conditions with peers and develop the expertise to empower them in interactions with health-care professionals.

An Exploration of How Young People and Parents Use Online Support in the Context of Living with Cystic Fibrosis

INTRODUCTION

The increasing role of the Internet in everyday life is changing the self-care support landscape for people with long-term conditions. Originally seen largely as a health information resource, the Internet is increasingly used for the delivery of self-management programmes and is heralded as the key arena for support[1]. Internet health studies have investigated three broad areas[2]. Firstly, how access to specialised information can transform relationships with health-care professionals by enabling patient involvement in decision-making[3,4]. A second body of research has examined the medically-defined accuracy and quality of health information provided by websites[5,6,7]. A third body of research has investigated the dynamics of virtual communities across a range of different conditions[8,9,10]. It is within this latter body of research that the study reported in this paper is situated.

On-line Communities and Self-Care Support

The Internet has extended the meaning of community from one based on a shared geographical location to one where the community is relational, based on a shared interest or purpose but devoid of face-to-face interaction and physical locality[11]. Over the past decade increasing use has been made of online peer support particularly in the form of asynchronous discussion groups[10,12,13]. In particular online forms of social support have proliferated for stigmatising conditions and those which are poorly understood by the medical community[14,15]. The role played by online support groups in relation to a range of health conditions and life situations has been examined [8,9,10,16,17,18, 19].

Exchanging information has been found to be the main form of support provided by online groups[3,4,10,13,20]. The emotional support role they play by providing opportunities for sharing experiences and receiving and offering social support within a 'safe' space has also been recognised[10,20,21,22]. It is apparent that there are similarities between the support offered by peer face-to-face support groups and online groups[10,20,21,22], with the same potential to engender feelings of fear, uncertainty and disapproval[9,13]. The advantages and disadvantages of online health-related communities are well recognised (Table 1). While there is no robust evidence in terms of effectiveness of online support groups[23,24,25] studies report that participants perceive personal benefits in terms of feeling better informed, having increased social confidence/self-esteem and increased access to social support[9,13].

Methodologically it has been noted that online communities provide a different insight into experiences than that obtained via interviews because they allow insight into the experiences 'of the moment' and reflections that are a product of interaction with multiple peers rather than with a single researcher[22,26].

On-line Support for Young People and Parents

Interest in how young people use the Internet for information and social interaction is growing, including its potential role in providing peer support. Studies have highlighted how young people see the Internet as an important information resource[26,27]. While Internet and computer-based self-management interventions have been developed for young people with long-term conditions, few include peer support[28]. However, research focusing on online support groups suggests that they can be an important source of social support for young people[29,30,31,32,33,34,35]. Young people appear to value their anonymity for enabling them to freely express their emotions[29,34,36]. Negative aspects of online support have been less frequently reported although discomfort with online interaction has been noted[29,33].

The Internet appears to be an important resource for parents to obtain not only 'factual' information but to interact with other parents and receive more experience-based advice about a range of child-related issues[37,38]. Studies examining parents' use of online communities suggests that they play an important role in providing information, emotional and social support[39,40,41,42,43,44,45]. However, it has also been noted that they can engender negative emotions[39,41]. In addition their tendency to be dominated by mothers can lead fathers to feeling marginalised[44].

Study Context: The Online Community

The aim of this study was to explore how online peer support is used by young people and parents to support self-care in relation to cystic fibrosis (CF). Focusing on CF is pertinent as young people with CF rarely have face-to-face contact with others with CF due to the widespread use of segregation policies by health-care organisations to prevent cross-infection with *Burkholderia cepacia* (leading to reduced lung function), therefore online support groups could play an important social support role.

The online support group that was the focus of this study was located on a CF charity's website. There were separate asynchronous discussion groups (DG) for young people, parents, adults and

partners of people with CF. When registering people assigned themselves a username and there was no formal verification of age, relationship or whether they had experience of CF. The study focused on DGs for young people and parents/carers. Each DG contained chains of inter-related messages structured under topic headings. Participants registered in order to post messages but postings were publicly accessible.

RESEARCH METHODS

The methodology used in this study was virtual observation (sometimes referred to as netnography or online ethnography), an emerging approach that has adapted ethnographical methods to explore the social interactions of online communities[46,47].

All postings made to the young people and parent DGs over a random four-month period were selected for inclusion apart from those relating to fundraising and non-CF issues (for example, favourite television programmes). During this period there were 182 participants on the parent's DG and 97 participants on the young people's DG. Virtual non-participation methods were used which involved observing and downloading the postings. A total of 103 (88,152 words, 721 postings, average length 125.5 words) discussion threads from the parent DG and 48 (29,000 words, 283 postings, average length 102.7 words) from young people DG were included in the analysis. Observational notes were also made during the period of data collection in order to record observations on the interactions occurring and emergant themes.

The discussion threads were downloaded into Word documents and imported into NVivo for analysis. The data were coded using an inductive Grounded Theory approach to identify themes and patterns emerging from the data[48]. Through the constant comparison process data were grouped into codes and overarching themes (Table 2). Both authors were involved in this iterative process. Data extracts are presented as they were typed and spellings are not corrected. Word deletions are signified by [.....].

Ethical issues

Online research blurs the distinctions between public and private spaces which make conventional ethical guidelines regarding anonymity, confidentiality and informed consent unclear[47]. Whether sites which allow people to post and read text with little or no restriction can be conceptualised as public spheres has been debated as has whether the use of postings as research data requires consent [47,49,50]. It is though unlikely that participants expect their posting to be used and presented as data in research reports. In this study the postings from the online groups were openly accessible

to the public. To protect users' anonymity their name/alias and any content that risks identification have been removed from data extracts. While consent was not obtained from online participants, permission to observe the groups for the purposes of research was obtained from the charity. Participants were informed about the researchers' presence and provided with information about the study. The study was approved by a United Kingdom National Health Service (NHS) Research Ethics Committee.

FINDINGS

This section examines how participants used the online DGs and the issues on which they sought support before presenting the five themes emerging from the analysis in relation to the nature of support provided.

The Online Context

Discussion Group Topics

In terms of broad topic areas the majority of postings from parents related to managing CF (Table 3). Although the young people posted queries relating to the management of medications/therapies, their postings revealed more of a concern about how to live with CF (Table 4). For both groups the discussion groups provided an opportunity to discuss their feelings. Both young people and parents posted about their relationships with others. For young people this related mainly to their peers, however, parent postings were dominated by discussion about relationships with healthcare professionals.

The Online Culture: Communication Styles and Community

There was a core of regular participants who had developed strong relationships with one another which in some cases had led to 'off-line' relationships through face-to-face meetings or interaction via social networking sites, email and text-messaging. Other individuals appeared to post messages only when they were experiencing a particular problem and did not engage in providing support to others. There was evidence of cross posting; of young people and adults with CF posting messages to the parent group and parents posting messages in the young people group. These postings were supportive and provided an alternate perspective on the topic being discussed.

Anonymity did not appear to be a concern for most participants. Although most participants used a pseudonym as a user name they frequently used actual names in their postings. A striking feature

was the personalisation of postings through the inclusion of photographs and signature lines providing information about family context ('mother of a six year old girl with CF'), philosophy on life (e.g. '*Its not the years in your life that count, its the life in your years.*') or tributes to friends/relatives who had died. From the usernames given, it appeared that it was mainly mothers participating in the parent group. Both males and females appeared to be participating in the young people's group.

Participants usually posted about a problem they were experiencing which was then responded to by other participants. The original poster often returned to thank the group for their support. Indeed there was a sense of synchronised conversations in many threads. There were occasional misunderstandings due to the absence of non-verbal communication and the use of emoticons to indicate tone was commonplace. Messages were informal in character, varied in length and in common with many cybercultures there was a lack of concern over spelling and grammar. The use of humour, warmth and affection was evident particularly in the parent discussion group. Many participants appeared to have formed emotional bonds with one another as postings reflected a high degree of intimacy and trust with discussion of personal feelings and relationships. While parents mainly used the site to seek specific advice or emotional support, young people used it as a social networking site; making postings to 'catch-up' with one another, either at home or when hospitalised:

> *hey Tina welcome back! how did you get on with the exams? i'm good thanx, back on the IV's in June. how are you?* 😃😃😃😃😃
>
> *aww i'm gd. on my Iv's atm. halfway there! yay! a week is too long though. i feel like pulling the needle out! glad to hear you're feeling good. i think i need a bronch to! havent had one in ages and sometimes you can just tell you need one! now is one of these times! (but don't tell the doctor!* 😌*)*

Group norms appeared to have been established in relation to socially acceptable discussion topics and interactional style. There was no evidence of impoliteness or 'flaming' and postings expressing feelings of anger were seen as acceptable as long as they were not directed at participants ('*ooh rant away, thats what the forum is for!!*'). On the parent site while there were some incidents of censuring and conflict, it appeared that participants concerned about risk of censure prefaced messages with comments such as '*you're going to hate me for this but*'. There appeared to be some self-regulation of online communication in terms of the advice being provided. Indeed participants would contradict the advice of others and also advise parents to contact health-care professionals. Formal online moderation only appeared to occur when personal information was shared.

Although the groups were a place where negative emotions could be expressed it appeared that there were boundaries to this. Indeed the online group was not always seen as being an appropriate place to discuss certain experiences and feelings:

This is a short post. I ashamed to say I often feel the same (perhapes manage it a little better though). I dont want to open up on this subject on here though. Feel free to email me on ***** (Parent DG)

The life-limiting nature of CF was not explicitly discussed apart from one parent asking for information about the process of death. Rather group norms appeared to be directed at maintaining a positive outlook, developing a sense of hope and discussing the day-to-day impact of illness on the young person/parent.

Participants' personal experiences of CF were the basis of the emotional and informational support provided. They exchanged experientially-derived advice and views on their strategies for managing treatments, emotions, relationships, identity and support from services; often giving detailed descriptions of how they had personally managed different situations.

Managing Treatments

Participants sought advice and support about how to manage different treatments and therapies. In response participants shared their own personal experiences as a means of offering information and emotional support. Users acknowledged the difficulties of managing and living with complex drug regimens/therapies drawing on examples from their own experience but encouraged others to persevere by highlighting the potential for this to be have future positive benefits.

I know its horrible, but they're not going to take it out just because you don't use it, so do the feeds, show that you can eat enough to replace a few feeds so that your Doc will reduce the amount you need, and before you know it, they'll be saying 'OK, try not using it for a few months, and if you gain weight on your own, you can have it out' (Young person DG)

The DGs provided the opportunity to inform treatment decision-making by enabling participants to discuss treatment options with those with direct experience. Participants described their experiences and reflections on making particular decisions (e.g. portacath insertion) and the subsequent impact on their health and lives. Participants shared advice on how to integrate complex treatment regimens into everyday life, for example how exercise and physiotherapy could be reconstructed as family activities to promote the young person's engagement.

Have you tried going swimming together just the girls in yr family make exercise fun and then when she has done it go and have lunch together or buy her a treat, That has worked with my son 13. (Parent DG)

We used to use straws - blowing cotton wool balls across the kitchen table - actually our physio who has retired showed us this one - it was great fun when we all joined in as a family. (Parent DG)

The online DGs provided a frame of reference for what was 'normal' in relation to CF; some postings reflected a need to assess whether certain symptoms were 'normal' (e.g. fatigue, pain, body image changes; treatment side effects). Participants expressed reassurance from knowing others shared their experiences and feelings. While participants mainly based their advice and support on their own personal experience of CF, suggestions were made to seek information from others such as healthcare professionals.

Managing Emotions

The DGs provided an outlet for young people and parents to express their emotions. It was apparent that it was seen as a safe space for sharing feelings of isolation, sadness, difference and frustration. For some the opportunity to express their feelings and frustrations was cathartic in itself as they were able to tell their story to an audience who could understand and relate to their experiences. The response to postings expressing negative emotions displayed empathy, with participants acknowledging and confirming that such feelings were justified. Moreoever normalisation of feelings was evident as participants emphasised that individuals were not alone in experiencing such feelings.

Hey, You are certainly not alone! I think everyone with CF has felt like tha sometimes. I know for a fact I hve felt like why do I bother but I tend to do it when i'm well bcoz i cant see any difference when i take my tablet sna if i miss them 😊 but I've learnt now that i have to do my nebs and stuff 😊
(Young person DG)

i know it is difficult at times but u always have here to vent ur concerns there are lots of parents on here who will recognise what ur feeling, keep ur chin up and keep doing what ur doing, take care (Parent DG)

Participants shared strategies they themselves had found helpful in managing negative emotions, which included sharing feelings with others, being positive and living in the present.

I think it is good to have a cry sometiimes, like Unless your friends have cf or soething else, they dont really know what your going through, and its good to talk to one of your parents about Cf and how you feel.(Wow!Im starting to talk more like a parent:) 😊 😊) (Young person DG)

I am a happy and upbeat person; I am positive most of the time and always look on the bright side of life. I see the good things in life and look past the bad. Because life is for living. Why be sad and depressed when there is a big world out there full of great and wonderful things. (Young person DG)

I know that you are bound to worry about the future but my advice is to take each day as it comes.If your child is well then go out ,have fun and make the most of it.If they are ill then put on your smile and tough it out.Try not to let cf take over your lives - stress is bad for kids it makes them poorly! Good luck. (Parent DG)

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Participants emphasised their availability and that of the online community to provide support for one another. These postings emphasised a sense of community by using the terms 'we' and 'us'.

> *We are here if you need us so feel free to post and hopefully we can help. In the mean time keep strong. (Parent DG)*

> *If you ever need someone to talk to, let us know or send me an email. I am here most days and will try my best to help you 😊 (Young person DG)*

Managing Relationships

Participants used the DGs to discuss problematic relationships with others. For young people this mainly related to peer relationships, with diagnosis disclosure of particular concern. Participants encouraged them to be open about their condition or to restrict this knowledge to their circle of close friends.

> *why don't you clear the air and tell your closest friends, and the people who don't need to know, don't tell them. 😊hope this was helpful*

Some young people were experiencing bullying at school and participants responded to these postings by sharing their own experiences and advising on different strategies to manage this situation. Woven through these postings were messages which appeared to aim at building the young person's confidence and self-esteem, with young people with CF being ascribed with particular strengths and qualities.

> *Be strong and take no notice of them bullies. You keep your head held high and study hard because school will be over before you know it and you will be going to collage. Rember you are the bright one. X*

> *At the end of the day, those bullies are ignorant know-nothings who will end up doing nothing with their lives whereas you will soar high above them. CF definitely gives you the drive to really go for what you want and having to cope with so much makes you more organised and more mature and those are some worthy traits right there*

Parents described problematic relationships with teenage children resulting from conflicts over engagement in treatment regimens and condition management. Support was provided through postings that highlighted the shared nature of this experience. Participants advised parents to reflect on potential reasons for their childrens' responses as well as describing strategies that could be tried.

> *Oh Molly 😊i wish i had a magic wand. Teenagers are a different breed. CF Teenage Girls are as bad as it can get 😐 Your youngest one is going through a phase. I know it's hard for you but it isn't your fault. She is taking time out from CF & she doesn't realise the damage she is doing. You do & that's what's so*

hard. My heart goes out to you.[...] At the end of the day, it's their bodies, their lives. We nurture them so that they can become independant Adults one day, we hope ☺Your daughter still has those strong foundations that you taught her. She grew up with the CF regime. She knows the do's & Don'ts. You will get through this stage. Sending you a big hug, x x x

I have given her full independance for her own treatments, she sets up her own nebs, does her physio & takes her tablets. If im lucky, it gets done but lately she's not bothering. So after much shouting, eye rolling (from her) & tears (from me!!) ive managed to get her to make a link between her ambition of going to college full time & not doing treatments now [....] You need to try & work out if he's not doing it because he's in denial, because he doesnt really understand why it should be done if he's well, or if like N, he's bone bloody idle!! Once you can work out the whys its easier to work out a way of getting thro to him.

Parents also sought advice on how to manage relationships with family members. Some mothers described feelings of frustration over their partner's lack of involvement in caregiving which in some cases appeared to reflect fathers' difficulties in accepting a CF diagnosis. While other mothers encouraged participants to discuss their feelings openly with their partners, a father provided an alternative perspective.

Women (in general, not all, so please dont pounce) often seem to want to talk it out, discuss their feelings and open up. Men, often dont. They see it as a problem that needs to be solved. Like fixing a car or working out a sum. We search for a solution often at the expense of addressing our partners feelings (I guess I get this wrong my fair share). If we cant solve the problem that bothers us (e.g. CF) we might take it out on other projects e.g. mowing the lawn, laying patio. I tend to go for a run or a bike ride rather than talk. If this happens it doesnt mean we dont care its just that that is what seems to help. Talking often makes me feel worse, especially if it isnt structured toward a solution or plan. Comprimise is needed to ensure both parties get their share at what helps them cope.

Parents could also experience difficulties in family members accepting the restrictions placed on children with CF, for example around diet. Postings from other participants encouraged them to '*stand your ground*' and '*stay strong*' when interacting with family members and reassured them of the appropriateness of their actions.

Managing Identity

In postings participants validated parents' actions and feelings by referring to these as indicators that they were 'great parents' which served not only as a way of developing their self-esteem and competence but also their identity as 'good' parents.

my daughter is 15 now but i remember like it was yesterday going through the stuff u r now and to be honest u sound like a great mum and my only advice is a mum knows best just listen to your heart and u wont go far wrong.

just keep doing what ur doing as i bet u r a great mum but at times i think we all need a little reassurance and all think well what if i did this differently, we cant change who we are nor who are kids are but have to try and be as strong as we can, i know it is difficult at times but u always have here to vent ur concerns there are lots of parents on here who will recognise what ur feeling, keep ur chin up and keep doing what ur doing, take care

Young people emphasised their 'normal' identify in postings, describing the normality of life with CF.

People always say to me is, "How do you do it? I couldn't go through it all" They never understand that this is the normal to me. I know no different to the way my life is now. Just like every other VF will say. So therefore, I don't miss what I haven't got or haven't had and I am grateful for what I have got not what I haven't.

Indeed participating in the DG normalised feelings and experiences further as well as boosting feelings of self-esteem and confidence through postings emphasising the inherent strengths of people with CF.

i always look on the positive and think of it as being special, i think you do have to be a special person to have cf and to cope with cf ,lots of people would crumble

Developing a positive self-identity contributed to wider norms of building and maintaining a sense of hope amongst participants.

Managing Support from Services and Health Care Professionals

Parent participants sought and received support about how to negotiate relationships and interactions with healthcare professionals (usually the CF multi-disciplinary team). Particpants provided explanations for particular professional actions, for example, the need for particular tests or proceeding with particular treatments/therapies. Postings displayed a mixture of reassurance and information-giving as well as advice on how to manage a future consultation.

Your consultant maybe holding off because ports do have an expiry date (usually when the child grows too big and they stretch the port line too much) so he maybe wanting her to be a bit more grown before they fit her first one. They may also not think that her run of bad health will continue much longer in which case you might not be needing it in 12 months time. I would ask them for a specific explanation about why they won't do it now and then ask what they would do if you insisted. I think you need their full reasons before you know whether to push it

At the same time participants advised parents to take an assertive stance and question medical decision-making.

I just wanted to say that I think your attitude towards your son's care is fantastic. I know a lot of parents struggle to stand up to/question medical staff (including my mum when I was younger) so it's great that you have already managed to gain the confidence to do it when your son is still at such a young age.

Postings on the young people's DG related to their sense of frustration that health care professionals appeared unsupportive of their desire to participate in 'normal' teenage activities and thus support the development of a 'normal' identity.

It seems like they say that you shouldn't let CF control you, then they insist upon CF being an absolute priority- over Parties and other great things. [...] what is the point of all this healthcare if you aren't using it to 'earn' a step closer to normality

they need to learn to let you have a balance between health and life

Participants were encouraged to remember that ultimately they, not healthcare professionals, had control over their lives and identities:

Just remember they don't control who you are and what you do... whatever they say.

DISCUSSION

This study has contributed to knowledge by examining how young people and parents use online forms of self-care support in the context of living with childhood chronic illness, in this case CF. The use of an online ethnographic approach has illuminated how peer support is exchanged and provides insight into the nature of the interactions occuring between young people and between parents; data that cannot be captured in face-to-face interviews[22,29]. Detailed reflexive accounts have been generated from peer interaction rather than interaction with a researcher which may have provided a more authentic account of how young people and parents experience and manage chronic illness. There are limitations to the study that relate to the use of online ethnography. Background information about participants and their social context is largely absent and responses could not be probed nor additional details elicited. In addition the findings relate to one particular online support group for one long-term condition during a specific four month period.

The online groups appeared to enable a geographically dispersed and physically disconnected group to connect and create a sense of community. A safe space had been developed where participants could collectively share their experiences and feelings and receive support in the form of experientially-derived personal strategies for managing and living with CF. Previous studies have similarly highlighted the role that virtual and face-to-face peer support groups can play in reducing social isolation and creating a community where feelings and experiences can be normalised[32,35,36,37,39,46,47]. For young people in particular, the importance of peer relationships and integrating peer support into self-management programmes is recognised[33,51]. However, incorporating peer support for young people with CF has been previously constrained by physical segregation policies.

The safety of the online group was a consequence not only of participant anonymity but also a product of the supportive, trusting relationships that appeared to have been developed. This characteristic of collective support is important for participants to freely share feelings and

experiences[22,30,34,40]. However, it appeared that there could be boundaries to what was appropriate to discuss that was influenced by a group norm of building and maintaining hope. Other research has similarly discovered that online group norms are established that determine acceptable discussion topics[8]

While parents sought information and support on managing specific therapies/services and ways of maintaining their child's health, the information and support young people desired appeared to be more directed at how to 'fit' CF into their everyday lives. The differing priorities of parents and young people in relation to living with long-term conditions has been highlighted previously[52,53] and has wider implications for developing self-care goals, patient-reported outcome measures and in understanding health expectations. Indeed young peoples' desire to 'background' or 'normalise' CF is reported in other studies[54,55].

The literature suggests that health-care professionals can have concerns over the Internet promoting 'inappropriate' self-management and challenging their power and status as experts[56,57]. However, there is no evidence of the harmful effects of online support groups[27] and consequently can be recommended by health-care professionals. Moreover in this study participants regularly advised members to seek professional advice and highlighted potentially unsafe information in postings. In postings it was also apparent that participants attempted to build individuals' self-esteem, which in combination with the sharing of information and support, may promote empowerment. The potential of online support groups to foster empowerment, potentially changing relationships with health-care professionals to ones based on partnership has been noted in previous research[58,59,60]. This study suggests that online support groups supplement professional support, enabling young people and parents to share experiences, feelings and strategies for living with long-term conditions with peers and develop the expertise to empower them in interactions with health-care professionals.

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Table 1: Advantages and Disadvantages of Online Health-related Communities[2,4,8,9 10, 17, 38]

Advantages	Disadvantages
Absence of geographical barriers	Inequity of access and creation of a 'digital divide'.
Absence of temporal barriers	Difficult to detect conversational nuances as non verbal elements of communication are missing. Consequently the meaning of messages can be misinterpreted.
Anonymity means that participants do not have to worry about their appearance or socio-demographical characteristics affecting the responses of others.	Anonymity and the virtual nature of the group can lower the threshold of acceptable behaviour leading to socially inappropriate and aggressive messages.
Facilitates open discussion of sensitive issues due to anonymity and disembodied nature of communication.	As there is a lack of control of information exchange participants can be confronted with the negative aspects of different conditions and have to contend with negative/pessimistic participants.
Participants can control their level of participation and play a passive or an active role	There is the potential for the exchange of inaccurate and potentially dangerous information
Access to an increased number and diversity of perspectives and resources.	Asynchronicity means that there is a time lag before participants receive a response.
Useful for people with rare conditions and for disabled people	Potentially addictive and may lead to a decrease in face-to-face socialisation.
As a text-based medium the process of writing about feelings may be therapeutic in itself.	
May provide insight into the experiences of those with long-term conditions for health professionals and relatives.	
Financial costs said to be 'reasonable' for stakeholders	
Enable exchange of information about particular conditions and treatments	

Table 2: Support provided by online groups: emergent themes

Theme
Managing treatments
Managing emotions
Managing relationships
Managing identity
Managing support

Table 3: Parent Discussion Group Topic Areas (105 Discussion Threads)

Topic Area	Number of Discussion Threads	Percentage of Discussion Threads
Managing cystic fibrosis treatments	85	81.0
Feelings about cystic fibrosis	13	12.4
Professionals and services	9	8.6
Connecting/reconnecting with the group	9	8.6
Benefits/finances	7	6.7
Nursery/school experiences	6	5.7
Relationships with others	5	4.8
Other (e.g. transfer to adult services; explaining cystic fibrosis to children; dying)	9	8.6

Table 4: Young People's Discussion Group Topic Areas (48 Discussion Threads)

Topic Area	Number of Discussion Threads	Percentage of Discussion Threads
Living with cystic fibrosis	26	54.2
Connecting/reconnecting with the group	16	33.3
Experiencing negative feelings	14	29.2
Managing cystic fibrosis treatments	13	27.1
Relationships with others	8	16.7
School experiences	7	14.6
Being in hospital	6	12.5
Parent seeking advice	5	10.4
Other (e.g. benefits, transfer to adult services)	6	12.5