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Exploring the lived experiences and perspectives of individuals with communication and swallowing difficulties associated with Long-COVID

Órla Gilheaney*, Naomi Rogers and Kathleen McTiernan
School of Linguistic, Speech, and Communication Sciences, Trinity College Dublin, Ireland

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Abstract.
BACKGROUND: Long-COVID occurs in individuals with a history of probable or confirmed SARS CoV-2 infection. Long-COVID can affect individuals who experience both mild and severe acute COVID-19 and can involve and affect multiple body systems. Research thus far acknowledges swallowing and communication difficulties as a characteristic of Long-COVID, however, this research lacks detail and does not address the psychosocial impact of these problems.
OBJECTIVES: To establish an understanding of the presence, severity, and trajectory of swallowing and communication difficulties as a symptom of Long-COVID among adults. To investigate the psychosocial impact of these characteristics and explore supports and barriers to recovery.
METHODS: The objectives were addressed by utilizing a qualitative research design. Semi-structured interviews were carried out with participants using online Zoom sessions. The interviews were recorded and transcribed and reflexive thematic analysis was used to analyse the data.
RESULTS: Seven participants from Ireland, Scotland and Australia were interviewed. Four main themes were identified including dysphagia-related issues, communication-related issues, psychosocial impact of dysphagia and communication disorders, and accessing Long-COVID related healthcare for dysphagia and communication disorders. The presentation of swallowing and communication problems was diverse and had significant psychosocial and mental health consequences. Furthermore, access to healthcare services to effectively treat these issues was challenging.
CONCLUSIONS: The lack of recognition of swallowing and communication as a symptom of Long-COVID and its adverse effects is a pertinent issue which warrants further research and updated guidelines for individuals living with Long-COVID and healthcare professionals alike.

Keywords: Long-COVID, post-COVID conditions, dysphagia, communication disorders, quality of life

1. Introduction

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the causative agent for coronavirus disease (COVID-19) illness. Symptoms of COVID-19 are diverse and wide-ranging, often including fever, cough, fatigue, dyspnoea and muscle pains (Chen et al., 2021). Presentations of COVID-19 range from asymptomatic to critical illness involving multiple organ failure impacting the pulmonary, respiratory, neurological, cardiovascular, digestive, renal, endocrinologic, dermatologic systems, among other symptoms (Tsai et al., 2021).

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*Corresponding author: Dr. Órla Gilheaney, Assistant Professor in Speech and Language Pathology, School of Linguistic, Speech, and Communication Sciences, Trinity College Dublin, Dublin 2, Ireland. E-mail: Gilheano@tcd.ie.

Long-COVID occurs in individuals with a history of probable/confirmed SARS-CoV-2 infection (WHO, 2021). Long-COVID typically occurs 3 months after the onset of COVID-19 with symptoms that last at least 2 months that cannot be explained by an alternative diagnosis (WHO, 2021). Long-COVID can affect the whole spectrum of individuals with COVID-19, ranging from those with mild to severe acute disease (Crook et al., 2021). Similar to acute COVID-19, Long-COVID can impact multiple organ systems, including, but not limited to, the respiratory, neurological, cardiovascular, musculoskeletal and gastrointestinal systems (Crook et al., 2021; NICE, 2020). Although research to date in the area of Long-COVID has emphasised variability in both the symptoms and severity of this disease (NICE, 2020), the most commonly discussed symptoms of Long-COVID include fatigue and dyspnoea (Yong, 2021), cognitive impairments (Theoharides et al., 2021), joint pain, chest pain, myalgia, smell and taste dysfunctions, cough, and headache (Yong, 2021; NICE, 2020). These wide-ranging symptoms reported by patients with Long-COVID have a significant impact on quality of life (Arnold et al., 2021). Early-stage research has also recently suggested that patients with Long-COVID have reported symptoms of swallowing problems (oropharyngeal dysphagia) and communication difficulties, although this area remains under-explored (Verma et al., 2022).

1.1. Long-COVID and oropharyngeal dysphagia

The mechanisms involved in swallowing are complex and multifactorial (Walton & Silva, 2018), involving precise coordination of neurological, respiratory and musculoskeletal systems (Walton & Silva, 2018; McGinnis et al., 2019). As discussed, Long-COVID can affect multiple systems including but not limited to respiratory systems, cardiovascular systems, gastrointestinal, neurological systems and musculoskeletal systems (Shah et al., 2021; Crook et al., 2021), all of which must coordinate precisely for a safe and effective swallow.

The prevalence of oropharyngeal dysphagia in critically ill patients with COVID-19 is reportedly as high as 96% (Osbeck et al., 2021). In severe cases of acute COVID-19 infection, endotracheal intubation and mechanical ventilation is commonly required (Regan et al., 2021) and research suggests that these patients may then experience dysphagia in the acute infection phase as a result of prolonged recurrent laryngeal nerve paralysis and severe respiratory injury (Okuda et al., 2022; Jungbauer et al., 2021). As such, studies have suggested that oropharyngeal dysphagia should be considered a potential Long-COVID symptom as it may persist beyond the acute phase of COVID-19 infection (Okuda et al., 2022). Although causation is not fully established yet, multiple factors are thought to contribute to the pathophysiology of dysphagia in patients with Long-COVID, including muscle-related injury, critical illness myopathy and polyneuropathy, central nervous system impairments, impaired laryngeal sensation due to intubation, dyspnoea, and desynchronisation of breathing and swallowing, among other factors (Chuang et al., 2022; Okuda et al., 2022; Jungbauer et al., 2021). Due to these complications, patients are at risk of delayed laryngeal elevation (Okuda et al., 2022). Consequently, food and drinks may accumulate as residue in the hypopharynx, potentially resulting in penetration and/or aspiration (Okuda et al., 2022). Moreover, oropharyngeal sensory and motor deficiencies and the subsequent long-term impact these issues have on the patient's quality of life and activities of daily living should also be considered as part of the constellation of Long-COVID characteristics (Jungbauer et al., 2021; Okuda et al., 2022).

1.2. Long-COVID and communication difficulties

Research suggests that the most common Long-COVID characteristics are dyspnoea, cognitive impairment, and fatigue (Marshall, 2020; Shah et al., 2021;Ceban et al., 2022). Having a robust respiratory system and cognition is vital to aspects of communication including speech, voice, receptive language and expressive language speech (Bahr & Sillman, 2015). It is estimated that 22–70% of individuals with Long-COVID experience cognitive dysfunction (Ceban et al., 2022; Guo et al., 2022). There is also growing evidence that individuals with Long-COVID experience cognitive communication disorders, including deficits in attention, memory, executive functioning and visuospatial awareness (Ramage, 2020), with "brain fog" already accepted to be a characteristic symptom of the illness (NICE, 2020; Shah et al., 2021; Theoharides et al., 2021; Ceban et al., 2022). Approximately 60% of people living with Long-COVID experience tip-of-the-tongue word-finding problems (Guo et al., 2022), and 44% experience semantic dysfluency (e.g.: saying the wrong word) (Guo et al., 2022).

Recent research also suggests that voice disorders are a common symptom of communication difficulties amongst those living with Long-COVID (Okuda et al., 2022; Jeleniewska et al., 2022). Dysphonia has been identified in acute COVID-19 patients (Regan et al., 2021), and these difficulties were found to be highly associated with mechanical intubation often required to manage severe acute COVID-19. Reportedly 42% of individuals with COVID-19 acutely presented with dysphonia based on perceptual voice quality rating scales (Regan et. al., 2022). An instrumental voice assessment of voice in individuals with Long-COVID found that individuals are presenting with severe dysphonia, characterised by vocal fatigue, vocal strain, aphonia, vocal pain, dryness and discomfort of the larynx and pharynx and frequent throat clearing and coughing (Jeleniewska et al., 2022). A quarter of hospitalised individuals with acute COVID-19 have also been found to present with dysarthria, with 14% still experiencing motor speech difficulties at the time of discharge (Regan et al., 2022). Commonly reported characteristics of dysarthria in this cohort have included dysfluent and slurred speech, impacting on communication engagement and success (Camargo-Martínez et al., 2021).

Research in the area of dysphonia and dysarthria to date has mostly focused on individuals who were severely unwell and hospitalised as a result of COVID-19 (Regan et al., 2021). Research does suggest that these issues persist among those living with Long-COVID (Jeleniewska et al., 2022), however, this research has primarily focused on individuals with severe cases of acute COVID-19, in which instance the main cause of dysphonia and dysarthria was mechanical ventilation (Jeleniewska et al., 2022; Regan et al., 2021), without consideration of those who experienced less severe acute COVID-19, thus limiting our knowledge currently.

1.3. Current challenges

Long-COVID is an emerging area of clinical research that is not yet fully understood. Although it is estimated that a substantial number of individuals with acute COVID-19 will develop Long-COVID (Crook et al., 2021), there is currently no definitive prevalence rate for Long-COVID, with rates so far varying from study to study depending on sample size and geographic location. However, given the large numbers expected to experience Long-COVID, it is therefore estimated that many of these individuals will also experience associated communication and swallowing difficulties.

Despite dysphagia being a reported Long-COVID symptom within early-stage research studies, there is limited definitive evidence about the specific mechanisms and pathophysiology of swallowing that are affected or the extent of the problem worldwide (Okuda et al., 2022). Understanding the pathophysiology of swallowing difficulties and the impact these difficulties have on individuals' lived experiences is vital so that the most suitable and effective treatment plans can be developed with the patient to optimise outcomes and reduce morbidity and mortality (McGinnis et al., 2019).

The same summation can be applied to research in the area of Long-COVID and communication difficulties. Communication difficulties in the form of cognitive communication disorders (Ramage, 2020; Ceban et al., 2022), dysphonia (Regan et al., 2021; Jeleniewska et al., 2022; Regan et al., 2022) and dysarthria (Camargo-Martínez et al., 2021; Regan et al., 2021; Regan et al., 2022) have been identified as enduring characteristics of acute COVID-19 and are suggested characteristics of Long-COVID. However, the nature and severity of these multiple possible communication difficulties as symptoms of Long-COVID are not yet fully understood and we do not yet know what domains of communication specifically are affected most and the impact these difficulties have on quality of life and activities of daily living.

Evidently, swallowing and communication difficulties can impact overall health and well-being. Dysphagia can impact nutrition with subsequent impact on weight management, hydration, malnutrition, and quality of life (McGinnis et al., 2019). Communication disorders can impact an individual's ability to access healthcare services and treatment, and these difficulties also have an impact on social life, professional life and quality of life. Therefore, it is essential we know more about dysphagia and communication disorders in Long-COVID in order for us to improve service delivery, patient outcomes and efficiency of care provision. Investigating patients' perspectives of their experiences will help not only guide our intervention and assessment but provide services that are relevant and specific for patients with Long-COVID. As such, this research aimed to understand the presence and nature of Long-COVID associated swallowing and communication difficulties and to explore the qualitative lived experience of individuals living with these difficulties.

2. Methods

This phenomenological qualitative study was guided by Consolidate Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). Semi-structured interviews using open-ended questions were conducted via online Zoom interviews between September 2022 and November 2022. This study received ethical approval from the Research Ethics Committee of the School of Linguistic, Speech & Communication Sciences at Trinity College Dublin (TCD) (application code: TT54).

2.1. Eligibility criteria

Individuals were eligible for inclusion in the study if they met the criteria outlined in Table 1.

2.2. Sampling and recruitment

Participants for this study were recruited using convenience snowball sampling which involved finding Facebook groups that provided support for individuals with Long-COVID. The administrators of these groups were approached via direct message, and if they agreed to act as gatekeepers, information about the research study was shared with group members via a wall post. If group members were interested in participating, they could contact the researcher using the email provided in the post. A Participant Information Leaflet was then emailed to potential participants, and if they wished to partake following a reflective period, they electronically signed an informed consent form.

2.3. Data collection

A semi-structured interview guide was piloted and subsequently used during interviews conducted by one researcher (NR) who was a student SLT. These explored 4 main areas: (1) demographic details, (2) physical characteristics of feeding, eating, drinking, and swallowing (FEDS) and communication issues, (3) Social and emotional impact of FEDS and communication issues, and (4) supports for the impact of FEDS and communication issues. Each interview was approximately 45 minutes in duration. Interviews were audio-visually recorded so that the interview could be transcribed later. Once the interviews were transcribed, they were returned to the participant who checked the text for accuracy.

2.4. Data analysis

The six stages of reflexive thematic analysis, outlined by Braun & Clarke (2021), were followed to analyse the data One researcher (NR) conducted the primary analysis and a second researcher (ÓG) available to review codes and address concerns if they arose.

3. Results

A total of 42 Long-COVID support group admins were contacted, with 9 agreeing to act as gatekeepers. In total, 11 group members initially indicated interest in participation and 7 ultimately took part (female = 6; male = 1; mean age: 49; age range: 33–66), with some dropping out due to other commitments. Participants resided in Ireland ($n = 3$), Scotland ($n = 2$) and Australia ($n = 2$). Four main themes and 17 sub-themes were identified within the data.

3.1. Dysphagia-related issues

Dysphagia-related issues were categorised into 4 main subthemes (Table 2).

3.2. Modifications to diet and mealtime

A total of 5 participants (71%) reported that they have to modify their regular diet to include more pureed or mashed foods, soups, broths and smoothies, with 4 (57%) reporting that foods that require more chewing (e.g.: bread and meat) were more difficult than softer foods or liquids. A total of 3 participants (43%) reported a loss in appetite and subsequent weight loss.

3.3. Oral phase difficulties

Overall, 4 participants (57%) reported oral phase swallowing difficulties, including masticatory issues and prolonged oral phases. Limiting distractions and conversations was reported by participants so that they could safely masticate their food. In total, 2 participants (28%) reported fatigue and discomfort around their jaw area. Overall, 3 (43%) reported fluctuating periods of no/mild oral phase difficulties and then severe oral phase difficulties.

Table 1
Eligibility criteria

Inclusion criteria	Exclusion criteria
Adults aged 18 years and older	Children aged under 18 years of age
Individuals experiencing Long-COVID, where Long-COVID is defined as; a history of probable or confirmed SARS CoV- 2 infection, which occurs 3 months from the onset of COVID-19 with symptoms that last at least 2 months that cannot be explained by an alternative diagnosis (WHO, 2021)	No experience of Long-COVID
Individuals experiencing self-reported swallowing and/or communication difficulties which have been experienced since the onset of COVID-19, but not prior to contracting COVID-19	Individuals experiencing swallow and/or communication problems which were experienced prior to contracting COVID-19
Individuals who demonstrate a level of English required to engage in an interview	Individuals who do not demonstrate a level of English required to engage in an interview

Table 2
Dysphagia-related issues

Theme: Dysphagia-related issues		Participant quote
Subtheme	Modifications to Diet and Mealtime	“*Soft foods were easier to eat, there were times when it was mainly soft foods. It was easier, for example, to eat pumpkin soup pureed than it was to eat chicken soup that had fluid and chunky bits in it.*” *(Participant 3)*
		“*So you’d have to kind of, you know, to be honest with you. I would eat a lot of soup still for my lunch and then for my dinner, I would just take my time over what I’m eating.*” *(Participant 5)*
		“*liquid I don’t seem to be too bad, I do have a little bit of trouble with my own saliva sometimes but I was completely on a liquid diet when the swallow first got affected.*” *(Participant 6)*
		“*It’s thinner foods . . . . I don’t seem to have it with thicker foods, actually. I just don’t really take thin soups and things like that anymore.*” *(Participant 1)*
Subtheme	Oral Phase Difficulties	“*I had a big glass of wine, and I sat and my niece was at the side of me and she went “Are you going to swallow that?” I had no idea. And I had the wine in my pouches.*” *(Participant 1)*
		“*That’s the thing. I had to actually think about chewing and swallowing. I would say eating slowly and not talking too much helped.*” *(Participant 5)*
		“*I just had to chew the whole time I had to really concentrate on what I was doing for fear of, choking*” *(Participant 6)*
Subtheme	Pharyngeal Phase Difficulties	“*And before I knew it, it just, you know, caught in a way that I was coughing and coughing and coughing. And so much that I had to go and get my inhalers, that I take for my asthma to try and get some relief and you know how quickly it obviously started to obstruct and it involved my throat . . . It just seems to be super sensitive that it can throw me into a coughing fit*” *(Participant 2)*
		“*The main swallowing symptoms I had was I had this feeling of like having a rock or a stick in my throat. I had, like, a feeling of something in my throat. And that just didn’t it didn’t stop . . . I developed just sort of a bit of a fear. There were a couple of times where I experienced a choke, but I didn’t actually choke, but I felt like I was going to choke on my food at that same time*” *(Participant 3)*
		“*There was a difficulty in always getting it down and getting it down. So when I would swallow, there would be just the remnants of food, always just there that I couldn’t quite shift everything down. And at the moment, as I was saying five, nearly six months later, I would still have that where smaller bits of food I still can’t quite- it’s like the muscle can’t contract to get the smaller bits and get it down. So I would have to still rely on liquid and stuff to shift smaller bits*” *(Participant 6)*
Subtheme	Oesophageal Phase Difficulties	“*It was like as if there was a narrowing of the oesophagus. That’s the only way I can describe it . . . . I’d have to drink a lot of water with my meals to try and get it and take a long time to eat my dinner*” *(Participant 5)*
		“*It became really conscious, and I wasn’t sure though, whether that was because I was so aware of this feeling. It kind of became a circular psychological reaction to it, or whether there was something, as well as the feeling that it was actually a mechanical issue going on*” *(Participant 3)*

3.4. Pharyngeal phase difficulties

Most participants ($n = 5$; 71%) reported difficulties coordinating the pharyngeal phase of swallowing and challenges initiating a swallow. Fear of choking and anxiety was reported by 3 participants (43%). Perceived swelling, pain, narrowing and oedema of the pharynx and its surrounding structures were also reported by 4 participants (57%). A total of 3 participants (43%) reported that fatigue was a contributing factor and that their pharyngeal phase difficulties were more common in the evening time. Perceived residue in the pharynx after swallowing was reported by 3 participants (43%), these participants required liquid washes to reduce residue. The onset of pharyngeal difficulties was varied, 3 participants (43%) reported that the onset was gradual, 2 participants (28%) reported it was sudden. Of 5 participants (71%) who reported pharyngeal phase difficulties, 4 participants (57%) reported that the severity of these issues fluctuated over time.

3.5. Oesophageal phase difficulties

Overall, 3 participants (43%) reported oesophageal phase swallowing difficulties including prolonged oesophageal phase and digestion difficulties. A total of 2 participants (28%) who reported swelling, discomfort and narrowing of their pharynx also experienced these characteristics in their oesophagus. The sensation of the narrowed oesophagus caused anxiety and distress to 2 participants (28%). A total of 3 participants (43%) reported that these difficulties were exacerbated by fatigue. Liquid washes were required by 2 participants (28%) to aid swallowing.

3.6. Communication-related issues

Reported communication problems included receptive and expressive language difficulties, voice difficulties and speech and fluency difficulties (Table 3).

3.7. Receptive language difficulties

Receptive language difficulties were reported by 5 participants (71%). Participants reported that their ability to process and understand both written and verbal language was impaired, with 4 participants (57%) reporting difficulties reading. Overall, 4 participants (57%) reported that distracting or loud environments exacerbated their receptive language difficulties. Difficulties understating both familiar language and complex or novel language was reported by 4 participants (57%). A total of 5 participants (71%) reported that listening to others in conversation requires more concentration.

3.8. Expressive language difficulties

Overall, 6 participants (86%) reported expressive word-finding difficulties. Fatigue was reported to impact word-finding abilities by 4 participants (57%). Three participants (43%) reported that difficulties with word-finding and formulating sentences disrupted the flow of conversations and interactions. One participant (14%) reported that their ability to write has been affected.

3.9. Voice difficulties

Most participants ($n = 5$; 71%) reported voice difficulties which fluctuated regularly in severity, including hoarseness ($n = 4$; 57%) and breathiness ($n = 2$; 28%). Vocal fatigue was reported by 5 participants (71%), and vocal strain and aphonia were reported by 4 participants (57%), with these characteristics reported to be linked to overuse of voice. The majority ($n = 4$; 57%) reported the loss of the ability to sing and restricted range. The onset of voice difficulties was sudden for 1 participant (14%) and gradual for 4 participants (57%) participants.

3.10. Speech and fluency difficulties

In total, 4 participants (57%) reported speech and fluency difficulties characterised by effortful speech, getting stuck on words and letters or dysfluency, slurred speech and speech incoordination. Speech and fluency difficulties were reported to be impacted by fatigue by 4 participants (57%). The onset of speech and fluency difficulties was varied; 3 participants experienced a gradual onset (43%), 1 participant reported a sudden onset.

3.11. Psychosocial impact of dysphagia and communication difficulties

Swallowing and communication difficulties were reported to have different psychosocial impacts, with 5 sub-themes identified (Table 4).

Table 3
Communication-related issues

Theme: Communication-related issues		Participant quote
Subtheme	Receptive Language Difficulties	"*I just think sometimes I'm not 100% sure what they're saying or what they're asking me, and that's actually with hearing and it's with written as well . . . . . . the International Journal of Palliative Medicines, I used to review some of the studies. I can't do that anymore, and yet I used to just sit for ages and look at them and think" Oh maybe why have you not got this? Maybe find this or maybe?" and now I can't make head nor tail of it*" *(Participant 1)*
		"*I say to my hubby "what did they say there?" And I would say, "what does that mean?" And they say, "you don't know what they're saying, look*!*?" I just didn't it wasn't making sense, whatever or however they said, it didn't make sense to me, you know. (Participant 2)*
		"*I was looking at people speaking, and I thought,* "*oh my God, have I had a stroke*!" *It was just like, a jump. And being able to discriminate, like if there's other like people, lots of people chatting around, it's not as easy to kind of focus on the person I want to focus on. Not being able to shut out other auditory kind of stuff that's coming in.*" *(Participant 3)*
Subtheme	Expressive Language Difficulties	"*At one point I thought I was getting dementia. I'm thinking, Oh my goodness, please tell me this isn't going to happen . . . .. I've got a picture, say it was a lamp, and I just can't get the word out.*" *(Participant 1)*
		" *I have word finding issues. I will have complete blanks around what it is that I'm trying to say or communicate to people . . . . I'd experienced a moment of time, like at least a substantial period where I couldn't make myself understood to my husband*" *(Participant 3)*
		"*I've had moments like that definitely where word finding has been tricky, and I've had moments where I've had that. That I've been trying to get it and I can't find it. And it's on the tip of the tongue. Can't find it, can't find it again*" *(Participant 6)*
Subtheme	Voice Difficulties	"*It's definitely got deeper in tone. Some days it's quite more breathy, is that a good word? That it's more whispier and breathy. I do think I say the awareness because as you talk, it starts to get painful not an excruciating painful, but a pain that you'd think that you know, stop talking.*" *(Participant 2)*
		"*That was just all of a sudden that happened. I remember the day it was a Saturday, and I was in work, and I kept going,* "*Jesus Christ, what is going on with my voice like?*" *And I kept kind of coughing all the time, you know what I mean? Like a hoarse, a hoarseness. And then when I woke up, then I had a really bad night that Sunday. And then I woke up on the Monday, and I was literally like, I don't know what.*" *(Participant 5)*
		"*Croaky voice is the other one that I've tracked. And this or even today I'm a bit croaky. So loss of voice, I had a lot of loss of voice. It comes in little waves, but it can be just gone.*" *(Participant 3)*
Subtheme	Speech and Fluency difficulties	"*I feel the effort of speech in a way that I have never felt. It's effortful to talk in many ways, and if I have to talk too much, I become quite tired. I think it's one of the things that I've realised is actually in terms of pacing, which I've learnt to do reasonably well*" *(Participant 3)*
		"*When I was very bad, like as if you had a stroke I would say, you know, that kind of way. My speech would be dramatically affected when I was very bad. With the fatigue because I would have had chronic fatigue. That's how fatigued I was, so to speak, was extremely difficult.*" *(Participant 5)*
		"*So if I'm saying words with the combination of letters in close proximity to each other. I start stumbling over my words more. Because of it being a specific combination of letters. it's in many things you would say it's not always noticeable.*" *(Participant 6)*
		"*So I can't increase the coordination of breath and speech is the issue. So if I continue to talk, I get breathless. Like it's the coordination of the breath of speech is the big issue for me*" *(Participant 7)*

3.12. Family and home life

Overall, 5 participants (71%) reported that swallowing difficulties impact their family and home life, with 4 participants (57%) reporting difficulties with swallowing impact their ability to engage in mealtime with family members, and 4 participants (57%) no longer enjoying eating. Restricted and modified diets had an impact on family members, 3 participants (43%) reported family members were unsure about what the participants could safely eat and/or drink.

Most participants ($n = 5$; 71%) reported that communication difficulties impacted on their family and home life. These difficulties affected connecting with their family members, with 3 participants (43%) reporting that not being able to communicate with family members in their pre-COVID style was distressing. In total, 4 participants (57%) reported family member distress as they witnessed

Table 4
Psychosocial impact of swallowing and communication difficulties

Theme: Psychosocial impact of dysphagia and communication disorders		Participant quote
Subtheme	Family and Home Life (swallowing difficulties)	“ *I actually only just realised that my husband is really stressed about my food. He doesn’t know what to eat, what he can cook, that I can eat. And he’s really confused because like one minute it’s on a soft foods and you know . . . I’ve got four sons with three partners, four grandchildren. And food is one of the ways we come together*” *(Participant 3)*
		“*Oh, massively, massively. Like, I love to cook. I love to eat. So being restricted to a liquid diet was very hard on the head let’s say because the enjoyment of cooking and enjoyment of eating was just totally gone.*” *(Participant 6)*
Subtheme	Family and Home Life (communication difficulties)	“*The slurred speech was very, very obvious. Like, it was actually as I said, I didn’t record myself, which I’m going mad, I didn’t. It was actually more traumatic for my family than for me. They used to be looking at me on the I swear I think back they must have been extremely worried because if somebody that’s fit and healthy is in that kind of a situation, it’s quite alarming.*” *(Participant 5)*
		“*You know, things like I don’t read stories and I have a six year old and I can’t read a story, so my husband does that . . . . So it’s my family life. It’s a big thing that’s been affected. If I have to, even just calling my children for dinner or something or, you know, all the things that you do, I’ll often say to my husband, “you call them” you know.*” *(Participant 7)*
Subtheme	Social Life (swallowing difficulties)	“*That’s the main impact that would have had on me was I didn’t really enjoy food . . . .you know that kind of a way. But if I was out, I would kind of be conscious like I wouldn’t want to talk and as well cause it would affect me. So if I was at home, I wouldn’t be talking as much when I’m eating, you know what I mean? But when I’m out, I wouldn’t be talking and eating that would affect me with the swallow as well.*” *(Participant 5)*
		“*That also affects going out to dinner or anything like that because you constantly have to have a drink nearby. You have to you just have to watch yourself in a way. This is just wouldn’t be it’s not normal and certainly not for me because I was a big eater and love to cook. So I would have just been scoffing things down. I would never think too much about it. I was just enjoying myself. So it took a massive amount of enjoyment out of anything to do with food, really.*” *(Participant 6)*
Subtheme	Social Life (communication difficulties)	“*So instead of getting involved in it, I sometimes can’t keep up with it because it’s too much drunken chats as well there’s 6 of us. And then, you know, instead of doing that, I just I just sort of sit quietly . . . I am still fiercely independent*
		– so it’s probably easier for me . . . to actually remove myself and become isolated because that way I don’t have to face anything and it’s okay” *(Participant 1)*
Subtheme	Professional Life (swallowing difficulties)	“*The impact on work my job is fairly public, and so I’m going out to dinners, and I travel for work and other things. So outside of the massive impact of I’ve had about five of the last eight months off work. I’m returning to work now three weeks and going to events and things, and I just I can’t eat or drink*” *(Participant 3)*
Subtheme	Professional Life (communication difficulties)	“*And then in public stuff, I’m just anxious now about not being able to find a word, being on a stage or whatever and or talking publicly*” *(Participant 3)*
		“*I used to be an exceptionally sociable person, needed in my work as a Specialist Palliative Care Nurse, but now I don’t communicate well with people generally. I don’t know why really but I can’t seem to take in what I need and retain it in my brain. I still work but now I can’t take shifts as Charge Nurse as I can’t be relied on to be consistent and dependable.*” *(Participant 1)*
		“*And that’s what I found in my workplace. That, because a lot of telephone calls, directing staff, speaking to parents you know things like that and on a on a 12 hour shift I was coming home and I hardly any voice at all or even the slightest feedback to say hello was extremely painful.*” *(Participant 2)*
Subtheme	Mental Health	“*I would have to say the one thing someone did say to me, so we’ve got a ladies at lunch group. We’ve gone out for 10 years, we’ve been terribly badly behaved quite often. And, and I just sit quietly now and one of them had said to me, “You’re a shadow of your former self”. And actually, you know, sometimes she’s spot on.*” *(Participant 1)*
		“*People have said* “*she’s awful quiet*”*, so they were worried because it wasn’t like me. I don’t I’m not consciously aware that I’m- I’ve withdrawn myself from that. But obviously that’s been noticed there, and I’ve still enjoyed my time being there. But other folk have asked my closer friends. “Is she alright because she just doesn’t seem herself? She seems quite different and a bit dampened*” *you know,*” *(Participant 2)*

(*Continued*)

Table 4
(*Continued*)

Theme: Psychosocial impact of dysphagia and communication disorders	Participant quote
	"*Well, definitely 100%. God yeah major, major. You're not the person you were before, you're a totally different person. I'm not this person that I am in front you. This is not me. I'm a very outgoing, bubbly person. I wouldn't be sitting here I'd be out doing Pilates or I'd be out for a walk. I wouldn't be sitting here, ever. That's how much my life has changed. I don't do anything, go anywhere, just sit at home*" *(Participant 5)*
	"*It is just an ever-present in your mind all the time. The way I described it to the counsellors as I'm not right. I can feel and see and tell that I'm not. A lot of people don't seem to be able to. I know I'm not functional at my level. And so it's just always there in your mind. If that makes sense? So it just makes you it makes you aware. And there is an element of anxiety around this, I suppose*" *(Participant 6)*
	"*It's hugely affected my life, really. I'm not, I can't be who I am or who I used to be. I mean your speech is everything, isn't it really . . . that is the hardest part of it, really. Communication it's just massive, it's everything really, It's huge*" *(Participant 7)*
Subtheme Supports	"*I think, I think my sister I've got a sister and I've got one friend who are probably the most understanding. I think other people think, oh my goodness, you look fine, you are fine. You're not working so much. You're having a great time. If I need to do anything, I'm quite fiercely independent, so I'm my own enemy actually*" *(Participant 1)*
	"*I'm quite lucky that way. Now I have a really good bunch of friends and like I have say a gang of about eight friends and they've been really supportive, to be honest with you. I've never- they've never, they've always taken everything I've said because they've seen me so ill, I think, in the beginning... but my one of my brothers now, he wouldn't have called ever really to see me. And he was kind of had the attitude of kind of pull yourself together a bit, cop onto yourself and get on with it. Yeah, that was a bit frustrating.*" *(Participant 5)*
	"*It's like people talk about brain fog and I think people think they know what that means. They think it's like when they forget where they put their keys, or they forget the name of somebody they've just been introduced to. It's not like that at all. It's terrifying, you know, it's a loss of vision. You know, it's horrible. I think there's a lot of this people don't understand . . . . but a lot of people, the minute if they ask you how you are or if they ask you about how she speech or whatever, they say things like, "I do that too. I forget words now and again. It's just our age. We forget the names of people." And it doesn't feel like that. It feels awful It feels really foreign. I just find that really frustrating. It's deeply unhelpful, it's minimising and it's about their need for comfort, not my need for anything.*" *(Participant 3).*
	"*Well, I mean, everyone tries, but there's not much you can do. You know, it's a very individual thing. As I say, my wife was having a soupy brothy stuff a lot with me and stuff just because that was what I was making, rather than making two dishes and stuff, but outside of that there's not much that can be done, other than checking in, very little that could be done . . . . it's very silent to a lot of people*" *(Participant 6)*

the deterioration in swallowing and communication function. A further 3 participants (43%) also reported that communication and swallowing difficulties have impacted their relationship with family members who don't understand the severity of the impact of their difficulties.

3.13. Social life

Overall, 6 participants (86%) reported that swallowing difficulties impacted on their social life, with 5 participants (71%) being embarrassed if people noticed they were having difficulties eating and drinking. Most prefer to be with people who understand their swallowing difficulties when they eat out ($n = 5$; 71%).

In total, 5 participants (71%) reported that communication difficulties impacted their social life, with 4 participants (57%) reporting that they are not as involved in conversations and find following interactions difficult. Participants once again feared being embarrassed and reported that it was easier to isolate and remove themselves from interactions.

3.14. Professional life

Long-COVID impacted on the ability to return to work for 28% of participants ($n = 2$). Overall, 3 participants (43%) reported that swallowing difficulties impacted on their professional life, and 3 participants (43%) reported they were conscious of their swallowing difficulties and feared having these difficulties in front of colleagues.

In total, 6 participants (86%) reported that communication difficulties impacted on their professional life. A total of 6 participants (86%) reported that their communication difficulties made interacting with colleagues challenging. Cognitive communication difficulties meant that 5 participants (71%) were unable to keep up with the demands of their workload which had a significant impact on their ability to return to work.

3.15. Mental health

All participants ($n = 7$; 100%) discussed the mental health implications of their swallowing and communication difficulties. Participants reported that their communication and swallowing difficulties have resulted in heightened anxiety and emotions, with 5 participants (71%) reporting that these difficulties have caused them to experience low mood/depressive episodes. All participants ($n = 7$; 100%) reported that changes in their swallowing and communication functions cause frustration and 6 participants (86%) reported they are distressing. Most participants ($n = 5$; 71%) reported that they have lost their sense of self and the person they were prior to Long-COVID. Overall, 6 participants (86%) reported that changes in their swallowing and communication functions and the impact they have had on mental health and personhood have been noticed by family, friends and colleagues.

3.16. Supports

Overall, 6 participants (86%) reported that close family and friends provided the most support for their swallowing and communication issues. However, 5 participants (71%) reported that they felt unsupported by family members and friends who did not understand the severity and impact of their difficulties. A total of 4 participants (57%) reported that they felt supported by their workplace colleagues. Supports for swallowing difficulties reported by 5 participants (71%) included prompting to eat slowly, preparing suitably modified meals and being patient. Supports for communication reported by 6 participants (86%) included others being understanding of their communication abilities, recognising when they are having difficulties and prompting or helping with their permission. A total of 5 participants (71%) reported that this support somewhat undermined their independence.

3.17. Accessing long-COVID related healthcare for dysphagia and communication disorders

Participants shared their experiences of interacting with Long-COVID related healthcare, with 4 subthemes identified (Table 5).

3.18. The need for specialised long-COVID services

All 7 participants (100%) reported frustration when accessing treatment for swallowing and communication difficulties associated with Long-COVID. All participants expressed anger with the lack of available services and subsequent waiting lists, reporting a need for specialised Long-COVID services, especially for swallowing and communication problems. All participants reported frustration, stress and anger related to accessing services that adequately recognised their Long-COVID characteristics and their impact.

3.19. Positive interactions with healthcare professionals

Positive interactions with healthcare professionals (HCPs) were reported by 4 participants (57%) when accessing treatment for swallowing and communication difficulties as a symptom of Long-COVID, with these individuals feeling supported by the HCPs who took the time to listen to and understand their swallowing and communication difficulties.

3.20. Negative interactions with healthcare professionals

Overall, 6 participants (86%) reported negative interactions with HCPs when accessing treatment for swallowing and communication difficulties as a symptom of Long-COVID. These 6 participants (86%) reported that negative interactions with HCPs were with those who they felt did not understand the severity of their swallowing and communication problems. A total of 5 participants (71%) also reported it was difficult to reach a Long-COVID diagnosis which subsequently impacted their ability to access specialised Long-COVID care. A total of 4 participants (57%) acknowledged that anxiety is

Table 5
Accessing Long-COVID related Healthcare for Dysphagia and Communication Disorders

Theme: Accessing Long-COVID related Healthcare for Dysphagia and Communication Disorders		Participant quote
Subtheme	The Need for Long-COVID Specialised Services	"*I'll tell you, the fight to try and get somebody to see you has been awful and I'm quite a feisty person and I've got really cross about it, but I don't have the energy to bother . . . I went to see the what the GP sent me to see. I saw the general physicians because there's no clinic in Edinburgh allegedly*" *(Participant 1)*
		"*Some of the medical profession's knowledge of the various disciplines that are involved in Long-COVID but, you know, the specialised kind of areas and yet you go to a generalist, and they've got no idea what swallowing, speech and swallowing and all the rest of it does to a person . . . there's a kind of feeling or a, there's a* "*wait and see*" *attitude around continuing ill health following COVID infections... particularly for the health system here.*" *(Participant 3)*
		"*This is mental because all the other symptoms are very obvious, like your chest, you know what I mean? They're well documented with this I couldn't see anything about this. And my friend is a Nurse and I kept saying to her,* "*this is so weird*"*. Like, she was just like she couldn't understand it either about the swallow, it's only when after you contacted me, I was saying to my friend who's a Nurse like obviously it's a known symptom, but at the time it wasn't known at all. That was where it was very frustrating, definitely . . . to be honest with you, even though it has affected me at different stages and that I wouldn't have gone about, you know, to be honest with you, because, I mean, there's so much stuff. It's so badly done in Ireland, I would have had to go to see an ENT specialist and like to get appointments, I wouldn't have the energy to.*" *(Participant 5)*
		"*So basically, within the last week when I got the results in the video fluoroscopy, he's kind of said, "Well, there's nothing I can do now." So he's leaving me with speech and language therapy, which I have. I am working with the Beacon, the Beacon Hospital. So they referred me to a local clinic to see a local speech and language therapist to work on a further, but as of a diagnosis, interventions, or anything, no. I've had the tests to identify the problem. They don't know why. So I'm in this limbo position and everyone's kind of relying on, the Long-COVID clinic to maybe give me more information than anything else, because they're all happy enough to say it's part of Long-COVID but what's going on, why it's going on, what we can do to help it- I've got nothing*" *(Participant 6)*
Subtheme	Positive Interactions with Healthcare Professionals	"*So I've been seen by speech and language, and I just love this girl because actually, you know, you couldn't see anybody at all. It was awful . . . but she gave me she sent me exercises, she sent this and that. And actually it was really helpful, in amongst thinking nobody was listening- she was really good.*" *(Participant 1)*
		"*I was lucky that I met a doctor who had worked up in Dublin through the pandemic. And he knew by looking at me that I had Long-COVID. He was kept he kept looking at the amount of steroids I was taking, and how fatigued I was, even though I was on a high dose of steroids." (Participant 5)*
		"*So I went to a specialist in the post-COVID clinic . . . they said they had a number of people similar to me who were working in jobs that required them to talk a lot. And they were getting quite breathless when talking. So, you know, they weren't back at work yet, and they were having, you know, significant issues with their symptoms. So they did a study trying to figure out what was what was causing it . . . . . . but I was lucky in that I worked with physio and speech and language therapists, and they worked with me, advise me around different things. And I was also in touch with an O.T. who was working in a clinic in St Michael's in Dublin. It was really good to talk to another O.T. about pacing because really, until you have to do it, you don't really know*" *(Participant 7)*
Subtheme	Negative Interactions with Healthcare Professionals	"*I had to chase up and do it again. I did say to the GP at one point on the phone I said,* "*I'm really fed up with this DIY GP-ing*"*. And it wasn't- so as I said, it wasn't till this year that I got somebody that was obviously a wee bit interested and she's been fine ever since . . . .. but she obviously, she just made ashamed to be a nurse. She obviously just had this tick box and was just and, she said "No, no, no, all right my lovely" and eventually I said to her "actually, I'm not your lovely. Can you just listen? I'm going to answer you."*" *(Participant 1)*
		"*The word I've heard many people use regarding GPs, particularly is that they "gaslight" you. Because they think, you know, and then they throw in "is it not just because you're anxious that you feel this happening?" And I said, "no, because it's there all the time*"*, you know? So there's a few, I don't think, don't take it seriously. And again, it's maybe because they don't really know much about it.*" *(Participant 2)*

(*Continued*)

Table 5
(*Continued*)

Theme: Accessing Long-COVID related Healthcare for Dysphagia and Communication Disorders	Participant quote
	"*And I did speak to a couple of doctors at that time, but they couldn't have cared less, to be honest. Sorry, but one of them told me, "Oh, that's a psychological thing some women get a feeling of something being stuck in your throat. It's called something or other." And I just you know, that's probably been one of the bigger issues with, doesn't matter which symptom you talk about.*" *(Participant 3)*
	"*The Emergency Doctor said, "I think you've got Long-COVID". That when I put that to my GP, after saying to him for months I think it's Long-COVID, and he would say "oh it will go away", but it hasn't gone away. Then he finally that- he mumbled, "yes, I agree". My husband was in the room with me like and said, "Did you hear that? He mumbled, yes!" so yeah.*" *(Participant 4)*
Subtheme Fear of Long-COVID Trajectory	"*I keep saying to people you know the speech therapist that am I'm getting input from you know, "is this normal and how long will it take?" You know, I'm probably quite impatient as well but that's the kind of thing that I'm going to, you know I've no control on it. You're trying your best to do what they're telling you to do to help me- hopefully make it better but you've got no control on it. I'd say, I hate to say the word. I just think I'm improving and then, then have a big bash and then I'm back to square one again. But I do feel some days there's maybe slightly more better days than what there used to be before, but see I've only had three speech therapy, and she feels that it would take a long time for me to try and control this*" *(Participant 2)*
	"*And I don't think it's really into it's probably I mean, the last two or three weeks where I started to think. You know, some of these things that I still have could be chronic like this might actually be a new reality for me, you know, like a new permanent sort of reality for me in some ways*" *(Participant 3)*
	"*I suppose that the likenesses of certain other pretty scary diseases to have these areas to be affected same that drive that anxiety as well . . . I know obviously there's a need for this. So I'm assuming there's a lot of people suffering from it. I've been in a number of different groups and I'm not really I'm not really seeing a lot of people suffering with the same specific set of symptoms. And yeah, certainly the fatigue and nerve problems and all that kind of stuff, but not specific to cranial nerve problems and swallow problems all that kind of stuff. That's been the difficulty for me in finding somebody who's going through the same thing. I've been in groups with several thousand people and the closest I've gotten you know is, "I had a little bit of swallowing difficulty, but it went away after a couple of weeks, two or three weeks." And I'm like, well, that's like that's not what's going on here then it's different*" *(Participant 6)*

a factor of their Long-COVID, however, they were frustrated when HCPs would label their persistent physiological concerns as anxiety.

3.21. Fear of long-COVID trajectory

Overall, 6 participants (86%) reported fear of the Long-COVID trajectory. All 7 participants (100%) reported that there is a lack of research and guidance surrounding Long-COVID, particularly with swallowing and communication difficulties, and 6 participants (86%) reported that they are scared as they know very few people who are experiencing the same swallowing and communication problems as them. A total of 3 participants (42%) reported that their characteristics are similar to neurological disorders that have adverse outcomes, and they fear the trajectory of Long-COVID. The majority of participants ($n = 6$ 86%) reported that their swallowing and communication problems have started to improve, but that their recovery has been non-linear and a slow process and they experience periods of highs and lows. Given the lack of Long-COVID specialised services, 6 participants (86%) reported that they feel helpless and that they will be forced to adjust to their swallowing and communication difficulties as a new part of everyday life.

4. Discussion

This qualitative study provided new data regarding the presence and nature of swallowing and communication difficulties associated with Long-COVID, establishing an understanding of the lived experiences and impact of these issues. The findings also explored currently available supports and barriers to recovery. Findings here highlight that multiple domains of swallowing and communication may be adversely affected by Long-COVID, with subsequent psychosocial impact which is sometimes misunderstood or under-recognised, due to the lack of public awareness, research, and guidance currently available on this topic.

4.1. Swallowing difficulties in long-COVID

Results here emphasise the variability of dysphagia within this group, with difficulties across all swallowing phases reported. Although previous research has discussed dysphagia as a symptom of Long-COVID (Tran et al., 2021; Okuda et al., 2022; Chuang et al., 2022), it primarily focused on participants who were hospitalised and required mechanical ventilation during the acute infection phase, with ventilation hypothesised to be a causative factor of this dysphagia (Okuda et al., 2022; Chuang et al., 2022). Therefore, this study provides new information as none of the participants were hospitalised or mechanically ventilated during the acute COVID-19 phase, thus suggesting a different, and as of yet unknown, causative mechanism.

Additionally, this study provides new information regarding the diversity of swallowing difficulties among those living with Long-COVID. Previous research has discussed swallowing difficulties, yet sample sizes have been small, and data has provided an overview of issues, as opposed to an in-depth understanding. In contrast, this study demonstrated that characteristics of Long-COVID related dysphagia are diverse and not limited to one specific phase of swallowing. For example, findings here provide insight for the first time into the myriad of oral phase swallowing difficulties associated with Long-COVID, with many participants here reporting difficulties such as prolonged mastication, jaw discomfort, fatigue and fluctuating severity of problems. Furthermore, this study also builds on the existing evidence regarding Long-COVID related pharyngeal phase difficulties, with the majority of participants perceiving difficulties coordinating swallowing, choking, fear of choking, swelling, pain, narrowing and oedema of the pharynx and its surrounding structures, and the sensation of something lodged in the pharynx. Therefore, this study elaborates on previous findings regarding pharyngeal stage dysphagia (e.g.: Okuda et al., 2022) by adding an account of lived experiences which is essential when planning effective and person-centred service delivery (McGinnis et al., 2019). Finally, oesophageal issues were also broadly discussed by participants here, with oesophageal transit and motility concerns experienced by nearly half of participants. Very little research has been done in this area and therefore, given this new information regarding the presentation and impact of swallowing difficulties across all phases of deglutition, it is imperative that these novel in-depth lived experiences are leveraged to guide future investigations and management provision.

4.2. Communication difficulties in long-COVID

Despite some suggestions that communication may be affected long after acute COVID-19 has resolved (Ramage, 2020), there has been thus far limited tangible evidence regarding the true effects and impacts of these challenges for individuals with Long-COVID. Findings here indicate that receptive language difficulties are commonly reported, with 71% of participants reporting an impaired ability to process and understand verbal or written language or follow conversations. Furthermore, 86% of participants experienced expressive language difficulties characterised by word-finding difficulties and difficulties formulating sentences which disrupted the natural flow of conversations and interactions. Additionally, research thus far has suggested that dysphonia and dysarthria in those living with Long-COVID may be primarily associated with mechanical ventilation (Jeleniewska et al., 2022; Okuda et al., 2022). This study provides new information that contributes to a clearer understanding of how voice and speech/fluency difficulties may present in individuals with Long-COVID who were not hospitalised or mechanically ventilated with acute COVID-19. There is a noticeable gap in research thus far in the area of voice and speech/fluency difficulties in individuals with Long-COVID. However, we must consider how COVID-19 is a severe acute respiratory syndrome, which can result in Long-COVID, and therefore, Long-COVID may also have a prolonged effect on respiratory and pulmonary systems (Crook et al., 2021; NICE, 2020). Therefore, these new findings here should be taken into consideration by all HCPs, especially speech and language therapists when providing care for clients with Long-COVID. Once again, participants expressed how, in the same way that their swallowing issues associated with Long-COVID go undetected, their communication difficulties are not well recognised or understood by the general public, HCPs, and researchers. Individuals with Long-COVID and language difficulties lack professional guidance and support for these problems, which should be taken into consideration when planning future research and care provision for individuals with Long-COVID.

4.3. Psychosocial impact of dysphagia and communication disorders in long-COVID

This study also found that individuals are experiencing varied psychosocial impacts as a result of communication and swallowing difficulties associated with Long-COVID. There is a growing body of evidence that identifies the psychosocial impact of Long-COVID as a pertinent issue, with these individuals experiencing psychological distress and poor quality of life, difficulties carrying out activities of daily living and socioeconomic adversities (Han et al., 2022; O'Mahony et al., 2022; Tsuzuki et al., 2022). The findings from this study build on the existing evidence of the psychosocial impact of Long-COVID, and it also provides specific information about the impact of the associated swallowing and communication difficulties. This study found that swallowing and communication difficulties as a symptom of Long-COVID pose a barrier to connecting with family and friends, whether that be challenges related to going out for a meal or engaging in conversations. Similarly, the professional lives of participants were impacted when these individuals ate lunch or went for meals with colleagues. Cognitive communication difficulties had a notable consequence, with 71% of participants who reported being unable to keep up with the demands of their workload, which had a significant impact on their ability to return to work.

Notably, 100% of the participants in this study experienced adverse mental health which they associated with their Long-COVID-related swallowing and communication difficulties. The participants in this study expressed how these difficulties are distressing for them and their loved ones, and that they have lost their sense of self and the person they were prior to their swallowing and communication difficulties. This study found that participants felt their concerns are often not understood by others, that they lack guidance, and that they feel isolated as they have often not heard of other individuals presenting with swallowing and communication difficulties related to Long-COVID. The prevalence of mental health difficulties and the significant impact swallowing and communication difficulties have on individuals with Long-COVID emphasises that the need for guidance for both clients and HCPs and that these issues require swift action within the realms of research, clinical, and policy development.

4.4. Accessing long-COVID related healthcare for dysphagia and communication difficulties

Findings here highlight the lack of available research and guidance about swallowing and communication difficulties associated with Long-COVID which contributes to limited public and HCP awareness of these challenges. Given that 100% of participants reported stress and frustration related to accessing treatment options for their swallowing and communication concerns, it can be hypothesised that if service delivery and HCPs' awareness of Long-COVID characteristics is improved, the burden and impact of swallowing and communication difficulties may be alleviated. This study contributes to the existing evidence base that individuals with Long-COVID are experiencing difficulties accessing and navigating specialised Long-COVID services (O'Mahony et al., 2022). While 57% of participants reported that they felt their swallowing and communication difficulties were understood and listened to by HCPs, challenges were also identified in accessing services. Perhaps due to the lack of available clinical guidance and support, most participants here reported some level of negative interactions with HCPs when accessing treatment for their swallowing and communication problems. Participants perceived that their swallowing and communication difficulties were sometimes dismissed, minimised, and not acknowledged as a physiological symptom of Long-COVID but rather a symptom of anxiety. This may be related to the clinical uncertainty that professionals face in providing care for this group in the absence of reliable evidence or guidelines, and it highlights the need for improvements in research and practice to support treating clinicians and therefore individuals with swallowing and communication difficulties associated with Long-COVID in their journey to recovery.

4.5. Limitations

The small sample size and primarily female distribution of participants recruited here may limit the generalizability of study findings. Although it was beyond the scope of this project, it is advised that in the future, a broader and more diverse sample distribution is sought over a longer period of time. This qualitative study, however, provides the first in-depth insight into the experiences and impact of swallowing and communication difficulties among adults living with Long-COVID, thus making a significant contribution to the existing evidence base.

5. Conclusions

This study investigated the presence and nature of Long-COVID associated swallowing and communication difficulties and explored the qualitative lived experience of individuals living with these difficulties. The findings indicate that multiple domains of swallowing and communication can be affected in individuals with Long-COVID. Furthermore, these difficulties have appreciable psychosocial and quality of life impacts for the individual and their loved ones, with limited access to specialised care for swallowing and communication problems in Long-COVID posing a barrier to recovery. Over 524 million individuals have been diagnosed with COVID-19 worldwide (WHO, 2022), and it is estimated that a substantial proportion of these individuals may subsequently develop Long-COVID (Crook et al., 2021), many of whom may also experience swallowing and communication difficulties and associated psychosocial and mental health implications. This study contributes to the existing research in the area of Long-COVID and goes beyond the scope of previous studies by investigating the nature and impact of swallowing and communication difficulties in Long-COVID. Individual perspectives and experiences need to be amplified and understood by healthcare professionals, so that the quality of care provision can be optimised for those who present with swallowing and communication difficulties associated with Long-COVID.

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Conflict of interest

Authors have no conflict of interest to declare.

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