Exploring how to deliver videoconference-mediated psychological therapy to adults with an

intellectual disability during the coronavirus pandemic

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Abstract

Purpose

The novel coronavirus and associated restrictions have resulted in mental health services across the United Kingdom having to adapt how they deliver psychological assessments and interventions. The purpose of this paper was to explore the accessibility and prospective acceptability of providing telephone and videoconference-mediated psychological interventions in individuals with intellectual disabilities.

Methodology

As part of a service evaluation, a mixed-methods questionnaire was developed and completed by clients who had been referred for psychological therapy at an adult intellectual disabilities' community health service in the north of England. All clients were assessed using the Red/Amber/Green (RAG) system by a consultant clinical psychologist for risk and potential suitability for indirect service delivery given their ability and needs.

Findings

Overall, 22 clients were invited to take part, of which, only seven (32%) were accepting of telephone or videoconference-mediated psychological therapy. Most of the clients were unable to engage in video-conference therapy and therefore, only suitable for phone therapy. This article presents the remaining findings, and discusses the clinical implications and unique considerations for intellectual disability services drawing on the existing literature.

Originality

This is the first article, that the authors are aware of, examining videoconference-mediated psychological therapy in this population. We hope the data will be used to help inform

practice or policy when using such therapeutic approaches in adults with an intellectual disability.

Key words:

Psychological therapy; intellectual disability; remote therapy; e-therapy; telehealth; teletherapy; videoconference; service development; mental health

Classification: Practice paper

Introduction

Infection control guidelines in response to the novel coronavirus (Covid-19) have resulted in mental health services in the United Kingdom (UK) having to adapt their routine practice. Due to the restrictions posed by the social distancing rule, specific changes have had to be made to the way in which psychological assessments and interventions are provided (NHS England and NHS Improvement, 2020). Barriers associated with face-to-face contact, coupled with client's elevated psychological distress, precipitated or perpetuated by the coronavirus (Holmes et al., 2020), has motivated services to divert resources with the aim of better understanding the acceptability, fidelity, feasibility and effectiveness of remote therapies (British Psychological Society, 2020a).

Prior to the coronavirus pandemic, telephone and videoconference-mediated interventions have been used with clients in a diverse range of medical settings. Improved access, cost-effectiveness and client satisfaction have been reported as the main benefits associated with such an approach (Banbury, Nancarrow, Dart, Gray, & Parkinson, 2018; Brearly et al., 2017). However, in the current climate, remote therapy also offers personal safety for both clients and healthcare professionals. Different health and social care organisations have proposed direction on using videoconference-mediated telehealth within the general population (British Psychological Society, 2020a; 2020b) .

A wide range of psychotherapeutic approaches originally developed for the general population have become available in adapted formats to people who have an intellectual disability (ID) (Beail, 2016a). Indeed, the National Institute for Health and Care Excellence (2016) recommends for psychological interventions to be tailored to the client's ability, level of understanding, need and strengths. As well as considering physical, cognitive, sensory and communication impairments that may impact the client's ability to engage with treatment. While interest is growing in the use of assistive technology to help improve the quality of life

of people with ID (Perelmutter, McGregor, & Gordon, 2017), there is a paucity of research to help inform practice or policy on telephone and videoconference-mediated psychotherapy within this population. Indeed, at the current time of writing, the authors are unaware of any published data examining the use of remote psychological therapy or interventions specific to COVID-19-related difficulties in individuals with ID. This could result in this group being left without acceptable or adequate treatment during the pandemic, further contributing to the inequality of access to care (Beail, 2016b).

The psychological and social impact of the coronavirus on the general population is only just beginning to be understood. Generally speaking, people with ID are more vulnerable to distress and have less helpful coping approaches (Janssen, Schuengel, & Stolk, 2002). Therefore, it is unsurprising to find that the pandemic is posing considerable challenges for this group (Navas et al., 2020). People with ID are currently experiencing a disruption in routine, challenges associated with close of day services, difficulties in understanding rules regarding social distancing and infection control, and limited insight into how others are impacted. Individuals are also encountering problems in communicating and self-regulating their own distress, deterioration in physical and emotional health, increase in challenging behaviours, and reduced contact with family and friends. Moreover, carers of adults with ID in the UK have experienced high levels of anxiety and depression, and a reduction of social support, which is likely to further impact those with ID (Willner et al., 2020). For example, adults with ID have reported to be providing support to others (Navas et al., 2020) - a role in which they may be less familiar of managing the associated demands. The profound impact of the coronavirus has been recognised in government policies (NHS England and NHS improvement, 2020) as people with ID have been given greater flexibility in terms of leaving their home for exercise during the first lockdown period (Department of Health & Social Care, 2020).

In light of this, we conducted a service evaluation study to explore the accessibility and prospective acceptability of videoconference-mediated psychological therapy with people with an ID. This evaluation is in line with the growing need of involving individuals with ID in decisions regarding their own care (Mattock, Beard & Baddeley, 2020).

Methods

The service

The service is part of an adult intellectual disabilities' community health service in a Metropolitan Borough in the north of England with a population of 245,200. The psychology service consisted of three clinical psychologists, an assistant psychologist, and two trainee clinical psychologists on placement. The psychology service provides direct work with clients, including psychological assessment and intervention, and indirect work through consultancy and training. For a more detail description of the service see Jackson and Beail (2016).

In March 2020, the government in England imposed a lockdown due to the Covid-19 pandemic (Prime Minister's Office, 2020), which was not eased until June 2020. During this time, people were required to stay at home and could only leave for specific reasons including (but not limited to) work if they were classed as a 'keyworker', exercise and essential shopping. This also resulted in our service stopping the provision of outpatient face-to-face appointments and home visits. All clients receiving a service or on the waiting list were rated by a consultant clinical psychologist using the Red/Amber/Green (RAG) system according to their level of existing risk, possible risk should they not receive a service, and potential suitability for remote/indirect service provision i.e. clients must have had the ability to engage in conversations remotely.

Service users

The RAG rating exercise identified 22 clients (15 women, 7 men; 20 White British, 1 Black, 1 mixed race; age range 18 to 57 years) who may have been suitable for telephone or videoconference mediated therapy. An additional 20 clients were assessed however based on clinical judgement; their presentations were too complex to be treated remotely for example, they were presenting with attachment or interpersonal difficulties.

Clients assessed as potentially suitable for remote therapy presented with mild to moderate symptoms largely of anxiety, low mood and anger, and were rated as low to moderate risk by a consultant clinical psychologist. All clients had been previously diagnosed with ID, had been referred for psychological therapy, and had had one face-to-face triage appointment to assess their needs before the lockdown.

Data collection and analysis

Clients were contacted via telephone in May 2020 by one of the two second year trainee clinical psychologists at the service. If clients did not answer on the first attempt, they were contacted an additional two times at different times of the day. If clients could not be contacted, they were sent a letter asking them to notify the service of a suitable time and date to be contacted.

The two trainee psychologists debriefed after each contact with a client discussing the client's response and if any issues were experienced. Responses were also routinely discussed with qualified clinical psychologists within the team. The team were unable to contact three clients by telephone as the phone number originally provided by clients had no dial tone.

Clients who would speak to the caller consented to take part in the evaluation. They were asked a series of questions from a mixed-methods questionnaire, which was iteratively developed by all authors of the current article. The questionnaire was split into four sections:

client's demographics, sensory ability, current use of technology and perceptions of telephone and videoconference-mediated therapy (see supplement 1). The questionnaire was initially piloted on one client to explore acceptability – no necessary revisions were identified.

The data was inputted into Microsoft Excel and analysed using descriptive statistics. A mixed method embedded research design was utilised to analyse the data. For this approach, the quantitative data was analysed first using descriptive statistics; then the qualitative data was used to augment and compliment key findings. This methodology was selected as it is commonly used to help inform implementation studies as the data can guide intervention design (Palinkas et al., 2011).

The service evaluation was requested by the Trust's Gold Command and registered with the Quality Improvement and Assurance Team of the Trust.

Results and discussion

In addition to the three clients who could not be contacted, five clients did not complete the questionnaire as they were unable to talk on the phone. For example, they struggled to understand people or did not feel comfortable talking on the phone. A further seven clients explained that they would not like to have therapy via telephone or video and would prefer to wait for face-to-face therapy, which would be available once social distancing rules had been lifted – however no specific date was available. For instance, one individual said that they "couldn't do it", while another reported not being "interested" in telephone or videoconference-mediated psychological therapy. In all cases, the psychologist explored whether the client retained and understood the information, and consequences of their decision.

Therefore, only seven (32%) clients were accepting of telephone or videoconference-mediated psychological therapy (six women, one man, all white British, age range 19-57 years). Three lived alone, three with their parents, and one with her son. Reasons for referral included anxiety (n=7), depression (n=3), anger (n=2), bereavement (n=1) and feeling disconnected with others (n=1) – a number of clients were referred for more than one difficulty.

Sensory ability

People with ID are more likely to have auditory or visual difficulties compared to the general population (Silver et al., 2008). However, five service users reported having no auditory problems, whereas one was partially deaf and another sometimes struggled to hear. Guidelines for conducting telephone and videoconference-mediated psychological therapy suggest encouraging clients to wear headphones to help with hearing, as well as to improve privacy and rapport (Kroll et al., 2020). However, sensory processing disorders are common in those with ID and therefore, placing objects on client's heads may not always be tolerated (Green et al., 2003). Only one client reported sight difficulties that may impact her ability to engage in video therapy explaining she can experience blurred vision.

Overall, sensory difficulties posed less of a problem than previously considered. However, it is important to note that people with ID can refrain from disclosing a difficulty as it can leave them feeling shamed and fearful (Valle, Solis, Volpitta, & Connor, 2004). Moreover, acquiescence (whereby clients show acceptance to a response rather than protest) is often observed in this population (Finlay & Lyons, 2002). Therefore, clients may have readily agreed with a statement without their response necessarily being accurate. Therapists should be aware of such behaviours during remote therapy as clients may confirm that they can hear or see the screen when they cannot. What is more, therapists should sensitively

explore with their client at the start, and throughout therapy, whether they may encounter any problems, what can be done to minimise this and how clients can feel safe expressing their difficulties. Indeed, repeatedly checking with clients that they have heard, processed and understood the information will be vital.

Problems with communication, social interaction and processing difficulties were more prevalent in our sample. While none of the clients reported having any recognised speech and language disorders that could pose a problem during remote therapy, it was common for clients to explain that they can "get shy", be left feeling "not knowing what to say", and become "confused and flustered". While clients are also likely to encounter such difficulties in face-to-face therapy, the nature of speaking over the phone or video may present additional challenges. For example, clients with ID may find it easier to communicate a degree of their needs through behaviour (instead of and/or in addition to verbally). This notion is reflected in behaviours that challenge in which, it is formulated that people with cognitive impairments attempt to fulfil an unmet need and communicate their distress through their behaviour (National Institute for Health and Care Excellence, 2015). Moreover, the lack of non-verbal and visual cues from the therapist may also cause difficulties as clients may be more at risk of misinterpreting what the therapist is communicating. Therefore, therapists should make greater use of simple language and short sentences.

One client felt that therapy would be "easier over the phone" as there would be "less pressure" and it would be "easier to answer [questions]", whereas during face-to-face therapy, she "would be more stressed and worrying [she] got things wrong". It has been recognised in remote therapies within the general population, that clients may engage in rapid disclosure of information. If unmanaged, this may result in the client feeling overwhelmed, regret and anger. The client could then disengage from therapy resulting in a rupture in the alliance. This may occur because the client cannot see the therapist and therefore, feel

anonymous and fail to experience others as real. Initial contracting with clients regarding the possible outcomes of any disclosures of information related to risk and limiting the use of free association by interrupting clients sensitively will be important. In addition, facilitating the client to feel less disinhibited by helping them to slow down, process and reflect on what is being discussed will be helpful (British Association for Counselling & Psychotherapy, 2020). Providing clients with a photo of the therapist may also help to build alliances with clients and facilitate in helping them feel less anonymous. Indeed, individuals with ID have recognised a positive therapeutic alliance as a dominant facilitator when engaging in psychological therapy (Ramsden et al., 2015). Of course, therapists themselves may also be challenged by feelings of disinhibition, which coupled with lack of non-verbal feedback, will result in therapists having to be particularly reflective on the content, tone and pace of conversations.

One client disclosed having difficulty with reading and writing. This can be common in those with ID. When engaging in face-to-face therapy with a client who struggles to, or cannot, read or write, a greater emphasis is placed on the use of speech, pictures and videos. For example, when developing a formulation with clients, pictures of faces showing emotions can replace words to describe feelings, and the use of figures or objects to represent people or relationships. Generally speaking, images can be easier to process compared to words, which are more abstract in nature. As such, video therapy has clear advantages over phone therapy.

Educational materials, such as leaflets, drawings and worksheets (and also standardised outcome measures) are important resources in face-to-face psychological therapy with this group. Such resources can supplement or replace verbal comprehension. Indeed, visual aids have been described as crucial adaptions in therapy by those with ID (Ramsden et al., 2015). All of the clients who were asked would prefer to receive materials via post, rather than email or phone. Such an approach also has the benefit of clients having a

hard copy of the materials, which is more concrete and easier to process. This means that in phone therapy, the therapist would need to plan ahead making sure clients had access to resources before certain discussions were had in sessions. Semi-manualised therapies are therefore particularly pertinent, rather than therapeutic sessions being solely guided by what the client decides to discuss. This is in line with phone-based treatments delivered within the general population. Therapies that can more easily be delivered in a manualised approach, such as cognitive behavioural therapy, have been shown to be effective for some presentations (Watzke et al., 2017).

Current use of technology

All of the clients contacted had access to a landline phone whereas, only five had a mobile phone, which they used daily and found it "easy" to use. Three clients reported at times having issues with the sound quality of their mobile phone. Four used their mobile phones to video call people. Five clients used a computer or tablet, which they said they found "easy" to use and used it daily or weekly. Only two clients used their computer or tablet to video call. Five clients used the internet daily, had unlimited wi-fi and reported having a good connection.

Arguably, one of the most difficult barriers that needed particular consideration was which computer program or app would be most suitable for therapists and clients to communicate over. This was due to factors such as the client's ability to use technology and the restrictions imposed by NHS governance and data security. The trust were piloting seven potential programmes for this purpose which included Zoom, AttendAnywhere, WhatsApp, Microsoft Teams, Skype, Airmid-System One and AccuRX. We asked clients how familiar they were with each program and how easy they found it to use. The most commonly used programs were WhatsApp and Microsoft Teams. None of the clients had heard of

AttendAnywhere, Airmid-System One or AccuRX. Two clients had heard of Zoom but never used it. Four clients used Whatsapp and found it "easy" to use. However, staff later raised the concern that Whatsapp shows people their phone number, resulting in the potential for clients to contact staff members directly, raising the issue of boundaries. Indeed, client's may attempt to transfer their typical behaviours regarding their phone and video use with other people, on to that of their therapist. Therapists and clients should have boundaries in place, in which the client does not attempt to contact the therapist outside of a therapeutic session, and if they do, the therapist needs to be consistent in their approach of not answering. Clients of course can still contact the service and request to speak to their therapist for urgent matters. One client used Microsoft Teams finding it "easy" as she used it at school/college – possibly suggesting accessibility is influenced by client's age. Five individuals had heard of skype, but only one had used it finding the program "okay" in terms of accessibility.

Taken together, these results suggest that the vast majority of clients referred to the service were unable to engage in video-conference therapy and therefore, were only suitable for phone therapy. Observing and formulating the behaviour of the client is viewed as an important tool for therapists in helping to understand the emotions of the clients (Beail, 2016a). As such, in phone therapy, a greater focus will be needed on what the individual says (and does not say), and how it is said. However, and in the context of a service evaluation study not aiming to be generalisable, some clients would be able to use video therapy and so therapists are encouraged to have such discussions and support their client in its use.

Five of the clients had someone to ask when they needed support using technology, which often included a family member. What is more, one client explained she feels she would need her carer on the phone for therapy to help her understand what is being discussed. This poses obvious confidentiality issues and also may influence how open clients are to discuss certain issues. There is also the added concern of working with a client whose carer

discourages them from engaging in therapy (Ramsden et al., 2016). Notwithstanding these matters, it is not uncommon for mental health difficulties of people with ID to be reported to healthcare services by their carers, as opposed to the client themselves (Chan, Hudson, & Vulic, 2004). Moreover, psychological therapies can be more effective when caregivers are involved in treatment as they can provide assistance in helping clients to attend sessions, provide additional information on the client's circumstance and support clients with behaviour change (Irvine & Beail, 2016). Caregivers are also likely to play a considerable role in manging some of the risk associated with remote therapy with this client group. People with ID have been suggested to frequently use less sophisticated psychological defences including acting out and denial (Newman & Beail, 2010). Therapists need to be considerate of such reactions when having conversations that may be distressing for clients. For example, when one client was asked a question that he did not know how to respond to, he panicked and put the phone down. Fortunately, when he was immediately contacted he answered his phone and was able to explain his reaction. Therapists need to develop contingency plans with clients and their caregivers, in the event of any problems arising with connectivity or the client abruptly ending the call and cannot be reached thereafter. Where suitable, caregivers should be encouraged to help facilitate remote therapies, while also taking into consideration the client's view on their involvement.

We asked clients how long they think they could talk to a therapist on the phone or video without feeling tired. Client's responses ranged from 20 minutes to an hour. However, it is not uncommon for individuals with ID to have a poor sense of time; for example, one client felt she could only stay on the phone for two minutes however had already been on for over 20 minutes. It is well documented that psychological interventions may take longer for clients with ID (National Institute for Health and Care Excellence, 2016). Moreover, adaptions are needed to help clients assimilate new information, such as making use of

repetition within and between sessions (Irvine & Beail, 2016). Indeed, remote therapy maybe well suited, as clients can be contacted more frequently and for shorter periods of time, breaking information down into smaller parts helping to make it more digestible and easier to retain. However, as with face-to-face therapy, clients with ID should be supported in making decisions regarding the pacing, timing and content of therapy. For example, four clients reported "always "or "sometimes" struggling to stay interested while talking to someone on the phone.

Perceptions of videoconference-mediated therapy

As discussed, the therapeutic alliance is viewed as an important aspect by both clients with ID and their therapist (Jones, 2014). Indeed, six of the clients felt it would be "easy" or "okay" to speak to a therapist remotely, thus indicating that alliances can be developed and maintained using this approach. That said, there was a sense from four of the clients that they felt anxious about speaking over the phone to someone they had never met in person. For example, one client explained she "feels scared when people contact" her over the phone as she does not know who is calling. Another reported concern over knowing if the person they are talking to on the phone is "genuine"; and not being able to see the therapist made another client feel uncomfortable. Moreover, one client explained she finds it "easier to talk to people face to face than over the phone" when she has to tell them something "important". This seems to suggest building an alliance will be easier for clients and therapists who have met prior to social distancing rules. For those who have not, it may be helpful for another member of staff to contact the client or be present during the first session to facilitate the building of the alliance. Typically, therapists consult with other members involved in the client's care prior to starting therapy and so this process should be relatively straightforward to be accommodated in practice. Of course, there will be clients who do not have other

professionals involved in their care and therefore, other strategies will be needed to help develop an alliance. Although this warrants further investigation.

None of the clients felt "unhappy" (but rather "happy" or "okay"), about having therapy over the phone. Whereas only one client felt "happy" about having therapy over video. Clients were not asked to provide a rationale for their decision and so no strong arguments can be proposed. Given that four clients used video calling in their day to day life, it is unlikely that accessibility is the main issue. Nevertheless, taken together with client's use of technology, phone therapy appears to be the most acceptable and accessible approach to delivering remote therapy with this population.

Clients were asked what they think some of the benefits of remote therapy may be. One felt that it was "safer doing it this way because of the coronavirus". Four clients discussed getting help sooner [opposed to having to wait until the service is offering face to face appointments] and "having someone to talk to" about their feelings. Individuals described remote therapy would allow them to get things "of their chest", "knowing someone is there" and talking to someone about their problems who is not a member of their family. This suggests that some people who have ID are experiencing challenges during the coronavirus pandemic. Clearly, research is needed into this area helping to identify the nature of their difficulties and therapeutic targets.

All of the clients felt they had access to a space where they could speak with a therapist over the phone or video, which was private and quiet. The importance of the therapeutic frame when working with clients with ID has previously been discussed (Beail, 1989). While this will likely depend on the approach to therapy being used, it has been suggested psychodynamic therapy should take place away from the client's home (Beail, 1989). However, this may not always be possible and moreover, home-based psychological treatments of individuals with a developmental disability have shown to be effective

(Sheinkopf & Siegel, 1998). Therapists should help the client consider the best location for them to be in during the session, discussing variables such as lighting, temperature, seating arrangements, privacy, potential distractions and comfortability. Beail and Jackson (2013) argue that consistency is an important factor in psychological therapy, as it can facilitate communication and the building of trust. This is particularly salient when working with clients whose difficulties are linked to unhelpful attachment styles, the development of which, may have indeed been influenced by inconsistent care. There is some evidence to suggest individuals with ID have a higher prevalence of disorganised and insecure attachment styles (Hamadi & Fletcher, 2019). When engaging in remote therapy with this client group, therapists within the service are recommended to set boundaries with the aim of maintaining consistency and preserving the therapeutic frame as recommended in face to face therapy (Jackson & Beail, 2013). Therapy sessions should be arranged to take place at the same time, duration and location, and mode of contact. For instance, the client should remain in the same room throughout the session and not be distracted by activities, such as making a drink or smoking. However, clients with ID have reported the benefits of their therapists being flexibility (Lewis, Lewis & Davies, 2016), which is also likely to improve adherence. Therapists should aim to check with clients at the start of therapeutic sessions that these rules have been met and refer to ground rules when broken.

Conclusion

Practice-based case series have historically played an important role in the development of psychological therapies for those with ID. The findings from such investigations have been used to inform research higher up the hierarchy of scientific evidence. While the current findings must be considered in light of the modest sample size, this figure is an accurate representation of the number of clients suitable for remote therapy

under the care of psychology within an adult ID community health service. We hope the findings presented here will be valuable to other services when informing their equality impact assessments at this time and as they attempt to fulfil their duty in adapting their routine practice to meet the psychological needs of people who have ID. Research is needed to explore the experiences of those clients who can engage in remote psychological therapies and evaluate the effectiveness of such interventions. The clinical implications of the findings have been drawn from the evidence base, however, given its limited availability and lack of specific research examining the use of telephone and videoconference-mediated psychological therapy with people who have ID, considerations have also been informed by discussions that have taken place within the service involving multi-disciplinary teams.

It is important to note that, this study was not comprehensive, as there will be many barriers and processes that will require consideration specific to individual clients. Moreover, it does not aim to discuss those clients with ID who are unable to engage in remote therapy, for instance due to complex needs or communication difficulties (Taylor, 2008). However, the service has concurrently increased remote working with families and caregivers to help support and assist with difficulties being faced at this time. The study has helped identify common issues when setting up remote therapy with people who have ID and hopefully encourage others to make this available as part of their service offer. A big next step will be to evaluate the effectiveness of this approach with people who have ID.

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