Article:

Rawlings, G.H. orcid.org/0000-0003-4962-3551 and Beail, N. (2023) Psychologists' experiences and perspectives of adults with long-Covid and neurodiversity, including intellectual disabilities. FPID Bulletin: The Bulletin of the Faculty for People with Intellectual Disabilities, 21 (2). pp. 23-32. ISSN 2056-3094

https://doi.org/10.53841/bpsfpid.2023.21.2.23

This is a pre-publication version of the following article: Rawlings, G.H., Beail, N., (2023) Psychologists' experiences and perspectives of adults with long-Covid and neurodiversity, including intellectual disabilities, FPID Bulletin: The Bulletin of the Faculty for People with Intellectual Disabilities, 21, (2).

Psychologists' experiences and perspectives of adults with long-COVID and neurodiversity, including intellectual disabilities.

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Data availability statement
Data is available on reasonable request.

Funding statement
This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Conflict of interest disclosure
The authors report no conflict of interest.

Ethics approval statement
Favourable opinion was granted by the Schools of Business, Law and Social Sciences Research Ethics Committee at Nottingham Trent University (1598526).

Participant consent statement
Informed consent was obtained for this study.

Permission to reproduce material from other sources
Not relevant.

Clinical trial registration
Not relevant.

Total word count: 4000
Abstract word count: 100

Abstract

While there is an increasing number of studies aimed at better understanding long-COVID, there is a lack of research involving people with intellectual disabilities (ID). We asked 12 psychologists working in long-COVID services, their views of the condition in adults with neurodiversity. Eight psychologists had never worked with someone with ID and long-COVID. Psychologists identified factors that may be predispose, precipitate, and perpetuate the condition in this group. Data reflects the importance of considering the intersection between ID and long-COVID. Guidelines recommend the adaptations of long-COVID treatments for people with ID; we provide examples of how this could be achieved.

Key words: COVID-19; pandemic; learning disability; post COVID syndrome; qualitative

Easy read summary

- The symptoms that people can experience after recovering from the COVID-19 virus has been called long-COVID or post-COVID syndrome.
- While we are learning more about long-COVID, there is little research that include people with neurodiversity.
- Psychologists in services for people with long-COVID do not see people with intellectual disability often.
- Our findings can help guide research being conducted in this area, and clinicians who are likely to encounter someone with long-COVID and neurodiversity.

Introduction

Long-COVID and post-COVID syndrome are terms used to describe the set of persistent symptoms that people can experience following the contraction and recovery of the acute symptoms associated with the COVID-19 infection (National Institute for Health and Care Excellence, Scottish Intercollegiate Guidelines Network & Royal College of General Practitioners, 2022). Long-COVID appears to be a heterogenous condition that can be debilitating and have a detrimental impact on quality of life (Tsuzuki et al., 2022). Common symptoms may include fatigue, dyspnoea, cognitive difficulties commonly known as brain fog, sleep problems, pain, and loss or change to taste and smell (Crook et al., 2021). The psychosocial impact of the condition must also be recognised, with high rates of anxiety and depression being observed (Klaser et al., 2021).

The condition has been described as a global health challenge by the National Institute for Health and Care Research (NIHR, 2022) – who are the largest funder of health research in the UK. There has been an increase in the availability of resources aimed at better recognising, understanding, and treating the condition. The NHS in England have funded 90 post-COVID services that provide access to specialist diagnosis, treatment, and rehabilitation (NHS England, date unknown). These services offer a multidisciplinary approach to care treating physical, cognitive, psychological, and psychiatric symptoms associated with the condition.

We are only aware of two articles – one of which was published by the current authors – that have reported specifically on long-COVID in people with an intellectual disability (ID). Both papers were written with the focus of highlighting the lack of data in this area with neither analysing primary data on people with ID (Rawlings & Beail, 2023; Shankar et al., 2023). Both groups of authors infer research conducted on long-COVID in the general population to those with ID. Authors suggest that people with ID may be disproportionally affected by the condition based on known risk factors, such as poor premorbid mental and physical health, in addition to the fact that people need to be infected by the virus in the first place (Linehan et al., 2022). Authors go on to postulate additional challenges this clinical group may experience, such as their symptoms of long-COVID not being identified, and barriers when accessing care. In fact, an NHS report on long COVID services published in July 2022 reported services are seeing very few people with ID (NHS England, 2022).

In the current article, we explored the experiences and perspectives of psychologists working in long-COVID services in England, specifically relating to long-COVID in adults with ID. We first identified key issues that we believed needed to be addressed based on our previous review (Rawlings & Beail, 2023), namely, what is the prevalence of the condition in this clinical group, barriers to care, treatments being offered and treatment outcomes. The role of psychologists in long-COVID has been described elsewhere with this profession having the skills to help design services; develop and deliver treatments; provide consultation, supervision, and teaching; work effectively with multidisciplinary teams, and support research (Siddaway, 2021).

Method

Design

Participants were recruited from a voluntary COVID rehabilitation psychology network in England. Favourable opinion was granted by the Schools of Business, Law and Social Sciences Research Ethics Committee at Nottingham Trent University (1598526). It was also registered as a service evaluation with our NHS Trust's Quality Improvement and Assurance Team.

Participants

To be eligible, participants must have been healthcare professionals providing care to people with long-COVID. Participants must have also been a member of the COVID rehabilitation psychology network.

Procedure

An advert about the study was circulated amongst the network. This directed people to a Qualtrics link where more information was available. Individuals were first asked to complete a consent form before answering a questionnaire about their clinical experience and views of long-COVID in adults with ID – and neurodiversity more generally. To protect the anonymity of participants, patients and their services, participants were instructed to not provide their name or any details of their workplace. Participants consented for their data to be used for the purpose of this report.

Questionnaire

A questionnaire was developed by the authors, which asked participants to first describe their professional role, years in their profession and how long they have worked with people with long-COVID. Next, participants were asked how often they have worked with someone with long-COVID and neurodiverse conditions.

Participants were next asked a series of open-ended questions examining the presentation of symptoms of long-COVID in people with ID, responses to treatment, barriers to care, what adaptions were required given the additional needs of people with ID, and their opinion on whether this group would be at a greater (or lesser) risk of the condition. Participants were instructed to answer the question by comparing people with ID and those of the general population as a reference. This would help us to understand how information from people with ID may differ to the prevailing evidence-base from the general population. Respondents were finally asked to rate their knowledge of ID, how confident they were in adapting long-COVID treatments for this group and how much training they had on treating long-COVID in people with ID

Data analysis

Descriptive statistics have been used to describe our sample. A qualitative content analysis was used. Participant's responses were first read multiple times before being synthesised into a narrative, which has been structured using the questions asked. Due to the modest number of participants who have taken part in the current study, and the relatively small number of psychologists working in services for people with long-COVID, we have taken the additional measure of not reporting direct quotes to further protect the anonymity of participants.

Results

Participants

In total, 12 participants completed the questionnaire: ten were qualified clinical psychologists and two were psychologists at the pre-qualified level. Psychologists had been practicing on average for 7 years (standard deviation = 4 years). All participants worked in a long-COVID service and had been treating people with the condition for a mean of 9.6 months (standard deviation = 6.2 months).

When asked about their experience of providing care for people with long-COVID and neurodiversity: eight participants described "*never*" having worked with someone with ID and comorbid long-COVID (four reported "*rarely*"). Other neurodiverse conditions appeared relatively more common than ID, as four participants had "*sometimes*" worked with people with ASD, three "*never*", four "*rarely*" and one "*often*"; ADHD or ADD also seemed more prevalent with seven reporting "*sometimes*" providing care to this clinical group, three "*rarely*" and two "*often*". People with learning difficulties such as dyslexia or dyspraxia, were also more commonly encountered than people with ID, with one participant reporting "*often*", seven "*sometimes*" and four "*rarely*" caring for this group. Finally, participants were asked about their experiences of working with clients with ABI with six reporting "*rarely*", five "*sometimes*" and one "*never*".

Symptoms of long-COVID in people with ID

The responses from five participants reflected the challenges in identifying whether long-COVID symptoms differed between people with ID and without ID. This was largely because they had not encountered anyone with ID in their service and so did not have any evidence to inform their answer. Lack of knowledge was also reflective of potential differences between the two groups not being examined systematically, or due to a lack of suitable tools that would allow for comparison.

Two participants discussed the likelihood that people with ID would present with different symptoms; for example, due to the additional challenges they may experience when managing aspects of their health, and their observation that adjustment and emotional difficulties are common in people with long-COVID and therefore those with ID may also experience further problems. Another participant explained that they would welcome more advice on this topic.

One participant who had worked with someone with ID and long-COVID explained that they seem to present with similar complaints, such as fatigue, memory difficulties and feelings of frustration – while another explained their symptoms were more severe. In people with long-COVID and other neurological conditions, such as those with ADHD, they were suggested to present with more severe or exacerbated symptoms and appeared to especially struggle with their cognitive functioning. The possibility of individuals with neurodiversity having fewer helpful coping strategies was also noted.

Risk of developing long-COVID in people with ID

Responses from all twelve participants appeared to reflect that this clinical group may be at a greater risk of experiencing long-COVID – or at least certain symptoms – than the general population. However, it is important to highlight many explained that they cannot be sure. Reasons for this perceived risk included comorbid physical health and neurological conditions, lower socio-economic status or income, global needs not always being met, and lack of equality in - or difficultly accessing - services. For instance, two participants specifically commented on diagnostic overshadowing (this could be a result of their ID or poor physical health), or symptoms being missed. Another explained how the patient’s physical signs may present as behaviourally or emotionally and subsequent treatments may not target the true cause.

The heightened risk of people with ID being infected with the virus was discussed explicitly by three participants. This was associated with individuals with ID being more likely to be living with others; have higher rates of contact including encountering healthcare professionals during the pandemic; premorbid health conditions; and poor compliance with infection preventative measures due to a lack of understanding or support.

Challenges commonly associated with ID were described as possibly predisposing individuals to the condition. For example, difficulties with communication were suggested to pose a barrier to seeking treatment. Other problems that were described included this clinical group finding previous strategies of coping ineffective, and difficulties with self-manging their health needs. For example, individuals with ID may have limited insight into their own physical functioning and may not always be able to develop or use helpful coping strategies in response to daily struggles. This was specifically discussed in the context of fatigue, where individuals may find it challenging to implement measures to reduce boom and bust (a behaviour often reported by people experiencing fatigue), such as pacing.

Interestingly two participants described how people with ID may be at a lower risk of the condition. One reported the link between the type of COVID-19 variant and long-COVID, suggesting people with ID may have been protected from earlier variants of the virus due to shielding at the start of the pandemic. Another explained how those with ID may not have some of the risk factors typically observed in the general population such as burnout; although, they explained individuals with ID may be at a greater risk of other factors, such as sensory dysregulation.

Barriers to accessing care in people with ID

As previously discussed, individuals with ID may be more likely to present with communication and cognitive impairments resulting in difficulties when trying to articulate their experiences - this was described as particularly problematic given the range of symptoms associated with long-COVID. One participant reflected how this may not be conjunctive with existing assessments, which can be long and contain a lot of text. Another explained how some individuals are more reliant on others to access care; one psychologist explained such factors could result in people being unheard.

In terms of service-related factors, an initial barrier that was suggested was individuals may experience difficulties accessing their general practitioner and being referred to physical health services. Clinicians may also assume cognitive and behavioural symptoms in people with ID are caused by other health conditions, including dementia. A lack of specialist knowledge and expertise on ID in professionals working in long-COVID services was mentioned as another possible barrier. That said, five participants reported their knowledge of ID as "*fair*", four "*good*", two "*very good"* and one "*poor*". Alternatively, one participant wondered whether this clinical group were being cared for in mental health services for their long-COVID related symptoms who do not have specialist knowledge of the condition. The provision of long-COVID services was also discussed, as appointments can usually be offered remotely. Indeed, a reliance on digital access or remote treatments was described as a barrier for those who struggle to use technology. Moreover, participants described how clients with ID may be unable to engage in group treatments and therefore need 1:1 support, which may result in longer wait times. Finally, the rigidity of long-COVID services was mentioned such as attendance policies.

Treating long-COVID in people with ID

Only four participants replied to the question on whether people with ID have different treatment outcomes compared to the general population. Three reported that they were unsure as they did not have enough clinical experience to inform their answer, this was not being assessed within their service, or they have been unable to offer more than an assessment to people with ID and long-COVID – the reason for this was not provided. The final participant explained they seem to have worse outcomes. This was linked to individuals with ID being less able to implement intervention strategies effectively, such as for managing fatigue. This could then have a knock-on effect on their mental health and cognitive functioning.

When psychologists were asked how confident they were in adapting treatments for long-COVID for adults with ID, seven participants felt "*somewhat confident*", four "*not very*", and one "*very confident*". In terms of which adaptations they believed were important, adapting language and communication tools (e.g., resources, handouts, website) was most described, such as making information more accessible, using images and checking that the language is clear and straightforward. In addition, cognitive, memory and communication aids were discussed. Tailoring how care is delivered was also reported, including offering home visits or appointments in the community, and having more individual sessions to help clients understand and implement self-management strategies. Finally, flexibility in appointment times and duration, and *did not attend* policies were reported, recognising that this group may be at a greater risk of forgetting appointments.

Participants' descriptions reflected a greater need to work with individual's support systems when treating this clinical group. Some highlighted that carers and family members could also serve the role of co-therapist. It was suggested that people with ID need a personalised and specialised approach to their care and within the context of a multidisciplinary setting. Participants discussed the intersection between ID and long-COVID, such as incorporating ID-related factors into formulations. This included neurodivergence, communication needs, comorbid conditions, physical ability, and emotional processing and expression difficulties. Moreover, one psychologist discussed that there may be a need to conduct cognitive assessments to help inform the formulation and treatment plan. Associated with this idea was making sure clinicians (and others involved in supporting the individual) had a full understanding of the client, their wider social context and presenting problem. This approach would help with suggesting strategies that were realistic, as well as support change and empower individuals. Consultations and joint appointments with other colleagues were also discussed as a helpful approach.

Two participants explicitly reported wanting more training on ID. When asked about whether they have received any training on long-COVID in people with ID, eight reported "*none at all*", three "*not a lot*" and one "*a lot". Relevant to all people with neurodiversity, one participant discussed the importance of services reaching out to different client groups and other professionals to help improve knowledge – this was in relation to their own on ID, and others on long-COVID.

Discussion

It is important to note that eight of the 12 participants interviewed had never worked with someone with ID and comorbid long-COVID. It was more common for psychologists to work with clients with other forms of neurodiversity, including ASD, ADHD or ADD, learning difficulties, and ABI. While this is a clear limitation in the context of our study, participants' insight is still valuable, especially given our focus was not solely on participants' direct clinical experience – this also reflects the different roles this profession can hold, in addition to delivering care plans. Eleven psychologists rated their knowledge of ID as fair or greater, which may be a result of their training which requires the development of competencies in working with clinical groups with cognitive impairments (Division of Clinical Psychology, Faculty for People with Intellectual Disabilities, 2021). Similarly, eight participants felt some degree of confidence in adapting long-COVID treatments for this group – despite eight having no specific training.

Our results appear to be consistent with previous evidence suggesting those working in long-COVID are rarely encountering individuals with ID (NHS England, 2022). This finding is particularly striking when also viewed alongside psychologists' descriptions of how this clinical group may be at a greater risk of developing the condition as predisposing, precipitating and perpetuating factors were proposed. Further research is required to explore the relationship between these factors in people with ID and comorbid long-COVID, which may also help us to identify those most at risk within the group of people with ID as well as targets for intervention.

It is too early to state with any confidence whether this group are underrepresented in services, given that the true prevalence of long-COVID in people with ID is currently unknown. For example, as participants described here, it may be that people with ID are protected against the condition, to some degree. Greater support from others could reduce the impact of the symptoms, or their difficulties only present as sub-clinical and therefore individuals do not require input from services. For instance, support from others may help to buffer individuals from the effects of common symptoms, such as fatigue and weakness, and supporting them to continue to engage in valued activities. This could in turn reduce the risk of depression and anxiety and overall help maintain quality of life. Indeed, while there is limited research into psychological factors associated with long-COVID, there is evidence to suggest health-related outcomes are associated with how individuals perceive the impact of the condition (Bierbauer et al., 2022).

Establishing the prevalence of the condition in this group and how it presents compared to the general population is a priority for future research. Achieving this aim may be difficult however as some participants described how services are not systematically examining differences between the two groups. Moreover, current tools for diagnosing long-COVID may first need to be adapted for people with neurodiversity (Hughes et al., 2022).

Participants interviewed reflected that their assessments for long-COVID tend to be long and contain a lot of text. Moreover, there may be a tendency for services to rely on technology for clients to access their services. These are possible barriers to care, especially as research has suggested that remote technologies are unacceptable to most individuals with ID, either due to practical issues or communication difficulties (Rawlings et al., 2021).

There may also be a need for services for people with ID to adapt their assessments to help screen for long-COVID. For example, when individuals present for difficulties such as depression, anxiety, cognitive decline, or behaviours that challenge, clinicians may consider long-COVID as either a differential diagnosis or contributing factor. However, the lack of awareness and research of the condition in this group is likely to impede on how this can be implemented in routine practice, especially considering the sensitivity and specificity of any assessment. Lack of awareness can more easily be addressed at this stage with teams linking up with long-COVID services in their local area and request additional information or training events. This is in addition to helping clients and caregivers to recognise the symptoms through conversations at assessments and using posters or flyers in waiting rooms.

Our findings can help expand on this key guidance as participants gave many examples of how this could look in routine practice. Tailoring the way in which clinicians communicate with this group was discussed, including how the therapeutic space could be created and the recognition that some policies and pathways designed for the general population may not always be suitable. Psychologists discussed how the intersectionality between long-COVID and neurodiverse conditions need to also be reflected in the assessment, formulation, treatment, and evaluative phases. Indeed, participant’s descriptions supported the notion that a greater systemic focus may be required when treating this group. Supporting people with the condition to self-manage their symptoms by learning new coping skills, developing insight, and making adaptions have been identified as an important aim in the treatment of long-COVID (Siddaway, 2021). While this may be suitable for a sub-group of people with ID, it is unlikely to be helpful for those with severe intellectual, adaptive functioning or communication difficulties.

It is important that we recognise the overall lack of evidence in this area. Therefore, we have taken a cautious approach when interpreting our findings; We are very keen to not over-extrapolate or -generalise the results. The modest sample size means that our findings are limited in their generalisability and transferability.

While we did discuss the study with a sub-group of the network as part of patient, public involvement, we did not share the questionnaire with members, nor did we discuss this study with individuals with neurodiversity or caregivers. This could have helped to identify additional questions that are also important to ask.

The findings here are consistent with current data suggesting very few people with ID are accessing long-COVID services. Key research questions remain including how to best recognise this subgroup and what its prevalence. Participants highlighted a need for long-COVID services to adapt the provision of care as they recognised the intersectionality between symptoms associated with long-COVID and neurodiversity.

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