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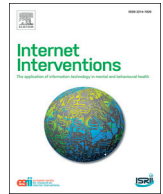
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“It's not one size fits all”; the use of videoconferencing for delivering therapy in a Specialist Paediatric Chronic Fatigue Service

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ABSTRACT

Background: There are few specialist paediatric Chronic Fatigue Syndrome (CFS/ME) services in the UK. Therefore, the distance some families have to travel to reach these services can be a barrier to accessing evidence-based treatment. Videoconferencing technology such as Skype provides a means of delivering sessions remotely. This study aimed to explore the views of children and young people, their parents, and healthcare professionals of treatment delivered by videoconferencing in a specialist paediatric CFS/ME team.

Method: To explore the experiences of the participants, a qualitative design was selected. Twelve young people (age 9–18), and 6 parents were interviewed about their experience of treatment sessions delivered via videoconferencing within a specialist CFS/ME service. A focus group explored the views of healthcare professionals (N = 9) from the service. Thematic analysis was used.

Results: Three themes were identified from the data: “Challenges and concerns”, “Benefits” and “Treatment provision”. Challenges and concerns that participants identified were; difficulties experienced with technology; a sense of a part of communication being lost with virtual connections; privacy issues with communicating online and feeling anxious on a screen. Participants felt that benefits of videoconferencing were; improving access to the chronic fatigue service; convenience and flexibility of treatment provision; a sense of being more open online and being in the comfort of their own home. In terms of treatment provision participants talked about videoconferencing as a part of a hierarchy of communication; the function of videoconferencing within the context of the chronic fatigue service; additional preparation needed to utilise videoconferencing and an assumption that videoconferencing is “part of young people's lives”.

Conclusions: Although the experience of sessions provided by videoconferencing was different to sessions attended in person, participants tended to be positive about videoconferencing as an alternative means of accessing treatment, despite some barriers. Videoconferencing could be an additional option within an individualised care plan, but should not be an alternative to face to face support.

1. Introduction

Chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME), is characterised by severe, debilitating and unexplained fatigue that is not alleviated by rest (C. NICE, 2007; Prins et al., 2001). The prevalence of CFS/ME in children and young people (CYP, < 18 yrs) is estimated to be between 1% and 2.4% (Crawley, 2013; Garralda and Chalder, 2005; Mackenzie and Wray, 2013). Affected individuals often find it difficult to attend school and maintain social contact (Crawley et al., 2011), feel isolated, lack independence (Winger et al., 2014) and are at increased risk of suffering from comorbid mental health difficulties (Fisher and

Crawley, 2012; Matsuda et al., 2009).

NICE (C. NICE, 2007) guidance recommends that CYP with mild/moderate CFS/ME be offered Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET) or Activity Management from a specialist service. These talking treatment approaches involve working with a therapist to make behavioural (and cognitive) changes (Brigden et al., 2017; Loades et al., 2017). However, CYP often experience delays and barriers to accessing specialist treatment (Beasant et al., 2014). In the UK, most affected CYP do not have access to a specialist CFS/ME service in their local area (Baos et al., 2018). Access to specialist treatment despite the challenges of geographical location can be

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enabled by specialist services offering sessions by videoconferencing using platforms like Skype.

Videoconferencing has not been investigated in paediatric CFS/ME, so we don't know if it is an acceptable or effective method of delivering treatment in paediatric CFS/ME, although the existing evidence in other health conditions does appear to be promising. Videoconferencing based interventions delivered in paediatric settings have been shown to be feasible, acceptable and as effective as face-to-face methods across a range of presenting difficulties such as OCD, chronic drooling, communication difficulties, haemophilia and anxiety (Comer et al., 2017; de Bruijn et al., 2017; Fairweather et al., 2016; Hooshmand and Yao, 2017; Jacobson and Hooke, 2016; McLellan et al., 2017) and the outcomes of an 8-week Cognitive Behaviour Therapy (CBT) programme for childhood depression were comparable for face-to-face and videoconferencing delivery methods (Nelson et al., 2003). CYP report a number of potential benefits of videoconferencing; they report that it is preferable to travelling vast distances to attend appointments, less financially burdensome and less disruptive to schooling and home routines (Grealish et al., 2005; Wood et al., 2016). Furthermore, videoconferencing does not appear to have a negative impact on the therapeutic alliance between the healthcare professional and the client (Freckmann et al., 2017; Sibley et al., 2017). However, potential disadvantages of videoconferencing include a lack of personal interaction, difficulty discussing sensitive problems and issues with technology (Goss et al., 2015; Simeonsdotter Svensson et al., 2014).

Including parents in treatment for paediatric CFS/ME is important (NICE, 2007), and some interventions have been explicitly developed for family-focused delivery (Lloyd et al., 2012). Although the views of parents of CYP with CFS/ME have not been investigated previously, the views of parents as both recipients and enablers of interventions for CYP provided via videoconferencing in other paediatric healthcare settings have been explored (Chavira et al., 2017; Fairweather et al., 2016). The advantages of videoconferencing, reported by parents in these existing studies, include practical benefits such as the possibility of more regular sessions for a CYP, which can promote learning, the ability for the CYP to attend independent of the parent, and the reduced costs associated with travel. However, parents have highlighted problems with technology, including a lack of confidence in their own ability to use this modality, and issues with the practicalities of a variable internet connection and of ensuring that a private space is available for conducting the session uninterrupted. Parents also reported that videoconferencing can constrain the healthcare professional's ability to see the CYP's functioning in practice. Parents seemed to view videoconferencing sessions as a helpful adjunct, but not a replacement for face-to-face sessions.

Similarly, healthcare professionals have endorsed the value of videoconferencing as an adjunct to face-to-face sessions which saves on travel time and increases accessibility to services (Chavira et al., 2017; Edirippulige et al., 2013), although they share parental concerns with regard to familiarity and confidence with the use of the technology. They have also expressed concerns about the potential effect on establishing a therapeutic relationship and rapport with a family, and have suggested that videoconferencing may be more appropriate for adults than for CYP (Edirippulige et al., 2013).

Videoconferencing therefore appears to be a promising way to address the problems associated with lack of access to specialist services for CYP with CFS/ME. However, although the use of videoconferencing has been investigated in other paediatric healthcare settings, it has not previously been investigated in paediatric CFS/ME specifically. Before we establish the potential utility of videoconferencing for delivering treatment for paediatric CFS/ME, we need to understand whether it is acceptable and how best to implement it by seeking the views of the key stakeholders. Thus, the current study aimed to explore the views of CYP, their parents, and the healthcare professionals of treatment delivered by videoconferencing in a specialist paediatric CFS/ME team.

2. Method

2.1. Setting

The study setting was a Specialist Paediatric CFS/ME service in the UK. The service provides specialist assessment and evidence-based treatment. The service introduced the option of videoconferencing sessions, using the Skype platform, as an alternative means of delivering evidence-based therapies due to the vast geographical area it covers. Video (where bandwidth allowed) and audio were used during sessions, as well as file-sharing and screen-sharing in some instances (for example, to review a completed diary together).

2.2. Participants

CYP were eligible to participate if they were 18 or under, receiving treatment (of any sort) within the specialist CFS/ME team (irrespective of whether they had a confirmed diagnosis of CFS/ME or not), and were well enough to complete an interview as judged by themselves, their parents and the healthcare professional providing their treatment. Initial convenience sampling was followed by some purposive sampling to ensure that some young people who had agreed to use of videoconferencing for therapy delivery and some young people who had opted not to use videoconferencing were included. Parents of eligible CYP were also eligible to participate. Participants were recruited until no new themes emerged from the interviews; 27 CYP completed consent to contact forms, 14 were subsequently uncontactable and 1 declined participation due to illness. A total of 12 young people aged 9 to 18 (9 female and 3 male; 6 were actively attending sessions by videoconferencing (variable frequency as dictated by clinical need), 3 previously attended by videoconferencing and 3 declined videoconferencing sessions). Although both mothers and fathers could take part, all 6 parents who were interviewed in this study were mothers. Additionally, 9 healthcare professionals from the paediatric CFS/ME team participated in a focus group. The healthcare professions represented included psychology, physiotherapy, occupational therapy and nursing (Table 1).

Table 1
Participants.

Pseudonym	Child/parent/health professional	Use of videoconferencing in the service
Claire	Child	Offered & attending
Sophie	Child	Offered, accepted but not again
Debbie	Child	Offered, declined
Rachel	Child	Offered & attending
Ben	Child	Offered & attending
Laura	Child	Offered & attending
Tom	Child	Offered & declined
Emma	Child	Offered & attending
Paul	Child	Offered, declined
Ruth	Parent	Offered, declined
Susan	Child	Not offered
Wendy	Parent	Not offered
Beth	Child	Offered, declined
Ann	Parent	Offered, declined
Samantha	Child	Offered, declined
Polly	Parent	Offered, declined
Brenda	Parent	Offered, declined
Lorraine	Parent	Offered and attending
Rhoda	Health professional	
Vicky	Health professional	
Mary	Health professional	
Delia	Health professional	
Paula	Health professional	
Erin	Health professional	
Kim	Health professional	
Moira	Health professional	
Tracy	Health professional	

2.3. Procedure

2.3.1. CYP and parents

Potential participants were identified from CFS/ME clinics. The healthcare professional briefly introduced the study, provided the patient and parents with an information sheet and sought consent for follow up telephone contact to be made by a member of the research team. The research team contacted the potential participant, further explained the study, and for those who agreed to participate, an interview was arranged at a convenient time over the telephone, via videoconferencing, or at their home according to their preference. Written consent was obtained from all participants before they took part in interviews. For children under 16, consent was sought from their parents, and assent from the young person themselves. The majority of interviews were conducted on an individual basis with either the parent or the CYP, however one parent and CYP were interviewed together as a dyad. Interviews followed a semi-structured interview schedule specifically designed for this study (Appendix i). This included questions about perceptions of treatment via videoconferencing, including the benefits and limitations of videoconferencing use. Interviews lasted between 15 and 35 min.

Data collection was an iterative process; initial interviews were used to inform subsequent stages of data collection and analyses. The interview schedule was adapted depending on whether the participant was receiving treatment via videoconferencing, had declined videoconferencing or had never used videoconferencing; Interviews were conducted by CW, RR, and NH-S, all of whom were psychology students; CW was a clinical psychologist in training, and RR and NH-S were undergraduate psychology students. All three had prior experience of qualitative research methods as well as an understanding of CFS/ME.

2.3.2. Healthcare professionals

All clinical staff working in the CFS/ME team (n = 15) were invited to participate in a focus group. The focus group took place after a team meeting at the hospital site. The focus group were asked the same questions included in the semi-structured interview schedule. The focus group was conducted by AHF and RR. AHF was a Health Psychologist working within the CFS/ME service at the time of the study and has extensive experience of conducting qualitative research.

Interviews and the focus group were audio recorded and transcribed verbatim by CW, AHF, RR and NH-S. All personal identifiable data was removed to ensure anonymity.

2.4. Ethical permissions

Initially, this study (May to October 2016) was deemed to fall within the remit of service evaluation and did not require full NHS ethics permission. It was reviewed and approved by the relevant NHS Research and Development department, and by the Department of Psychology Ethics Committee at the University of Bath (Reference Number 16–013). Due to the importance of the emergent themes and the consequent expansion of the study beyond service evaluation and to include a larger number of young people, as well as parents and professionals, the latter stages of recruitment (September 2017 to December 2017) were covered by NHS REC approval (East Midlands – Derby Research Ethics Committee, 17/EM/0302).

2.5. Data analysis

The transcripts of the 18 interviews and 1 focus group were analysed using inductive thematic analysis (Braun and Clarke, 2006) to identify shared themes across the participants. Themes were identified on the semantic level and the analysis was underpinned by an essentialist/realist framework which aimed to report on the experience, meaning and reality of participants (Braun and Clarke, 2006). This

methodology lends itself to this study, because of the exploratory focus. Data analysis followed the six stages of analysis outlined by Braun and Clarke (2006) and was led by AHF, with input from CW, RR and NH-S, with a subset of early interviews independently analysed by other members of the research team (ML, LB, JS). All transcripts were systematically read and re-read to ensure familiarity with the data. Transcripts were then hand-coded using annotation, hand-drawn diagrams and tables in Microsoft Word. Codes were then collated into potential themes, which were reviewed and discussed by the research team. Analysis began while data collection was ongoing in order to explore developing themes. Recruitment continued until we were satisfied that we had achieved “thematic exhaustion” (Guest et al., 2006). Thematic exhaustion refers to a point where no new themes emerge from the data. In line with recommendations made by Guest et al., the process involved checking the frequency of code application after analysing the first 6 transcripts, checking again after an additional 6 transcripts and so on. No new codes were identified from transcripts 13 to 18, therefore it was decided that thematic exhaustion was achieved at this point.

Criteria suggested by Lincoln and Guba (1985) were used to establish the quality of this study, and enhance trustworthiness. Firstly, peer debriefing was employed. According to Guba (1981), peer debriefing “provides inquirers with the opportunity to test their growing insights and to expose themselves to searching questions” (Guba, 1981, p. 85). In the current study, the lead researcher (AHF) facilitated two formal research team meetings at the early and mid-stages of analysis. Secondly, purposive sampling was used to help focus on key informants, who are particularly knowledgeable of the issues under investigation (Schutt, 2011), in this case CYP with CFS/ME and their parents who had either accepted or declined videoconferencing and the clinical team. Thirdly, a reflexive journal was kept by the lead researcher and other members of the research team. Finally, two types of triangulation were adopted; investigator triangulation and data triangulation. Investigator triangulation meant that all researchers were involved in the analysis of data. Two different sources of data were used, interviews and a focus group, with 3 types of stakeholders participating, enabling data triangulation.

3. Results

The thematic analysis process identified 3 themes and 12 sub-themes, which are summarised in Table 2. What follows is the exploration of each theme with illustrative quotes; pseudonyms have been assigned to all participants.

3.1. Theme 1: challenges and concerns

The problems participants perceived and the concerns they had about videoconferencing were captured in the sub-themes “technical problems”; “something lost with a virtual connection”; “privacy concerns”; and “feeling anxious”.

Table 2
Themes and subthemes identified in thematic analysis.

Main themes	Subthemes
Challenges and concerns	Technical problems Something lost with a virtual connection Privacy concerns Feeling anxious
Benefits	Access to service Convenient and flexible Opening up Comfort of home
Treatment provision	Hierarchy of communication Function of videoconferencing Preparation Technology part of YP's lives

3.1.1. Technical problems

Technical issues associated with videoconferencing included: issues with connection speed, reduced quality of the picture, reduced sound quality sometimes muting the therapist and occasions when videoconferencing would just intermittently stop working, all leading to disruptions to the session.

Technical difficulties were considered as a barrier to effective communication, especially because it could exacerbate the problems in interaction that result from a young person's CFS/ME symptoms:

“if your WiFi signal drops out and then you've got to sort of reconnect again that could make the conversation flow a little bit disjointed erm, and I think especially maybe with young people with chronic fatigue they're really tired anyway, and actually that might they might lose their train of thought”.

(Ruth; Parent, declined videoconferencing).

Although technological issues were frustrating, some participants felt that they could be dealt with and almost accepted this as part of the experience:

“sometimes it was a bit slow but not that bad it didn't really affect anything”.

(Laura; Young person, active videoconferencing user).

Although the majority of the discourse around technological issues was negative, for some participants there were positive experiences of using the technology:

“I mean the first time we had the first one it took a little while for us to get it working but ever since then it's been perfectly fine it sorted out and it works really well now.”

(Emma; Young person, active videoconferencing user).

3.1.2. Something lost with a virtual connection

Participants talked about communication being negatively affected by a virtual connection, and it seemed that the screen could become a “barrier” (Ann) to effective communication. That with a virtual connection you “can't tell exactly how people are feeling” (Beth). Voices would sound different and subtle emotional cues could be missed. For some, the inability to have direct eye contact via videoconferencing was something that was problematic:

“One of the issues I suppose with Skype is that you are looking at the face onscreen and then you are not looking at the camera so you aren't having the eye contact.”

(Rachel; Young person, active videoconferencing user).

Not being able to see the whole person on videoconferencing also made things difficult:

“its not easy to see somebody, um, as you would in person so from a, from a clinician's point of view assessing I don't y'know they might feel that actually it's better to have somebody sat in front of them because always you don't always see um a true picture um over sort of technologies”.

(Wendy; Parent, not offered videoconferencing).

Young people, parents and healthcare professionals all talked about how subtle emotional cues may be missed via videoconferencing:

“On a phone conversation or like Skype you can't like tell exactly how people are feeling.”

(Beth; Young person, declined videoconferencing).

“It's not just something you get you know if you just have the little face on the screen I think you know I you miss that you miss that bit potentially... I think that there's something about meeting in person, human beings connecting in person, that helps you”.

(Delia; Health professional).

The participants talked about how interacting via videoconferencing was inherently different from interacting face-to-face:

“Obviously if I was looking at her I wouldn't feel like it was in person”.
(Sophie; Young person, tried videoconferencing then declined).

“It's not quite the same as having a face-to-face conversation”.

(Paula; Health professional).

Some young people felt that the virtual sessions constrained both the content and the depth of what they would discuss:

“Sometimes you might be a situation where you actually want to be with that person because there is a different connection when you're with someone, I guess it depends how you're feeling but might be that you feel like you need to be with the person.”

(Laura; Young person, active videoconferencing user).

Lack of, or reduced engagement was a potential result:

“if you were over the screen, I don't know if you get the full experience because you could be like ‘yeah yeah’, would you be so engaged with it, I don't know, I don't think Skype is engaging as an actual appointment”.

(Tom; Young person, active videoconferencing user).

Healthcare professionals wondered whether this potential lack of engagement was because a therapist was not seen as a “real person” when on screen:

“if you see somebody in person and say ‘right, try and do this by next time’ and they're seeing you in per- whether ‘cause that virtual reality's slightly removed they're like ‘oh well you're not actually a real per...’ I, I mean you are a real person but they can kind of put it to a side one side a bit more”.

(Paula; Health professional).

3.1.3. Privacy concerns

Participants had concerns about confidentiality via videoconferencing, expressing a concern that they would be overheard by other family members when they were at home, which could potentially limit what they felt they could share via videoconferencing. There were also some questions as to how secure the connection would be.

“if you're on Skype other people can hear what you're saying like if somebody- if you're like in a house and then people can hear what you're saying cos you're not like privately talking and then you don't want other people to hear.”

(Beth; Young person, declined videoconferencing).

“the fact that mum and dad were in the house it seemed that it did restrict me on telling information at some points”.

(Claire, Young person, active videoconferencing user).

Potential confidentiality and security issues arising from using videoconferencing at home were a concern for parents:

“I mean obviously if you're at home and you've got just family people around the only thing would be if from a confidentiality point of view”.

(Ruth; Parent, declined videoconferencing).

“from a security point of view I'd need to know if we were going to use it that it was 100% secure so that people weren't able to listen in or gain access to it”.

(Brenda; Parent, declined Skype).

For the health professionals privacy was also a concern, though they talked about videoconferencing being “intrusive” (Tracy) for young people or even an invasion of their own privacy:

“I wouldn't skype from home, I don't want to, for me that feels like an invasion of my privacy.”

(Erin; Health professional).

One of the parents surmised that videoconferencing might be invasive of her teenager's privacy:

“well I suppose if [yp] is having a bad day then he would be in bed, essentially, erm so I suppose from his point of view he wouldn't feel very comfortable with being, umm, with being on skype whilst in that position, erm, you know he's a teenager now so I think that he would find that quite difficult.”

(Brenda; Parent, declined Skype).

3.1.4. Feeling anxious

Some participants talked about a sense of increased anxiety with connecting via videoconferencing, this was described as feeling “awkward” (Beth) or being “self-conscious” (Erin) when on screen, which would make them less likely to open up during therapy. One young person surmised that, for some, there could be a sense of discomfort from “putting their face through the internet” (Ben). Another young person made reference to her own pre-existing anxiety being triggered by videoconferencing:

“and also I have this thing where like I think that like people are watching me but I don't know it so like er, sometimes I feel like when I'm talking to people through the internet that like people are watching.”

(Claire, Young person, active videoconferencing user).

This was also something that was echoed by one of the health professionals:

“you can see yourself on the screen and just being a bit self-conscious of it's not quite the same as having a face-to-face conversation and just feeling a bit awkward”.

(Paula; Health professional).

3.2. Theme 2: benefits

The positive aspects of videoconferencing were encompassed within the sub themes “access to service”; “convenient and flexible”; “opening up” and “the comfort of home”.

3.2.1. Access to service

Participants felt a benefit of videoconferencing would be that patients who either lived too far away to receive a specialist service or were too unwell to attend hospital appointments, would still be able to access evidence-based therapies. Travel was frequently cited as a potential difficulty in terms of increasing CFS/ME symptoms, therefore the use of videoconferencing was seen in a positive light because it meant that patients would not have to travel long distances to access support.

“I don't think that we would've been able to use the service coming out every month; we wouldn't be able to afford it to be able to travel that much, no I wouldn't be able to go to school and everything it would've been a lot more limiting. It would've had to have been every couple of months if that, whereas now I feel totally supported I mean even like my actual ME has improved so much since I've been actually using the service that if I wouldn't have been able to access it and still be where I was say a year ago. The service has just helped so much and we wouldn't have been able to do that without Skype.”

(Emma; Young person, active videoconferencing user).

Even participants who had declined videoconferencing appointments had still used videoconferencing to communicate with others in their lives, for example, with relatives who are geographically distant.

“it's used predominantly for family conversations. Erm, family that are living abroad”.

(Brenda, parent, declined videoconferencing).

3.2.2. Convenient and flexible

Participants talked about videoconferencing being beneficial for young people because it was more convenient and flexible, and could “fit around school hours” (Claire) and for parents especially if they were “struggling to get time off work” (Ruth). There could also be flexibility in terms of appointment times, both in terms of “length of appointment and the right time of day” (Samantha) for the patient. Videoconferencing was easier to fit in to the busy lives of families:

“it draws less attention to it if you've got to take half a day off school or more to come all the way here people will know. And for some of our patients that's a real issue you know if they can just subtly have their appointment at home and get in to school for ten o'clock.”

(Erin; Health professional).

3.2.3. Opening up

In contrast to theme 1, videoconferencing could potentially facilitate more open communication than face to face sessions:

“I'm quite open anyway but I do think that sometimes if you were to say something it's sometimes easier to say it through a screen that it is to a person so I think certain things are easier to talk about I think”.

(Emma; Young person, active videoconferencing user).

Being physically removed from the therapist was seen as a possible reason why young people may find it easier to open up:

“teenagers and adolescents find it an awful lot easier to talk to you about things which are a little bit difficult if they're not looking at you...so I'm just wondering whether that helps a lot of our young people on Skype as well because they don't feel that you are right there in their face”.

(Vicky; Health professional).

3.2.4. The comfort of home

Negative view of the hospital environment contrasted with the comfort of home. Hospitals were described as “sterile” (Lorraine), “intimidating” (Vicky), “not the most friendly” (Ruth) and “boring” (Wendy), while the home environment was described as “pretty chill” (Emma), “relaxed” (Rachel) and “very comfortable” (Wendy).

“there's something quite nice about sitting at home and you know just having a chat as well.”

(Lorraine; Parent, active videoconferencing user).

“it was actually nice to have a conversation in your own home if you get what I mean because you feel more comfortable giving out information that you don't in the clinic if you get what I mean?”.

(Claire; Young person, active videoconferencing user).

Not only can the hospital environment be seen as intimidating, there was a suggestion that it can be particularly problematic in CFS/ME:

“I don't know about anyone else but you become quite noise sensitive so sometimes travelling here it's quite noisy and it can be a bit that sometimes it's difficult”.

(Laura; Young person, active videoconferencing user).

Conversely, the healthcare professionals talked about home being a place where you might not want to see a therapist:

“it's not a neutral space it's their home it's like tha- that's most peoples' sanctuary”.

(Delia; Healthcare professional).

3.3. Theme 3: treatment provision

Videoconferencing in wider context of treatment provision was seen as a choice that could be offered, although face-to-face support was considered superior. This is explored with the subthemes “hierarchy of

communication”; “function of videoconferencing”; “preparation” and “technology part of young people's lives”.

3.3.1. Hierarchy of communication

Participants expressed a preference for face-to-face appointments over videoconferencing appointments, mainly because it was considered important to “see the whole person” especially at the first appointment. A face-to-face appointment was considered to be “the full experience” (Tom) making it easier to “build more of a relationship with the person you're talking to” (Pauline) and helping patients feel “safer” and “more reassured” (Wendy). Conversely, there were participants who felt that there was no difference between face-to-face and videoconferencing appointments. Some participants felt that videoconferencing appointments were preferable to phone calls, because of the visual element of videoconferencing, thus forming a hierarchy of communication.

“I think the fact that you can see somebody. Erm, so you know [yp] there's not an awful lot of conversation with him at the moment, with regards to, just because he's tired, and gets tired very quickly. Erm, so the fact that you can see expressions, erm, you know, if it, if it, with regards to the service it would mean that whoever was looking after [yp] then they would be able to see him, it wouldn't, you know, whereas over the phone that would be more difficult to perhaps be able to read how he is at that time”.

(Brenda; parent, declined videoconferencing).

3.3.2. Function of videoconferencing appointments

Many of the participants mentioned that they would not want videoconferencing appointments to replace regular face-to-face appointments. Some felt that videoconferencing appointments could function as a “mini-appointment” (Ann), essentially to supplement the “main” face to face appointments. It was also suggested that videoconferencing appointments could occur with increased frequency compared to face to face appointments:

“I don't think it can completely take over from a physical appointment I think it has a place in sort of maintenance appointments and um y'know sort of check-up type appointments”.

(Ruth; Parent, declined videoconferencing).

“there's a lot of added benefit for Skype calls perhaps from a more frequent point of view touchpoint with the service”.

(Ann; Parent, declined videoconferencing).

Participants talked about having a mix of videoconferencing and face-to-face appointments, some said that they felt that this had “worked well” (Lorraine) in their experience. Participants talked about the importance of having a choice of appointment modality.

“probably at the original like when you first enter the service and you go for an original meeting um maybe discussing it then is an option”.

(Wendy; Parent, not offered videoconferencing).

3.3.3. Preparation

The importance of planning and preparation for videoconferencing, both at an individual and service level was seen as key. Some of the participants reflected that there seemed to be an assumption that videoconferencing is already widely known and used:

“I think I felt like it was a everyone's doing videoconferencing so you guys should automatically know how to do it don't you? Erm it's a bit like being with adolescents everyone you know would never er 'fess up to saying I don't know what Instagram is and I don't know how to use it (laughter from group) so it was kind of just 'let's just do it'. So I was a bit concerned about that”.

(Delia; Healthcare professional).

Participants talked about a lack of guidance in terms of setting up videoconferencing or using it; for some this was not a problem because they were familiar with it, though for others this was an issue:

“I think if they gave like people like me who are not terribly at home with computers if they gave um when they're first diagnosed if you give them access to that y'know with instructions how to set it up and how to do it”.

(Ruth; Parent, declined videoconferencing).

Some participants wondered whether the CFS/ME service could prepare patients for videoconferencing use through, for example, an online tutorial or having a test run of using videoconferencing before an actual appointment:

“I know appointment times are quite restricted and quite short but maybe if there was a computer in the room this is what it will look like or even if there was a YouTube video or something go and have a look at this see what you think”.

(Rachel; Young person, active videoconferencing user).

The amount of training required should be decided on an individual basis:

“so I think you've got to judge it as a service and just offer it as a, 'right we can make sure that that's all set up for you, you know, if you're ever not feeling confident about it' erm, but err, certainly if you know about Skype you don't want to spend another ten minutes going 'yes, this is Skype”.

(Lorraine; Parent, active videoconferencing user).

The lack of familiarity with videoconferencing and need for more training/support was echoed by the healthcare professionals:

“I think that training is obviously key”.

(Delia; Healthcare professional).

Once people had tried videoconferencing in a therapeutic context then they realised it was better than they had anticipated:

“it wasn't as bad as I thought like it was really good, I got to like erm, have the same conversations that I would in a regular appointment”.

(Claire; Young person, active videoconferencing user).

3.3.4. Technology part of YP's lives

There was a perception that young people may not find it too unusual to be treated via videoconferencing because they “use technology so much” (Debbie). Young people are perceived to be adept at using technology as part of their day-to-day life, making virtual connections commonplace:

“Of all the kids I know I can't imagine anyone would have problems speaking to someone over a computer really because they're so used to it, and they're so, you know, computers are such a part of their lives so I can't see why it would be an issue.”

(Lorraine; Parent, active videoconferencing user).

It was therefore felt that the use of videoconferencing for the provision of therapy was appropriate for young people and could perhaps be considered preferable:

“it feels quite sort of young person appropriate”.

(Mary; Healthcare professional).

“children like to use technology nowadays, erm, and maybe they find that easier than being in person”.

(Brenda; Parent, declined videoconferencing).

This was mainly talked about by the adult participants, though at least two of the young people mentioned this too:

“I think it is really a good idea because seeing as so many people nowadays, especially young people, use technology so much using it to actually help them would be, yea, a pretty good way of doing it and

taking advantage".

(Debbie; Young person, declined videoconferencing).

4. Discussion

This study aimed to explore the views of young people, their parents, and healthcare professionals of treatment delivered by videoconferencing in a specialist paediatric CFS/ME team. The interviews with young people and parents, and a focus group of healthcare professionals showed that generally, videoconferencing is perceived to be a useful option for treatment provision, preferable to telephone sessions, although less favourable within a hierarchy of preferred communication than face-to-face meetings. Videoconferencing was particularly useful in enabling accessibility, and in providing a different option to attending hospital appointments which may be particularly difficult, given CFS/ME symptoms such as sensitivity to noise and light and fatigue which can be exacerbated by travelling. The comfort of being in the home environment and the ability to be more in control of the interaction was seen as a benefit. Practicalities and technical issues, although problematic, did not seem to be seen as insurmountable, particularly to the young people. Videoconferencing was perceived to be restrictive of communication in some ways, particularly related to non-verbal cues including eye contact and not seeing the whole person, and therefore potentially missing subtle emotional cues, which could result in lack of engagement. In other ways, the screen was perceived to enable communication about difficult topics. Participants felt that choice was important, and saw technology like videoconferencing as a natural way for young people to communicate.

The barriers to effective communication in videoconferencing identified are consistent with previous research. In the current study, some patients felt constrained in terms of sharing potentially difficult information over the internet as well as potentially having family members overhearing therapeutic conversations. This relates to wider issues around confidentiality, safety and privacy when using technology, which have been cited as barriers in other studies of young people (Huby et al., 2017) and healthcare professionals (Edirippulige et al., 2013). Other studies have also found that technological problems can be a perceived barrier to effective communication, for example in educational settings (Simeonsdotter Svensson et al., 2014). Conversely, some studies have not found privacy concerns to be a significant barrier (Knowles et al., 2014; Lundgren et al., 2018) and it may be that technical solutions, like text based interventions, could be a way to overcome such issues.

A perceived advantage of videoconferencing was that of enabling service access, particularly for interim treatment appointments, which could be done more regularly with less disruption to daily life. This is similar to findings from studies in other paediatric healthcare settings (Grealish et al., 2005; Wood et al., 2016). Compared with other paediatric chronic illnesses, quality of life in CFS/ME can be significantly more impaired (Kennedy et al., 2010) so it may be of particular benefit to use videoconferencing in CFS/ME by reducing the stress and burden of attending clinic and minimising additional school absence as a result of clinic appointments.

Paradoxically, the screen was both a barrier to effective communication and a safe conduit for sharing difficult information. The concerns raised about communication via the screen appeared to centre around the difficulties with conveying and interpreting subtle non-verbal cues, but the control the screen afforded and the ability to be in the comfort of home enabled young people to open up. This may partly be generational and both the parents and healthcare professionals in the current study assumed that young people are more comfortable with virtual connections and may find it easier to discuss difficult information with the slight disconnect of the computer screen. Reassuringly, when the technology issues were brief or infrequent, many participants were quite accepting and accommodating of these issues. While

previous studies have reported that videoconferencing does not impact negatively on the therapeutic alliance (Freckmann et al., 2017; Sibley et al., 2017), in the current study, participants reported a lack of engagement that may result from the barrier of the screen and limits imposed by the virtual interaction. It may therefore be preferable to use videoconferencing in the context of an established therapeutic relationship to supplement face-to-face meetings, rather than in place of these. Patient choice is of paramount importance, rather than a 'one size fits all' approach.

Although generally, the views of the young people were consistent with parents and healthcare professionals, a view primarily held by the adults who took part in the current study was that videoconferencing is ingrained in the everyday life of young people and thus they are adept at using technology and utilising virtual connections. Only two young people mentioned this, though they had both declined videoconferencing use. Perhaps we can conclude that the young people in this study did not talk overtly about virtual communication because it is indeed so ingrained in everyday life, thus it is the norm and evades further discussion. Alternatively, this could perhaps be indicative of a generational misunderstanding that communicating virtually is "a young person thing", when in reality virtual communication is simply an extension of more traditional ways of communicating.

Videoconferencing was seen as an additional tool for provision of therapy, though not on a par with face-to-face support it was seen as better than telephone contact, especially when illness severity and distance were barriers to accessing treatment. Perhaps over time, as technology improves and enhanced privacy and confidentiality can be assured online, the restrictions to communication via videoconferencing will diminish and the positive aspects will flourish.

4.1. Strengths and limitations

This is the first study to explore the use of videoconferencing to deliver treatment in a specialist CFS/ME service for children and young people. It explored the views of the key stakeholders, including young people, parents and healthcare professionals. However, this study is based on the experiences and opinions of a small number of participants from one specialist paediatric CFS/ME service and therefore, may not necessarily be assumed to be representative of all young people with CFS/ME.

The authors' involvement in the CFS/ME service may have introduced bias with regard to the analysis and presentation of the findings. Because the findings represent a construction made by the authors, it is most likely that an analysis by other researchers would lead to different findings. In the context of qualitative research this is a familiar issue. The fact that there could be multiple constructions from one dataset does not negate the trustworthiness of any one construction, though it is important that various steps are taken to enhance the trustworthiness, credibility and reflexivity and dependability of any qualitative enquiry. In the current study; providing a detailed and transparent description of the analysis process added to the trustworthiness of the enquiry. Credibility of the findings was enhanced through the use of multiple triangulation processes, peer debriefing and purposive sampling. Reflexivity and dependability were facilitated by the lead researcher keeping a reflexive journal.

The focus of this current study was on Skype as a platform for videoconferencing as this had been utilised within the service for several years. However, as technology continues to develop, other platforms which may overcome some of the technical and practical limitations should also be investigated, and we cannot conclude that the findings from the current study necessarily apply to other videoconferencing platforms or indeed, other conditions relevant to CYP.

4.2. Implications

Videoconferencing should be offered as an option within a package

of care, not as an alternative to face-to-face support. The importance of planning and preparation should not be overlooked when introducing it into a service. It would be helpful for technical, privacy/security, anxiety issues to be addressed at the beginning of therapy, particularly if these concerns potentially have a negative impact on the therapeutic relationship. It may also be helpful to establish guidelines for healthcare professionals around using videoconferencing therapeutically. Videoconferencing could potentially increase access to service by reducing the travel time/cost to attend sessions, and future studies should investigate both effectiveness and cost-effectiveness of this modality of treatment provision.

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Declaration of conflicting interests

EC acts as a medical advisor for the Sussex and Kent ME society. The other authors declare that there is no conflict of interest.

Statement of contribution

What is already known on this subject?

- Videoconferencing technology such as Skype provides a means of delivering therapeutic sessions remotely.
- Videoconferencing based interventions delivered in paediatric settings have been shown to be feasible, acceptable and as effective as face-to-face methods across a range of presenting difficulties.
- It is not yet known whether videoconferencing is an effective method of delivering treatment in paediatric CFS/ME.

What does this study add?

- This is the first study to explore the use of videoconferencing to deliver treatment in a specialist CFS/ME service for children and young people.
- There were benefits and challenges in using videoconferencing to deliver specialist treatment in this setting, and it seemed to be a useful option as an adjunct to rather than a replacement for face-to-face sessions.
- While the screen was sometimes referred to as a barrier to effective communication, it was also seen as a conduit for sharing difficult information.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.invent.2018.12.003>.

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