COVID-19 AND SPEECH-LANGUAGE PATHOLOGY

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COMMUNICATION-RELATED QUALITY OF LIFE IN ADULTS WITH LONG COVID

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Louise Cummings

43-year-old woman with Long COVID; 8.6 months post onset:

> "I am unable to do a tiny fraction of a life. Unable to care for myself or my children. Unable to work and generate income. Unable to read, write, speak. Long COVID is crippling physically and mentally. The pain and impairment are just too vast to put across."

6.1 Introduction

The COVID-19 pandemic continues to pose health and economic challenges for populations around the world. But behind the large and growing deaths from COVID-19 lies a more insidious threat to human well-being and economic stability. This is the threat posed by Long COVID. It is now known that as many as one in seven people who contract SARS-CoV-2 still have symptoms 12 weeks after the onset of their illness (Office for National Statistics 2021). These children and adults have been variously referred to as having Long COVID, the post-COVID syndrome, or more informally as COVID long haulers. People with Long COVID can suffer debilitating physical and cognitive symptoms, with many unable to return to work and resume their social roles due to these difficulties. A set of cognitive-linguistic problems (so-called "brain fog") has proved to be particularly challenging for individuals with Long COVID (Callan et al. 2022). This group of problems is still rather poorly defined and includes behaviours such

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as word-finding difficulties, poor memory, and lack of concentration. The consistent reporting of language and communicative problems by people with Long COVID has prompted the author to investigate the nature of these difficulties (Cummings 2021a, 2021b; see Chapter 5 this volume). This chapter extends this investigation by considering the impact of these problems on the quality of life of adults with Long COVID.

The chapter unfolds as follows. Definitions of Long COVID are continually revised as more becomes known about the onset, clinical presentation, and progression of the condition. In section 6.2, Long COVID is defined using the most recent definition adopted by the World Health Organization. This section will also consider risk factors for the development of Long COVID, the prevalence of the condition, and the types of physical and cognitive symptoms that constitute the post-COVID syndrome. Cognitive-linguistic difficulties in people with Long COVID can persist after physical symptoms have resolved and are often the difficulties that most compromise occupational and social functioning. In section 6.3, the nature of these difficulties is considered by examining extracts from the personal narratives of adults with Long COVID who report symptoms of "brain fog." These qualitative reflections are then supplemented in section 6.5 by the findings of a survey of 973 adults with Long COVID. This survey aimed to quantify the effect of Long COVID on spoken and written communication skills and to investigate the impact of post-COVID communication difficulties on an individual's quality of life. The chapter concludes in section 6.7 with an assessment of the implications of these findings for the management of adults with Long COVID. It is argued that speech-language pathologists should play a significant role in the rehabilitation of people with Long COVID.

6.2 Long COVID: some background

On 6 October 2021, the World Health Organization published a clinical case definition of post-COVID-19 condition arrived at by a Delphi consensus. Whilst WHO acknowledges that this definition will need to be revised as new evidence emerges about COVID-19, it is nonetheless a valuable starting point for our discussion of Long COVID:

> Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time. (World Health Organization 2021)

The noteworthy features of this definition include the persistence of symptoms **3 months** after COVID onset with a duration of at least **2 months**. There must be **no alternative diagnosis** of the symptoms, which can include **physical problems** (e.g., fatigue) and **cognitive dysfunction**. Symptoms have an impact on everyday functioning. They may **persist** from the acute COVID illness or may be **new onset**. They may also **fluctuate or relapse** over time.

When examined as part of a definition, these features somehow fail to reflect the true magnitude of the post COVID-19 condition. This condition is a lived reality for millions of people worldwide and will be with us for years to come in the form of a large burden of illness and economic inactivity. It is for these reasons that there is now considerable research effort directed towards understanding Long COVID and its impact on people's lives. In this section, we throw light on this largely hidden part of the COVID-19 pandemic by examining the prevalence, symptoms, and risk factors for this chronic condition.

The prevalence of Long COVID varies considerably across studies, ranging from 4.7% to 80% according to a recent review of 25 observational studies (Carbrera Martimbianco et al. 2021). In a systematic review and meta-analysis of 15 studies examining 47,910 patients, Lopez-Leon et al. (2022) estimated that 80% of patients infected with SARS-CoV-2 developed one or more long-term symptoms. Jacobson et al. (2021) found that at 3–4 months post-COVID-19 diagnosis, 81.8% of hospitalised patients and 64.2% of non-hospitalised patients had any COVID symptoms, suggesting a significant burden of long-term illness even in patients with milder COVID illness in the acute stage. The prevalence of Long COVID in children has also been investigated. In a review of 14 studies, Zimmermann et al. (2021) reported that the prevalence of persistent COVID symptoms in children varied considerably from 4% to 66%. Similarly high Long COVID prevalence figures are reported in other countries and territories. The prevalence of Long COVID symptoms at 12 weeks in 2,198 participants in Bangladesh was 16.1% (Hossain et al. 2021). Osikomaiya et al. (2021) examined 274 patients attending the COVID-19 outpatient clinic in Lagos State, Nigeria. More than one-third (40.9%) had persistent COVID-19 symptoms after discharge.

Symptoms in Long COVID have been investigated in several large-scale studies. Over 60 physical and psychological symptoms were reported in a review of studies that examined 10,951 people with Long COVID (Michelen et al. 2021). In a study of 273,618 patients diagnosed with Long COVID, one in three patients had one or more features of Long COVID between three and six months after diagnosis of COVID-19. From most to least common, these features included anxiety/depression (15.49%); abdominal symptoms (8.29%); abnormal breathing (7.94%); "other" pain (7.19%); fatigue/malaise (5.87%); chest/throat pain (5.71%); headache (4.63%); cognitive symptoms (3.95%); and myalgia (1.54%). For two in five of these patients, they had no record of these features in the previous three months (i.e., they were new-onset features) (Taquet et al. 2021). The five most common long-term symptoms reported by Lopez-Leon et al. (2022)

were fatigue (58%); headache (44%); attention disorder (27%); hair loss (25%); and dyspnea (24%).

To control for background symptom prevalence, Wanga et al. (2021) compared symptom persistence (> 4 weeks) in people who received positive SARS-CoV-2 test results (n=698) and people with negative test results (n=2,437) in the United States between January 2020 and April 2021. More persons with positive test results (76.2%) reported persistence of at least one initially occurring symptom at four weeks compared with those with negative test results (69.6%). This higher prevalence was found in fatigue (22.5% versus 12.0%); change in sense of smell or taste (17.3% versus 1.7%); shortness of breath (15.5% versus 5.2%); cough (14.5% versus 4.9%); and headache (13.8% versus 9.9%).

A question of some interest is whether certain population groups are more at risk of Long COVID than others. Taquet et al. (2021) examined the electronic health records of 273,618 patients diagnosed with COVID-19 and reported a higher risk of Long COVID features in patients who had more severe COVID-19 illness and a slightly higher risk in women and in young adults. There was no difference in Long COVID risk between White and non-White patients. Female sex and increasing age and body mass index were associated with Long COVID in a study of 4,182 incident cases of COVID-19 in which individuals self-reported their symptoms prospectively in an app (Sudre et al. 2021). Younger age, female gender, rural residence, prior functional limitation, and smoking have been found to predict the length of Long COVID in a patient cohort in Bangladesh (Hossain et al. 2021). Old age, female sex, severe clinical status, a high number of comorbidities, hospital admission, and oxygen supplementation at the acute phase were risk factors for Long COVID in Carbrera Martimbianco's systematic review of 25 observational studies. The only factor that is consistently reported to increase the risk of Long COVID is female gender.

6.3 Brain fog in Long COVID

The term "brain fog" has been coined to characterise cognitive symptoms that are commonly reported by people with Long COVID. Davis et al. (2021) recorded cognitive symptoms, including problems with memory, in approximately 88% of adults of all ages in a study of 3,762 people with COVID illness lasting over 28 days. Many cognitive symptoms are present at the acute illness stage and then persist for weeks and months. Orrù et al. (2021) found cognitive impairment (brain fog, loss of concentration) in 40% of study participants who were currently positive for COVID-19. Cognitive symptoms were also reported in 47.06% of participants who had had COVID-19 but had not been positive for less than a month, 59.46% who had not been positive for at least a month, 47.40% who had not been positive for at least two months, and 48.68% who had not been positive for at least three months. Other cognitive symptoms appear to arise for the first time after the acute phase of illness. It is possible, however, that these symptoms are present during the acute phase of COVID-19 and are masked by physical symptoms and extended periods of rest. Cognitive problems may then become apparent for the first time as some physical symptoms improve and people with COVID start to resume work and social functions.

45-year-old woman; 21.1 months post onset:

> "Cognitively it felt like my brain was 'full' – I couldn't follow instructions, hold conversations, follow storylines or anything where I had to hold information in my head."

The symptom of brain fog is a constellation of wide-ranging cognitive and linguistic problems. These problems include issues with memory and concentration but also difficulties with speaking, reading, writing, and comprehension. Language is the vehicle through which we communicate with others, and its disruption has been one of the most distressing symptoms experienced by people with Long COVID. The author recorded the responses of 92 people with test-confirmed or clinically diagnosed COVID-19 as they characterised the impact of their illness on language across the four areas of speech and writing (expressive language) and comprehension and reading (receptive language) (see Chapter 5). Some understanding of the impact of COVID-19 on each of these areas can be gleaned from examining the comments of several study participants as they reflect on the effect of their illness on language skills (see Table 6.1).

Language difficulties have left previously articulate, skilled communicators unable to participate in conversation with family members and friends, enjoy hobbies such as reading, and struggling to complete tasks required of them in their occupational roles. Once mundane activities like writing a birthday card require rehearsal and additional time; considerable editing is needed to write a text. The frustration resulting from these difficulties is palpable in at least one of these participants. Another reported feeling embarrassed by his language and communication skills, even attempting to "cover" for his difficulties in conversation with others. It is unsurprising that these difficulties have left adults with Long COVID wanting to avoid communication with others, change the way in which they communicate with others, and reduce the frequency of communication with family members, friends, and colleagues. There is also a marked negative impact on the desire to communicate, with many adults with Long COVID no longer feeling motivated to communicate or confident enough to communicate with people other than family members (see Table 6.2).

TABLE 6.1 Participant reports of impact of COVID-19 on language

Receptive language	
Comprehension	*Reading*
Woman: 38.3 years; 18.3 months post onset: "It's mostly when fatigued that I have difficulty following a conversation. It's not so much that I forget what they said – most of the time I don't even register what they're saying." ***Woman: 40.6 years; 18.6 months post onset:*** "Someone says something to me and I have to sit and think for a minute to try to process what they've said and how I need to respond. If I'm asked a question with more than one part to it, I find I can only remember one part of the question."	***Woman: 51.4 years; 10.6 months post onset:*** "Reading has been a challenge – I was an avid reader, and it's like I can't digest the info – I can see the words, read the words, but it doesn't go in." ***Woman: 45.6 years; 7.6 months post onset:*** "I can't read. AAAAAARRRGGGHHH. One of my two jobs is to read large volumes of evidence for General Medical Council fitness to practise case examiner work. Brain fog descends after a couple of minutes, and I can't concentrate. I used to be in a book club and read a book every two to four weeks but have read nothing for pleasure."
Expressive language	
Speech	*Writing*
Man: 55.5 years; 17.9 months post onset: "I can keep things going but I can start rambling and introduce things to cover for not knowing something. I sometimes get into a complete mess as I can't keep talking and think about what comes next at the same time." ***Woman: 44.1 years; 10.8 months post onset:*** "General easy chit-chat at home now easier, but it wasn't always easy as I couldn't string a sentence together for four months [. . .] I can now manage conversation on phone for longer, but I know when it's about to go [. . .] all of a sudden speech will become slurred."	***Woman: 61 years; 15.4 months post onset:*** "The first birthday card I wrote after becoming ill was a disaster – my hand would not do what I wanted it to. I ruined it and had to find another one. I now practise what I'm going to write in a card and take lots of time over it. Rushing is impossible." ***Woman: 51.3 years; 8.9 months post onset:*** "I was wrong in saying the effects hadn't affected my written communication. Predictive text and auto correct mask the mistakes, but when I investigated, I was slower and made many more mistakes in writing too. I just go back and edit all the time."

These responses provide sufficient evidence of a significant burden of communication disability and related impact on quality of life in adults with Long COVID to warrant further investigation. To this end, an online survey of 973 adults with Long COVID was conducted. The aim of the survey was twofold: to capture the type of communicative difficulties that occur in adults with Long

TABLE 6.2 Participant reports of impact of COVID-19 on communication motivation, frequency, and mode

Motivation to communicate	
Woman: 53.6 years; 9 months post onset: "Sometimes I find I do not want to engage in conversation (I am usually very chatty) and will give one-word answers to people." ***Woman: 45.3 years; 15.2 months post onset:*** "To be honest, it [conversation] feels like a lot of hard work, and I'm not sure it's worth the effort at the moment." ***Woman: 42.3 years; 15.2 months post onset:*** "I tend to shy away from conversations with strangers as I come across as stupid, and that makes me feel vulnerable. Family make allowances for me, but out and about I withdraw."	***Woman: 61.6 years; 7.5 months post onset:*** "I do want to be connected with people still, but a lot of the time, I don't bother talking because I know the words will come out wrong, or I have too little energy to have a conversation." ***Woman: 50.9 years; 8 months post onset:*** "I will not participate in conversations as sometimes I just can't be bothered." ***Woman: 53.3 years; 22.2 months post onset:*** "Lost all confidence in joining in any academic conversation or with people that didn't know me before I had COVID, as I feel I come across as stupid and ill-informed."
Frequency of communication	
Woman: 43.8 years; 8.6 months post onset: "Decreased as embarrassed. Couldn't trust myself to say the right thing or behave normally. It was like I was very drunk or drugged." ***Man: 61.6 years; 7.4 months post onset:*** "Probably less than usual. I think on reflection I don't initiate so many calls as before."	***Woman: 61 years; 15.4 months post onset:*** "Family and friends understand my word blindness, word substitution, and losing my way during a sentence, etc. It can be highly embarrassing with strangers or those who don't know me well especially with medical matters, so I minimise those." ***Woman: 58.4 years; 16.3 months post onset:*** "I would have spoken to my daughter once a week, and now it's once a fortnight at most."
Mode of communication	
Woman: 53.6 years; 9 months post onset: "I have noticed I am reluctant to chat to family members via the phone and sometimes will ignore the phone." ***Woman: 42.3 years; 15.2 months post onset:*** "I'd rather communicate with others via text as I am in control of the speed of reading and replying."	***Woman: 64.3 years; 7.5 months post onset:*** "Because of the difficulties and the embarrassment I feel, I have reduced the communication I have with others face to face or on the phone and resort to messaging more." ***Woman: 51.4 years; 10.7 months post onset:*** "I find I'm texting to keep up with friends – it's easier and less tiring."

COVID and to examine the impact of these difficulties on a person's interpersonal relations, work and leisure experiences, and quality of life. The results of this survey are presented in section 6.4. But first, the contribution of communication to quality of life in people with Long COVID is examined.

6.4 Communication and quality of life in Long COVID

It has been documented in several studies to date that Long COVID has a significant adverse impact on a person's quality of life. In a review of studies examining 10,951 people with Long COVID, Michelen et al. (2021) found that 37% of patients reported reduced quality of life. Long COVID has been found to compromise quality of life across several domains, including social relationships, occupational functioning, and psychological well-being. Jacobs et al. (2020) examined 183 hospital-discharged patients who reported persistent COVID symptoms at 35 days. These patients gave poor to fair ratings on each of the following domains: quality of life (23.2%); mental health (16.9%); social relationships (60.4%); and active participation in social roles (31.5%). In their study of 3,762 people with COVID illness lasting over 28 days, Davis et al. (2021) found that 1,700 respondents (45.2%) required a reduced work schedule compared to pre-illness, and an additional 839 respondents (22.3%) were not working at the time of the survey due to illness.

These studies provide strong evidence that Long COVID compromises quality of life across a range of domains. But what is less clear is the *specific* contribution that communication problems make to quality of life and daily functioning in people with Long COVID. This is because the instruments used to measure quality of life in people with Long COVID do not assess communication as a unique domain. This can be illustrated by considering how Jacobs et al. (2020) and Davis et al. (2021) examine quality of life and functioning in their respective studies. Jacobs et al. used PROMIS® survey questions to assess general health, quality of life, physical health, mental health, social relationships, social active role, physical activity, emotional problems, and fatigue (Choi et al. 2011; PROMIS Health Organization 2018). The daily living activities examined in their study included dressing, walking, climbing stairs, meal preparation, washing dishes, sweeping, making the bed, lifting, lifting and carrying, and walking fast. Communication is not examined or even mentioned in this investigation.

In their study, Davis et al. consider the impact of memory and cognitive dysfunction on three aspects of language and communication: (1) the ability to communicate thoughts; (2) the ability to have conversations with others; and (3) the ability to follow simple instructions. Whilst this study at least acknowledges communication, it also omits any examination of the contribution that communication difficulties make to quality of life and daily functioning. Communication impairment is assessed as an *outcome* of cognitive dysfunction rather than as a *cause* of reduced functioning in areas such as work and social relationships. Clearly, a shift of focus is required to give greater prominence to communication problems in an explanation of poor quality of life and reduced functioning in people with Long COVID.

To address the omission of communication in instruments used to measure quality of life, speech-language pathologists have increasingly focused on communication-related quality of life (CRQoL) in their development of clinical scales and assessments. CRQoL is now assessed in clients with voice disorders, stuttering, and aphasia through dedicated instruments (Yaruss 2010; Zraick and Risner 2008; Hilari et al. 2003). One such instrument is the Quality of Communication Life (QCL) Scale. Devised by Paul et al. (2004) for the American Speech-Language-Hearing Association (ASHA), the QCL is designed to assess the impact of a communication disorder on an adult's relationships; communication interactions; participation in social, leisure, work, and education activities; and overall quality of life (2004, p. 1). The scale is designed to supplement measures of impairment and functional communication and is validated for use with adults who have communication disorders resulting from various neurological conditions (e.g., aphasia and dysarthria). The items used in the scale are displayed in Box 6.1 in the Appendix.

Whilst the QCL was not developed for use with adults with Long COVID, it can contribute to our understanding of the impact of impaired communication on quality of life and daily functioning in people with this condition. The scale assesses in a simple, transparent way the areas that are impacted by poor communication skills in adults with Long COVID. The QCL is normally administered in person, with the clinician assisting the client with marking up his or her responses to test items on a visual analogue scale (when necessary) and ensuring comprehension of task instructions and test items. In-person administration is not possible for adults with Long COVID, all of whom are geographically remote from the author and are unable to meet the author face to face in any event due to COVID restrictions. Also, in-person administration is not needed for adults with Long COVID who have no physical disability that requires the author's assistance in marking the visual analogue scale and who have adequate language comprehension skills to comply with task instructions. Along with adaptations to the scale that permit it to be administered online – to be outlined in the next section – these considerations were judged not to limit the utility of the QCL in understanding the impact of COVID-related communication difficulties on quality of life.

6.5 Exploring communication-related quality of life in Long COVID

To establish the impact of communication difficulties on quality of life and daily functioning in adults with Long COVID, an online survey was conducted in

February and March 2022. The survey link was posted on Twitter and on Long COVID Facebook groups in the UK and Europe. It was shared widely amongst the Long COVID community. The survey was eventually completed by 973 people in 32 countries (see Table 6.3). It was part of a wider study of cognitive-linguistic difficulties in adults with COVID-19 which was approved by the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University. Some respondents to the survey also participated in other parts of the study, whilst most respondents had no prior contact with the author and her work.

The survey was conducted in five parts (see Box 6.2 in Appendix). In part one, participants were required to read information about the study and the eligibility criteria that were required for participation. They were then asked to indicate that they satisfied the criteria for participation and that they consented to participate in the study. In part two, participants were asked to provide their date of birth, gender, ethnicity, educational background, employment status before their COVID illness, and their status as an English speaker. In part three, participants were asked to rate their physical health, mental health, and spoken and written communication skills before their COVID illness. They were also asked to indicate their preferred method of communication before becoming unwell with COVID-19. In part four, participants were asked about their COVID illness, including when their symptoms first developed and their test and diagnostic status. They were also asked to rate their physical and mental health and spoken and written communication skills since developing COVID. Part four also asked respondents about their employment status and preferred method of communication following COVID. There were several questions about Long COVID, including its severity and whether respondents were under medical supervision for their condition. Respondents were then asked to select statements that described their experience of brain fog. In part five, participants were presented with the items used in the Quality of Communication Life Scale. These items were appropriately modified for use in an online survey format, with respondents rating statements on a five-item scale from "strongly disagree" to "strongly agree" rather than on a visual analogue scale. The entire survey could be completed in under 15 minutes. The results of this survey are presented as follows:

Participant characteristics: There was a total of 973 respondents to the survey. They ranged in age from 18 to 80 years, with a mean age of 47.4 years. Most respondents were female (89.6%), had White British ethnicity (62.8%), and lived in the United Kingdom (69.4%). English was a first language for 83.6% of respondents. High levels of education were reported, with 40% of respondents having an undergraduate degree and 38.4% having a higher degree (see Table 6.3).

Health before and after COVID-19: Most respondents reported good to excellent physical health (96.6%) and mental health (94.8%) prior to COVID-19. This decreased significantly following COVID infection, with only 5.6% and 35.2%

TABLE 6.3 Characteristics of 973 survey respondents

Age			*Gender*		
Age (mean): 47.4 years			Male: 101 (10.4%)		
Age (range): 18–80 years			Female: 872 (89.6%)		
Ethnicity					
White British:	611	62.8%	Asian Other:	8	0.8%
White Other:	250	25.7%	Asian Pakistani:	6	0.6%
White Irish:	48	4.9%	Black British:	6	0.6%
Mixed or Multiple Ethnicities:	19	2.0%	Black Other:	4	0.4%
Other Ethnic Group:	9	0.9%	Asian Chinese:	3	0.3%
Asian Indian:	8	0.8%	Asian Bangladeshi:	1	0.1%
Country					
United Kingdom	675	69.4%	Jersey	2	0.2%
United States of America	99	10.2%	Portugal	2	0.2%
Belgium	61	6.3%	Switzerland	2	0.2%
Netherlands	37	3.8%	Austria	1	0.1%
Ireland	28	2.9%	Bahrain	1	0.1%
Canada	13	1.3%	Barbados	1	0.1%
Spain	10	1.0%	Bermuda	1	0.1%
France	8	0.8%	Brazil	1	0.1%
Germany	4	0.4%	Czech Republic	1	0.1%
South Africa	4	0.4%	Lebanon	1	0.1%
Australia	3	0.3%	Mexico	1	0.1%
Norway	3	0.3%	Saudi Arabia	1	0.1%
Philippines	3	0.3%	Singapore	1	0.1%
Denmark	2	0.2%	Slovakia	1	0.1%
Finland	2	0.2%	Sweden	1	0.1%
Isle of Man	2	0.2%	Thailand	1	0.1%
Education			*English language*		
Primary and secondary education only: 210 (21.6%)			English as a first language: 813 (83.6%)		
University undergraduate degree: 389 (40%)			English as a second language: 109 (11.2%)		
University higher degree: 374 (38.4%)			English as a third language: 51 (5.2%)		

reporting good to excellent physical health and mental health, respectively (see Table 6.4).

Communication before and after COVID-19: An equally marked decrease occurred in respondents' self-rated spoken and written communication skills following COVID infection. Prior to COVID-19, 99.8% of respondents rated their spoken communication skills good to excellent. This dropped to 41.6% following their COVID illness. A similar decrease was observed in written communication

TABLE 6.4 Physical and mental health in respondents before and after COVID-19

	Physical health	
	Before COVID	*After COVID*
Excellent	467 (48.0%)	8 (0.8%)
Good	473 (48.6%)	47 (4.8%)
Poor	33 (3.4%)	918 (94.4%)
	Mental health	
	Before COVID	*After COVID*
Excellent	475 (48.8%)	17 (1.7%)
Good	448 (46.0%)	326 (33.5%)
Poor	50 (5.2%)	630 (64.8%)

skills, with 99.7% reporting good to excellent skills before COVID and 54.1% reporting good to excellent skills after COVID (see Table 6.5). Consistent with the perceived deterioration in communication skills, there was a marked change in how respondents chose to communicate with people after COVID-19. Prior to their illness, most respondents (61%) opted for face-to-face communication. Reflecting the communicative challenges caused by COVID-19, face-to-face communication was the preferred means of communication for just 12.6% respondents after their illness. Whilst there was a significant move away from face-to-face communication, with its high cognitive processing demands in real time, there was an equally marked shift towards the use of texts and emails. These written forms of communication afford the user more time for planning and editing of messages. Text use increased from 14.6% before COVID to 50.2% after COVID. Social media use also increased, from 3.5% before COVID to 6.8% after

TABLE 6.5 Spoken and written communication in respondents before and after COVID-19

	Spoken communication	
	Before COVID	*After COVID*
Excellent	856 (88.0%)	15 (1.5%)
Good	115 (11.8%)	390 (40.1%)
Poor	2 (0.2%)	568 (58.4%)
	Written communication	
	Before COVID	*After COVID*
Excellent	847 (87.1%)	43 (4.4%)
Good	123 (12.6%)	484 (49.7%)
Poor	3 (0.3%)	446 (45.9%)

TABLE 6.6 Preferred method of communication in respondents before and after COVID-19

Preferred method of communication		
Category	*Before COVID*	*After COVID*
Phone calls	94 (9.7%)	79 (8.1%)
Texts	142 (14.6%)	488 (50.2%)
Emails	96 (9.9%)	183 (18.8%)
Video calls	13 (1.3%)	34 (3.5%)
Social media	34 (3.5%)	66 (6.8%)
Face-to-face communication	594 (61.0%)	123 (12.6%)

COVID. This increased use of social media most likely reflects the psychosocial support that many respondents received from participation in Facebook and other online groups for people with Long COVID (see Table 6.6).

Employment before and after COVID-19: For respondents, who are largely adults of working age, one of the most profound impacts of Long COVID has been on employment. Most respondents (67.9%) were employed full-time before developing COVID-19. Full-time employment for these respondents dropped to just 24.6% following their illness. There was a corresponding increase in all "no employment" categories after COVID-19, with the biggest increase registered for the category "not working due to disability." This increased from just 2.4% before COVID to 32.5% after COVID, an increase that reflected the high level of debilitation that people with Long COVID experienced and the work incapacity that this condition had caused (see Table 6.7).

COVID-19 illness: The onset, diagnosis, and testing of COVID-19 was also explored in the survey. Most respondents (33.4%) developed COVID-19 in the

TABLE 6.7 Employment of respondents before and after COVID-19

Employment		
Category	*Before COVID*	*After COVID*
Employed full-time	661 (67.9%)	239 (24.6%)
Employed part-time	206 (21.2%)	187 (19.2%)
Unemployed	10 (1.0%)	42 (4.3%)
Not working due to retirement	26 (2.7%)	35 (3.6%)
Not working due to disability	23 (2.4%)	316 (32.5%)
Student	10 (1.0%)	8 (0.8%)
Other	37 (3.8%)	146 (15.0%)

first quarter of 2020. This was when the pandemic first reached the UK. Onset of illness was also high in the fourth quarter of 2020 (16.9%) and the first quarter of 2021 (11.1%), when the UK experienced a second, severe wave of infection. Reflecting the lack of testing that was available at the start of the pandemic, most respondents (35%) had received a clinical diagnosis of COVID-19 only. Amongst respondents, 98.7% reported having Long COVID currently, and 81.2% are under medical supervision for the condition (see Table 6.8).

Turning to brain fog, at its worst, this was rated to be severe by 60.3% of respondents. Over time the severity of brain fog decreased. However, there was

TABLE 6.8 COVID illness and brain fog in survey respondents

COVID illness						
Onset	First quarter 2020	325	33.4%	First quarter 2021	108	11.1%
	Second quarter 2020	130	13.4%	Second quarter 2021	18	1.8%
	Third quarter 2020	34	3.5%	Third quarter 2021	70	7.2%
	Fourth quarter 2020	164	16.9%	Fourth quarter 2021	97	9.9%
	Date omitted or incorrect				27	2.8%
Diagnosis & testing	Clinical diagnosis only				341	35.0%
	Positive PCR test only				301	31.0%
	Positive antibody test only				59	6.1%
	Clinical diagnosis and positive PCR test				123	12.6%
	Clinical diagnosis and positive antibody test				37	3.8%
	Positive PCR test and positive antibody test				34	3.5%
	Clinical diagnosis and positive PCR test and positive antibody test				78	8.0%
Long COVID	Long COVID currently	YES	NO	Currently under medical supervision for Long COVID	YES	NO
		98.7%	1.3%		81.2%	18.8%

Brain fog			
Severity of brain fog at worst	Severe	587	60.3%
	Moderate	354	36.4%
	Mild	32	3.3%
Severity of brain fog currently	Severe	94	9.7%
	Moderate	598	61.4%
	Mild	281	28.9%

still a significant burden of impairment related to brain fog at the time of survey completion, with 61.4% rating their current brain fog as moderate in severity (see Table 6.8). A constellation of language difficulties occurred in brain fog. The most marked language problem was word-finding difficulty. This was reported by 93.1% of respondents (see Figure 6.1). Amongst 11 language difficulties explored in the survey, all but two were reported to occur in over 50% of respondents. This reflects the high burden of language and communication problems in this population of adults. These difficulties caused frustration and embarrassment for 83.2% and 54.9% of respondents, respectively. Long COVID also resulted in reduced frequency of communication with others and less desire to communicate with others in 71.3% and 65.8% of respondents, respectively (see Figure 6.1).

Quality of Communication Life Scale: The items in the QCL Scale were administered to respondents of the survey. Despite their communication difficulties, adults with Long COVID reported a high degree of autonomy, responsibility, and independence, with 79.9% reporting that they make their own decisions, 66.8% stating that they had household responsibilities, and 83.5% agreeing with the statement "I speak for myself." Respondents also indicated for the most part that they liked to talk to people (64%) and felt included in conversations by others (55.3%). However, this positive stance towards communication with others was not always realised in terms of actual communication, with fewer than half of respondents (48.1%) agreeing that they stayed in touch with family members and friends. This may simply have reflected pre-morbid patterns of communication between adults with Long COVID and friends and family. However, combined with the finding that 71.3% of respondents reported that they communicated less frequently with others since their COVID illness, it is likely that communication difficulties and communication-related fatigue were significant factors in limiting contact with family members and friends. Other positively rated items were "people understand me when I talk" (72.6%); "I keep trying when people don't understand me" (74.3%); "I use the telephone" (61.1%); "I follow news, sports, and stories on TV/movies" (55.5%); and "I see the funny things in life" (66.2%). Clearly, adults with post-COVID communication difficulties were still able to engage in meaningful communicative interactions with others, sought out ways to undertake those interactions (e.g., use the telephone), enjoyed certain leisure activities (e.g., watching TV), and appreciated humorous moments in their daily lives.

Notwithstanding these positively rated items, there was considerable disagreement expressed by respondents towards several items on the scale. Most respondents (55.9%) did not agree that it was easy for them to communicate, whilst just under half of respondents (49.1%) were confident that they can communicate. These findings confirm the many narrative comments describing communicative difficulties and reduced confidence in communication produced by adults with Long COVID (see Tables 6.1 and 6.2). There was a significant impact of these communicative difficulties on survey participants' self-esteem and occupational and familial roles. Only 34.7% of respondents agreed with the statement "I like

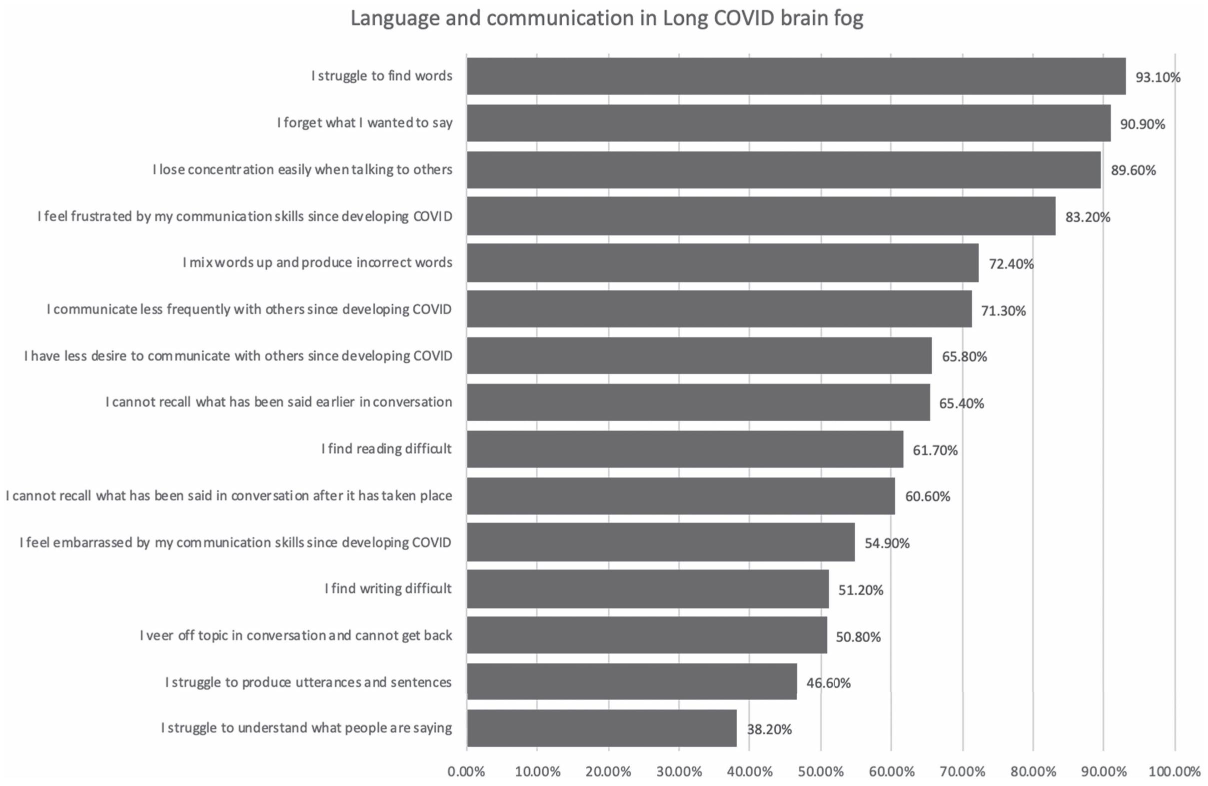

FIGURE 6.1 Language and communication in Long COVID brain fog

myself." Some 69.3% of respondents did not agree with the statement "I meet the communication needs of my job or college," and 62.9% disagreed with the statement "My role in the family is the same." Also, 74.8% of respondents disagreed with the statement "I get out of the house and do things." Communication problems almost certainly contributed to this reduced participation in activities outside the home – adults with Long COVID are unlikely to participate in activities outside the home, especially social activities, if communication skills are compromised. Fatigue and general debilitation are also features of Long COVID and are likely to be equally significant factors in preventing adults from participating in a range of activities outside the home. Most worryingly of all is that some 68.3% of respondents did not agree with the statement "In general, my quality of life is good." The impact of communication difficulties on self-esteem and on functioning in occupational, familial, and social domains resulted in reduced life quality for most survey respondents.

TABLE 6.9 Respondent ratings of items in the modified QCL scale

Quality of communication life scale					
	Strongly disagree	*Somewhat disagree*	*Neither agree nor disagree*	*Somewhat agree*	*Strongly agree*
I like to talk with people	7.1%	19.3%	9.6%	37.8%	26.2%
It's easy for me to communicate	14.5%	41.4%	14.4%	23.3%	6.4%
My role in the family is the same	30.3%	32.6%	7.5%	16.5%	13.1%
I like myself	17.1%	29.3%	18.9%	22.6%	12.1%
I meet the communication needs of my job or college	44.0%	25.3%	7.9%	18.6%	4.2%
I stay in touch with family and friends	9.7%	31.3%	10.9%	35.5%	12.6%
People include me in conversations	3.4%	18.1%	23.2%	37.6%	17.7%
I follow news, sports, and stories on TV/movies	10.0%	22.3%	12.2%	40.3%	15.2%
I use the telephone	7.1%	21.5%	10.3%	41.2%	19.9%
I see the funny things in life	4.7%	14.4%	14.7%	44.5%	21.7%
People understand me when I talk	1.7%	13.2%	12.5%	49.2%	23.4%
I keep trying when people don't understand me	2.9%	11.2%	11.6%	47.8%	26.5%
I make my own decisions	0.9%	9.4%	9.8%	38.6%	41.3%
I am confident that I can communicate	7.1%	28.7%	15.1%	34.9%	14.2%
I get out of the house and do things	48.8%	26.0%	7.1%	12.9%	5.2%
I have household responsibilities	11.2%	13.6%	8.4%	31.5%	35.3%
I speak for myself	0.4%	6.2%	9.9%	38.4%	45.1%
In general, my quality of life is good	33.7%	34.6%	11.7%	15.6%	4.4%

6.6 Discussion

The results of the survey combined with an examination of the personal narratives of adults with Long COVID reveal a high burden of communication disability amongst this population. The impact of this disability on functioning and quality of life is considerable. In this section, that impact is explored further by examining how adults with Long COVID perceive the consequences of their illness on communication and the implications of their communicative difficulties for their ability to work, maintain social relationships, pursue leisure activities, and fulfil family responsibilities. The sudden onset and persistent nature of communication problems led many participants to express concern about the medical causes of these problems and to voice anxiety about the likelihood of recovery. These understandable worries about their communication problems and what they may signal about future health are also explored.

A striking feature of adults with Long COVID is how perceptive these adults are about their language and communication difficulties. Many of these adults can give detailed accounts of specific language problems, such as word-finding difficulties, substitution and reversal of sounds, syllables, letters and words, sentence-processing problems, and written language difficulties (see Table 6.10). These accounts often state the exact contexts in which language and communication difficulties arise. Respondents were adept at describing the communicative partners who were present; compensations that were adopted (e.g., the use of mime); consequences of poor communication (e.g., not getting a job); and feelings that are triggered when communication is problematic (e.g., shame). Metaphorical descriptions were often used to capture the experience of poor communication, such as when a word-finding difficulty was described in the following terms: "It was as if the word was behind a wall." Linguistic features relating to meaning and grammar are skilfully captured, such as when a respondent expressed that she could not distinguish between the different (homonymous) senses of the word *bank*. The author's overall impression is that adults with Long COVID are not only keenly aware of their communication difficulties but that they are also able to characterise them in a range of sophisticated ways:

TABLE 6.10 Self-reported language and communication problems in Long COVID

Word-finding difficulties	
Woman: 54.8 years; 11.2 months post-onset: "My close friends and family are aware and are able to fill in the gaps or help me find the word that's just out of reach . . . When they say it, I recognise it immediately. My husband reminded	**Woman: 45.3 years; 15.2 months post-onset:** "I struggle to find the right words quite a lot. Yesterday, after I'd discovered I had missed last month's credit card payment, I said to my wife, 'What's the word for if you hope someone might choose to not

(Continued)

Word-finding difficulties

me that I mimed holding a phone to my ear two nights ago when I could not remember the word 'telephone.' I sometimes give a long-winded explanation of something in an attempt to remember the correct word."

Woman: 61.6 years; 7.5 months post-onset:

"At its worst, I couldn't even think of the word 'cat' to tell my husband what our cat was doing (he went blind through COVID). It was as if the word was behind a wall. That was very upsetting."

charge the default payment fee . . . What's the word for someone to say I won't have to pay it . . . The only word I can think of is 'sway' . . . Could they sway the payment . . . but I don't think that's the right word . . . or is it 'sway'? She very patiently said it's 'waive.' Of course it is! Not a difficult word!"

Woman: 64.3 years; 7.5 months post-onset:

"I have had to pause and allow other people to suggest the word I am so obviously looking for."

Substitution and reversal of sounds, syllables, letters, words

Woman: 61.6 years; 7.5 months post-onset:

"I remember distinctly typing a complete 7 letter word in reverse order without even thinking about it. I couldn't even do that normally (I'm a proficient touch typist)."

Woman: 45.6 years; 17.8 months post onset:

"I bought a new dishwasher, and when I was talking to my mum to tell her I was buying a silver one, I kept visualising silver but saying the word 'gold' to her."

Woman: 49.5 years; 11.2 months post onset:

"Sometimes I use words which are not words but vaguely sound like the word that I am trying to say. Sometimes I will say a word that rhymes with the word that I am trying to say."

Woman: 52.9 years; 7.4 months post-onset:

"I found after the first three to four months, I had almost forgotten how to speak. Didn't know until I started speaking – would stop, badly swap words around. Could not pronounce certain words at all. Swapping syllables."

Woman: 51.4 years; 8.9 months post-onset:

"Often type incorrect letter or words. Sometimes like dyslexia, sometimes completedly (sic) the wrong word."

Sentence-processing problems

Woman: 43.8 years; 8.6 months post-onset:

"It made me not be able to converse. I found it so difficult to understand what was being said to me. I couldn't begin to respond."

Woman: 58.3 years; 17.8 months post-onset:

"I had a job interview. Halfway through answering a question, I not only forgot what I was saying and the question. Needless to say, I didn't get the job."

(Continued)

Sentence-processing problems	
Woman: 49.5 years; 11.2 months post-onset: "I sometimes start a sentence somewhere in the middle and don't know how I'm going to finish it." **Woman: 59.8 years; 7.5 months post-onset:** "One example was when I had to call my works Pensions Dept regarding an early retirement application. I found it impossible to take in the information and had to ask them to slow down and even wait while I tried to process what they were telling me. I found I was unable to write down the information so in the end I had to make three separate calls asking just one or two questions at a time."	**Woman: 45.6 years; 7.6 months post-onset:** "I frequently mix up words at the end of sentences or if I have moved on to think about something else while completing the sentence." **Woman: 47.3 years; 17.1 months post-onset:** "I often mix up words or struggle to understand the correct meaning of a word in a conversation (e.g., when someone talks about a 'bank,' I am confused if it's a riverbank or an actual bank)."
Written-language difficulties	
Woman: 38 years; 6.8 months post-onset: "Writing is difficult. I make much more mistakes than usual, grammatical ones, but also just writing words I didn't want to write. Once I wrote to a friend I would come to her 'after eating my child' instead of 'giving him his dinner.'"	**Woman: 48.4 years; 12.1 months post-onset:** "Writing can have interesting consequences. It often seems completely lucid, sensible, and well-written. When looking back, it can be quite incredible what I have written. Sometimes a sentence doesn't make sense, but mostly it will be a case of missing out information and spelling, grammar, or punctuation mistakes. As an English teacher, this fills me with shame."

There is also a high level of awareness amongst adults with Long COVID that they are no longer able to cope with the communicative demands of their occupational roles, social relationships, leisure activities, and family responsibilities. Participants expressed this change in communicative performance in a wide range of ways, with statements often comparing language and communication skills in each of these domains *now* to how these skills were used *before* their COVID illness. The loss of language and communication skills required for employment was an area of particular concern for adults with Long COVID. Most of these adults are of working age. Many had demanding professional roles prior to their COVID illness, and the impact of their illness on their professional identity was keenly felt. Respondents expressed feelings of fear that their communication skills may never return. The communicative loss was characterised by one respondent as going from being "at the top of my game" to being "second or third division at best" (see Table 6.11).

The loss of social relationships and networks was a dominant theme, with many participants reporting that friends and family members no longer make contact or have reduced contact, possibly because the adult with Long COVID and communication difficulties is no longer fulfilling the needs of others. Consistent with the finding on the QCL Scale that 62.9% of respondents reported a change in their family role, participants reported an inability to fulfil normal parental duties like assisting children with homework and participating in parent-teacher evenings at their children's school. One participant reported how her husband "now has a different wife." Leisure activities such as sociable meals with

TABLE 6.11 Self-reported impact of communication difficulties on work, leisure, social relationships, and family responsibilities

Occupational roles
Woman: 31.5 years; 8.5 months post-onset: "I used to read for a living. Now I struggle if text is more than a paragraph. Typing is a struggle, and I misspell more."
Woman: 41.1 years; 16.2 months post-onset: "As a clinical lead in psychiatry, my job is all about talking, listening, reflecting, and evaluating – synthesising really pertinent information and making complex risk assessments. I'm terrified I will never get back to feeling fit enough to do this."
Man: 55.5 years; 18 months post-onset: "I'm used to working with plays from 16th/17th centuries, so am adept at 'difficult' language. I haven't tested this, but as with much else, I get the impression that I have gone from being right at the top of my game, as would be needed in my role as a teacher in a number of top schools (and with results to match), to being second or third division at best."
Woman: 45.3 years; 15.2 months post-onset: "With coaching clients, I am fully present and listen incredibly carefully – that's a key part of the job. I'm usually very good at then being able to go back to things they mentioned earlier (earlier that session or indeed a session many months earlier) and make connections, etc. But quite often at the moment, I'm not so able to do that."
Social relationships
Woman: 43.8 years; 8.6 months post-onset: "[Conversation is] too hard and confusing to do but craved social inclusion as felt so isolated."
Woman: 44.1 years; 10.8 months post-onset: "People do not have the same contact with me. I rarely hear from many of my friends or certain members of the family. Maybe it's because with my communication problems I no longer fulfil their needs."

(Continued)

Social relationships

Woman: 42.3 years; 15.2 months post-onset:

"I struggle to communicate with strangers and am more withdrawn than I was before."

Woman: 49.6 years; 7 months post-onset:

"From an extrovert, garrulous teacher who craved company and an audience to a reticent, hermetic recluse with a vow of silence, seeking peace, who has lost their exuberant confidence and now feels a sense of vulnerability in social settings."

Leisure activities

Woman: 55.5 years; 22.3 months post-onset:

"I also used to be an avid reader, reading at least a book a week, but no longer read at all."

Woman: 44.1 years; 10.8 months post-onset:

"This is something I miss, a sociable meal with my husband and children and with our friends/family and their children."

Woman: 37.2 years; 9.3 months post-onset:

"I find myself zoning in and out of films. I tend to miss things these days and have to rewind and rewatch as I've missed key points. I have also noticed that if I can't lip-read the person speaking, I struggle to keep up and follow the conversation."

Woman: 40.9 years; 18.4 months post-onset:

"I don't watch difficult films or series for the moment, making it easy for myself to follow. If it's too difficult, I find myself scrolling back several minutes to see it again to understand. Worst case it has been that I had to do that three to four times."

Family responsibilities

Woman: 45.6 years; 7.6 months post-onset:

"[I] find I have 'tuned out' of conversations, e.g., in the car when child telling me about the day at school."

Woman: 44.1 years; 10.8 months post-onset:

"My family have been affected the most, my kids have a different mum, my husband now has a different wife."

"I've struggled to even attend a parents evening on Zoom. I can't focus on the screen, process the words being said, or respond appropriately."

"Of all the things Long COVID has taken away from me, it's the ability to speak properly after an evening meal. An evening meal has always been a family time for us to share what's happened in the day. The energy involved in digestion affects my cognitive ability and language. Therefore, I am unable to speak after we've eaten food."

"Homeschooling was horrendous. I couldn't even read words. I was blending words like a child. Long COVID has affected my ability to read. I can no longer help my children with their homework."

other families, reading for relaxation, and watching films with complex plot lines were also reported to be compromised by communication difficulties in Long COVID (see Table 6.11).

Many adults with Long COVID expressed anxieties about the medical causes of their communication problems. The onset of language and communication

TABLE 6.12 Self-reported medical concerns relating to communication problems

Stroke	*Dementia*
Woman: 49.6 years; 15.5 months post-onset: "In October [2020] I had some type of extreme event, but a stroke was ruled out. This is where all the language problems started to happen. I lost the ability to communicate for around 18 hours. This just wasn't finding words – I had no language or comprehension of language at all."	**Woman: 41.1 years; 16.2 months post-onset:** "It feels like some sort of dementia, like bits of my brain that used to/should work just don't anymore."
	Woman: 56.4 years; 8.3 months post-onset: "I sometimes felt that I had dementia as could not remember what I was trying to say."
Woman: 49.6 years; 7 months post-onset: "Is this what dementia or a stroke feels like? Is this the lived experience of someone with autism?"	**Woman: 43.8 years; 8.6 months post-onset:** "The neurological symptoms which mimic dementia, autism, MS, and others are very worrying."

difficulties was sudden for some of these adults. This led to a concern that they had sustained a stroke. For other adults, the loss of language and communication skills created an anxiety that they were developing dementia or another neurological disorder. Most adults with Long COVID had received an extensive range of medical investigations, including MRI and CT scans, ECGs, blood tests, and X-rays. With few exceptions, these investigations produced normal results. The lack of medical explanation of the language difficulties that these adults experienced gave rise to concerns that their communication problems may be permanent in nature and may indicate a poor long-term prognosis for their health (see Table 6.12).

The significant impact of communication problems in Long COVID on the four domains of employment, social relationships, leisure, and family responsibilities culminated in a marked reduction in quality of life. Participants expressed this reduction through their responses to the survey and in their personal narratives. Only 20% of those who responded to the items in the QCL Scale reported that their quality of life was good. The personal narratives of adults with Long COVID vividly captured this reduced quality of life. There was a profound sense of loss of the once-fulfilling lives that had been taken away by Long COVID and its accompanying communication problems. The core of one's being, expressed in terms of "purpose and identity" and "soul," had been torn apart. No part of one's existence was untouched by Long COVID and the impairments of language and communication that affected many of those with the condition. Long COVID had truly destroyed people's lives, with many individuals fearing that they might never make a full recovery (see Table 6.13).

TABLE 6.13 Self-reported quality of life in adults with Long COVID

Quality of life
Woman: 49.6 years; 7 months post-onset: “To have your son with autism with whom you’d done intensive interaction, PECS, and Makaton gaze at you perplexed as you struggle to sign “I can’t talk” whilst bedridden tore my soul in two. To then experience slurring and stuttering, word loss, to feel as if your IQ dropped.”
Woman: 44.1 years; 10.8 months post-onset: “Long COVID and my communication problems have affected every part of my life. They have taken away everything I had [. . .] This has had a massive impact on my life, taken away my purpose and identity.”
Man: 55.5 years; 18 months post-onset: “I am certainly not what I was prior to early 2020, and the nature of my hearing and communication issues have affected my quality of life substantially.”

6.7 Implications

This chapter has presented evidence of a significant burden of communication difficulties in adults with Long COVID. These difficulties have impacted employment, social relationships, leisure activities, and family responsibilities and have served to reduce quality of life in these adults. Long COVID presents unique challenges for agencies that must address the ongoing health and economic needs of people with this condition. This section briefly considers ways in which health service providers and employers can support adults with Long COVID who experience communication difficulties as part of their condition.

Long COVID clinics: Health systems around the world are increasingly recognising the complex medical needs of clients with Long COVID. Many have established dedicated Long COVID clinics.[1] In the UK, there are 90 post-COVID assessment clinics under the auspices of the NHS (National Health Service 2022). Similar Long COVID clinics are also operating in several countries across the European Union (Baraniuk 2022). These clinics are typically staffed by specialists in respiratory medicine, infectious diseases, and paediatrics. However, speech and language therapists have not to date been consistently part of the multidisciplinary teams that assess and treat people with Long COVID (Royal College of Speech and Language Therapists 2021). The inclusion of speech and language therapy (SLT) in multidisciplinary teams that manage the health needs of people with Long COVID is one of eleven recommendations in a report published by the Royal College of Speech and Language Therapists in the UK in 2021. Other recommendations include the need to upskill the SLT workforce to address the communication and swallowing problems of this new group of clients and to conduct research into the presentation of COVID-19 and Long COVID in the community (non-hospitalised patients). The combined aim of these recommendations is to ensure that any person with communication and swallowing needs after COVID-19 receive "timely, person-centred rehabilitation" that will "support and maximize their mental health and wellbeing, participation in society, and ability to return to work" (RCSLT 2021, p. 19). The extent to which this aim can be achieved depends ultimately on funding, both of Long COVID recovery services but also regular SLT services that have experienced significant backlogs due to the pandemic.

Return to work: The non-linear recovery of people with Long COVID presents unique challenges for occupational health and human resource professionals who must manage return to work for people with this chronic condition. People with Long COVID may return to work for days or weeks in some cases, only to experience a significant relapse in their condition that requires them to take a further period of sickness absence. Phased returns that facilitate work re-entry for people with other health conditions are often of an intensity and duration that exceed the physical and cognitive capacities of people with Long COVID. These issues are not lost on the Royal College of Speech and Language Therapists in the UK. It calls on speech and language therapists to make the wider public and other health and care professionals aware of the communication and swallowing problems experienced by people with Long COVID and of the implications of these problems for work re-entry. The College's eleventh recommendation in its 2021 report states that "[m]ore information needs to be provided specifically on the impact of Long COVID and implications for people returning to work" (RCSLT 2021, p. 20).

There is clearly a job of work to be done to encourage better understanding amongst occupational health and human resource professionals of how communication problems affect return to work for people with Long COVID. One 44-year-old woman with significant communication difficulties studied by the author (Cummings 2021b) received excellent support from her occupational health consultant, remarking, "I continue to be really well supported by Dr XXX. I genuinely would not be getting through this without him." Her experience is far from universal, however. The author studied a 49-year-old woman who had marked communication difficulties following COVID-19. She described her treatment by her human resources department in the following terms:

> I expected support and empathy at a raw, vulnerable moment. Their belittling tone, aggressive agenda, and patronisation when I couldn't express myself without word loss was highly insensitive and haunting. Tears of frustration at speech loss were perceived as a histrionic expression of stress. I felt invisible, humiliated, unheard, and alone.

To ensure a high standard of support for people with Long COVID, the Chartered Institute of Personnel and Development (CIPD) recently published a report in which it made several recommendations to assist employees with Long COVID in returning to work (CIPD 2022). These recommendations can be implemented by

individual employees, ***g***roups, ***l***ine managers, ***o***rganisations, and ***o***utside resources (the IGLOO framework). By avoiding barriers and encouraging facilitators at each of these levels, the CIPD argues that a successful return to work can be navigated by people with Long COVID. A communication-related facilitator at the group level, for example, is to take conversations at an employee's pace.

6.8 Summary

This chapter has examined the impact of Long COVID on language and communication skills and the effect of impairment of these skills on daily functioning and quality of life in people with this chronic condition. Drawing on evidence from an online survey and personal narratives of adults who have not made a good recovery from their COVID illnesses, the chapter has demonstrated that there is a significant burden of communication disability in adults with Long COVID. Moreover, this disability compromises functioning in a range of areas, including work, social relationships, leisure activities, and family responsibilities. The combined effect of reduced participation in these areas of functioning is a marked reduction in the quality of life of people with Long COVID. The chapter concludes by recommending a prominent role for speech-language pathology in the rehabilitation of people with Long COVID and for increased awareness amongst occupational health and human resource professionals of how communication difficulties can affect return to work for adults with this condition.

Note

1. It is worth remarking that access to these clinics, even when they do exist, has been patchy at best. As one 55-year-old man from the UK remarked in my study, "I have given up on my Long COVID referral ever leading to anything."

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APPENDIX

BOX 6.1: TEST ITEMS USED IN THE QUALITY OF COMMUNICATION LIFE SCALE

Item #	*Item*	*Score*
1.	I like to talk with people.	___________
2.	It’s easy for me to communicate.	___________
3.	My role in the family is the same.	___________
4.	I like myself.	___________
5.	I meet the communication needs of my job or school.	___________
6.	I stay in touch with family and friends.	___________
7.	People include me in conversations.	___________
8.	I follow news, sports, and stories on TV/movies.	___________
9.	I use the telephone.	___________
10.	I see the funny things in life.	___________
11.	People understand me when I talk.	___________
12.	I keep trying when people don’t understand me.	___________
13.	I make my own decisions.	___________
14.	I am confident that I can communicate.	___________
15.	I get out of the house and do things.	___________
16.	I have household responsibilities.	___________
17.	I speak for myself.	___________
18.	In general, my quality of life is good.	___________

BOX 6.2: ONLINE SURVEY ADMINISTERED TO ADULTS WITH LONG COVID

Cognitive-linguistic difficulties in adults with COVID-19

You are invited to participate in a study conducted by Professor Louise Cummings who is a staff member of the Department of English and Communication in The Hong Kong Polytechnic University. The project has been approved by the Human Subjects Ethics Sub-Committee (HSESC) (or its Delegate) of The Hong Kong Polytechnic University (HSESC Reference Number: HSEARS20210712001).

The aim of this study is to understand the impact of the SARS-CoV-2 virus on language and communication in adults with COVID-19 infection. In the following questionnaire, you will be asked to provide some personal information such as your date of birth and educational background. You will also be asked questions about your COVID illness and its impact on your communication skills. The responses require you to tick boxes and enter numbers to grade statements. The entire questionnaire can be completed in under 15 minutes and will not cause you any discomfort or psychological stress. All information related to you will remain confidential and will be identifiable by codes only known to the researcher.

To participate in this study, you must satisfy the following criteria:

- You must be 18 years of age or older.
- You must have had COVID-19 confirmed through testing (PCR test or antibody test) ***or*** have received a clinical diagnosis of COVID-19.
- You must have experienced Long COVID, defined as the persistence of COVID symptoms beyond 3 months from the onset of illness.
- You must have experienced cognitive-linguistic difficulties (so-called “brain fog”) as part of your Long COVID.

To give your consent to participate in the study, please tick the boxes next to each of the following statements:

- I satisfy the criteria required for participation in this study ☐
- I give my consent to participate in this study ☐

If you would like to obtain more information about this study, please contact me at any time by email (louise.cummings@polyu.edu.hk) or telephone on (852) 2766 7978.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Miss Cherrie Mok, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in writing (c/o Research Office of the University), stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Thank you for your interest in participating in this study.

Professor Louise Cummings
Principal Investigator

Date of birth: ☐

Gender: ☐ male ☐ female

Ethnicity: ☐ White: British ☐ White: Irish ☐ White: Other
☐ Black: British ☐ Black: Other
☐ Asian: Indian ☐ Asian: Pakistani ☐ Asian: Bangladeshi
☐ Asian: Chinese ☐ Asian: Other
☐ Mixed or Multiple Ethnicities ☐ Other Ethnic Group

Education:
☐ Primary and secondary education only
☐ University undergraduate degree
☐ University higher degree

Employment before COVID-19 illness:
☐ Employed full-time ☐ Employed part-time ☐ Unemployed
☐ Not working due to retirement ☐ Not working due to disability
☐ Student ☐ Other

Which of the following best describes your use of English?
☐ I speak English as a native or first language
☐ I speak English as a second language
☐ I speak English as a third language

Which of the following describes your physical health **before** COVID-19?
☐ Excellent ☐ Good ☐ Poor

Which of the following describes your mental health **before** COVID-19?
☐ Excellent ☐ Good ☐ Poor

Which of the following describes your spoken communication skills **before** COVID-19?

☐ Excellent ☐ Good ☐ Poor

Which of the following describes your written communication skills **before** COVID-19?

☐ Excellent ☐ Good ☐ Poor

Before developing COVID, my preferred method of communication with others was:

☐ phone calls ☐ texts ☐ emails
☐ video calls ☐ social media ☐ face-to-face communication

When did you first develop symptoms of COVID-19? Please try to give a specific date. ☐

Which of the following categories applies to you? Please tick as many boxes as necessary:

☐ Clinical diagnosis of COVID-19
☐ Positive PCR test
☐ Positive antibody test

Which of the following describes your physical health **following** COVID-19?

☐ Excellent ☐ Good ☐ Poor

Which of the following describes your mental health **following** COVID-19?

☐ Excellent ☐ Good ☐ Poor

Which of the following describes your spoken communication skills **following** COVID-19?

☐ Excellent ☐ Good ☐ Poor

Which of the following describes your written communication skills **following** COVID-19?

☐ Excellent ☐ Good ☐ Poor

Which of the following categories applies to you currently?

☐ Employed full-time ☐ Employed part-time ☐ Unemployed
☐ Not working due to retirement ☐ Not working due to disability
☐ Student ☐ Other

Are you currently experiencing Long COVID? ☐ Yes ☐ No

Are you currently under medical supervision for Long COVID?

☐ Yes ☐ No

Have you had brain fog as part of Long COVID? ☐ Yes ☐ No

Which of the following describes your brain fog **at its worst**?

☐ Severe ☐ Moderate ☐ Mild

Which of the following describes your brain fog **currently**?

☐ Severe ☐ Moderate ☐ Mild

Which of the following statements applies to your brain fog? Please tick as many boxes as necessary:

☐ I struggle to find words
☐ I struggle to produce utterances and sentences
☐ I mix words up and produce incorrect words
☐ I find reading difficult
☐ I find writing difficult
☐ I struggle to understand what people are saying
☐ I lose concentration easily when talking to others
☐ I veer off topic in conversation and cannot get back
☐ I forget what I wanted to say
☐ I cannot recall what has been said earlier in conversation
☐ I cannot recall what has been said in conversation after it has taken place
☐ I communicate less frequently with others since developing COVID
☐ I have less desire to communicate with others since developing COVID
☐ I feel embarrassed by my communication skills since developing COVID
☐ I feel frustrated by my communication skills since developing COVID

Since developing COVID, my preferred method of communication with others is:

☐ phone calls ☐ texts ☐ emails
☐ video calls ☐ social media ☐ face-to-face communication

Quality of Communication Life Scale*

Is today an especially good, average, or especially bad day for you?

☐ Especially good ☐ Average ☐ Especially bad

Before reading each of the following statements, ask yourself "Even though I have difficulty communicating after COVID. . . . " Then rank each statement from 1 (strongly disagree) to 5 (strongly agree) or indicate "does not apply":

☐ I like to talk with people
☐ It's easy for me to communicate
☐ My role in the family is the same
☐ I like myself
☐ I meet the communication needs of my job or college (such as typing, giving and following directions, reading)

☐ I stay in touch with family and friends
☐ People include me in conversations
☐ I follow news, sports, and stories on TV/movies
☐ I use the telephone
☐ I see the funny things in life
☐ People understand me when I talk
☐ I keep trying when people don't understand me
☐ I make my own decisions
☐ I am confident that I can communicate
☐ I get out of the house and do things (such as sports, dinner, shows, parties)
☐ I have household responsibilities (such as shopping, cooking, home repairs)
☐ I speak for myself
☐ In general, my quality of life is good

* Items in this section are adapted from the following: Paul, D. R., Frattali, C. M., Holland, A. L., Thompson, C. K., Caperton, C. J., & Slater, S. C. (2004) *Quality of Communication Life Scale*. Rockville, MD: American Speech-Language-Hearing Association.