



Original research

# Using qualitative free-text data to investigate the lived experience of the COVID-19 pandemic for a large cohort of Australians with different multiple sclerosis related disability levels

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## ABSTRACT

**Background** No large-scale qualitative studies have investigated the lived experience of people living with multiple sclerosis (PwMS) during the pandemic according to their disability level. We used qualitative research methods to investigate the lived experience of a large cohort of Australians living with differing multiple sclerosis (MS)-related disability levels during the COVID-19 pandemic. We also provided useful contextualisation to existing quantitative work.

**Methods** This was a retrospective survey-based mixed-methods cohort study. A quality-of-life study was conducted within the Australian MS Longitudinal Study during the pandemic. Disability severity was calculated using the Patient Determined Disease Steps. Qualitative free-text data regarding COVID-19 impacts was collected/analysed for word frequency and also thematically (inductively/deductively using sophisticated grounded theory) using NVivo software. We also triangulated word frequency with emerging themes.

**Results** N=509 PwMS participated providing n=22 530 words of COVID-19-specific data. Disability severity could be calculated for n=501 PwMS. The word 'working' was important for PwMS with no disability, and 'support' and 'isolation' for higher disability levels. For PwMS with milder disability, thematic analysis established that multitasking increased stress levels, particularly if working from home (WFH) and home-schooling children. If not multitasking, WFH was beneficial for managing fatigue. PwMS with severe disability raised increased social isolation as a concern including prepandemic isolation.

**Conclusions** We found negative impacts of multitasking and social isolation for PwMS during the pandemic. WFH was identified as beneficial for some. We recommend targeted resourcing decisions for PwMS in future pandemics including child-care relief and interventions to reduce social isolation and suggest that these could be incorporated into some form of advanced care planning. As the nature of work changes postpandemic, we also recommend a detailed investigation of WFH for PwMS including providing tailored employment assistance.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ No large-scale studies exist that use qualitative research methods to investigate the thoughts and feelings of people living with multiple sclerosis (MS) with differing disability levels during the COVID-19 pandemic.

## WHAT THIS STUDY ADDS

⇒ Using rich qualitative data, this study provides a contextualisation to inconclusive quantitative studies, particularly regarding the psychosocial impacts of the COVID-19 pandemic for PwMS according to their disability level. The study also builds on the findings of existing exploratory qualitative studies.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Key findings include the negative impacts of multitasking for PwMS during the pandemic when they were working from home (WFH) and managing other caring responsibilities, particularly for school-aged children. Social isolation for people with higher disability levels was a concern and it also highlighted pre-existing social isolation for these PwMS. WFH for some PwMS was also identified as beneficial for managing their fatigue levels. We suggest that forms of advanced care planning with healthcare providers could address social isolation concerns for people with more severe forms of disability. We also suggest that WFH arrangements be explored with tailored employment assistance.

## INTRODUCTION

In the third year of the COVID-19 pandemic, where we have observed new COVID-19 variants, increased vaccination rates and the easing of COVID-19-related restrictions in many jurisdictions, the work of several *quantitative* studies indicates that the protracted nature of the pandemic has resulted in diminished mental and physical health for people living with multiple sclerosis (PwMS).<sup>1,2</sup> A recent systematic review

conducted by our group investigated quantitative survey-based studies regarding the psychosocial health impacts among PwMS during COVID-19 and the pandemic's associated lockdowns.<sup>1</sup> We found that the main diminished mental health outcomes were depression, anxiety, stress, sleep quality and therefore reduced health-related quality of life.<sup>1</sup> However, this review also suggested that the current quantitative evidence was not conclusive due to methodological issues encountered when attempting to compare with pre-pandemic levels of, for example, anxiety and depression. The review also suggested that future research could examine the methodological issues and outcomes.<sup>1</sup> Importantly, qualitative research could address these quantitative evidence gaps, as qualitative research methods can provide contextualisation and nuance to quantitative findings.<sup>3</sup> More specifically, the use of qualitative research methods can improve practice in study design, reporting and ultimately, research translation. Additionally, health policy development, research and management can benefit from more in-depth, textured descriptions of what happens in practice settings, healthcare markets and patients' lives.<sup>3–5</sup> Further, healthcare resource allocation decisions should be informed with robust qualitative and quantitative evidence regarding the things that matter to patients with respect to high value care.<sup>6</sup>

Despite the increasing prevalence of multiple sclerosis (MS) in Australia and worldwide,<sup>7,8</sup> few studies have adopted qualitative research methods to investigate the lived experience of PwMS (ie, thoughts and feelings expressed in their own words) during the COVID-19 pandemic. Existing qualitative studies regarding the impact of the COVID-19 pandemic for PwMS have generally investigated small samples and narrow research questions or have adopted a mixed-methods approach where the qualitative data have only supplemented the quantitative findings. For example, one Australian study interviewed eight PwMS to elucidate their experiences of accessing healthcare during the pandemic.<sup>9</sup> Another international study that examined health impacts of the COVID-19 pandemic for PwMS adopted a mixed-methods approach, with the quantitative survey data being the focus and some verbatim quotes of free-text data supporting the quantitative findings.<sup>10</sup> Another qualitative study based in the UK conducted individual interviews for PwMS with severe disability and their families (early in the pandemic and before lockdowns occurred) explored the concept of Advanced Care Planning (ACP).<sup>11</sup> Key findings of this study included: that many participants wanted to engage in ACP, often in concert with their families (although with some caveats); that their accounts are nuanced and sometimes contradictory reflecting the complexities of ACP; and that this situation can often be amplified with neurodegenerative conditions like MS.<sup>11</sup>

Therefore, the rationale for our study is twofold. The first is against the backdrop of a lack of conclusive synthesised quantitative evidence and standalone qualitative studies of a sufficient sample size about PwMS during the COVID-19 pandemic. Despite the lack of qualitative evidence from studies of sufficient sample size, the second rationale is to examine some of the findings of these smaller exploratory studies in comparison to our study. Therefore, we aimed to investigate the impact of the pandemic on the lived experience of PwMS in a large cohort of Australians living with varying levels of MS-related disability. We analysed the data grouped by disability level (none, mild, moderate or severe) and compared and contrasted themes between groups. Further, we also triangulated word frequency

of the qualitative data with common themes to gain a deeper understanding of the participants' lived experiences.

## METHODS

### Study design, validated guidelines and data sources

This was a retrospective survey-based mixed-methods cohort study. We adopted validated guidelines for mixed-methods studies including the Standards for Reporting of Qualitative Research<sup>12</sup> and the Big Tent Criteria for Qualitative Quality<sup>13</sup> (online supplemental table 1). Qualitative data and quantitative data (except education level) were sourced from the Australian MS Longitudinal Study (AMSLS) 2020 Quality of Life Survey (2020QoL). The AMSLS survey-based cohort study commenced in 2002 and has been shown to be nationally representative.<sup>14</sup> Recruitment to the study is ongoing, with all participants required to provide informed consent prior to admittance. The AMSLS currently includes over 2600 active participants (defined as PwMS who have completed a survey in the past 2 years), with an estimated 96% of participants diagnosed with MS by neurologists in accordance with the McDonald criteria.<sup>15</sup>

The 2020QoL included six quantitative quality of life survey instruments and bespoke COVID-19 questions quantitatively assessing the impact of COVID-19 on living arrangements, ability to deal with daily life, relationships, emotional well-being, ability to maintain activities of daily living, ability to maintain personal financial circumstances and income.<sup>16</sup> Within the context of the 2020QoL quantitative surveys and a detailed Participant Information Sheet that provided additional context, the 2020QoL Study Questionnaire included a free-text qualitative question regarding COVID-19 to further explore and understand the thoughts and feelings of PwMS across differing disability categories during the COVID-19 pandemic. This question was: "Would you like to provide any other information on your physical and emotional circumstances regarding the COVID-19 pandemic?" The word limit for the free-text responses was not constrained. All free-text qualitative data were deidentified with a unique researcher identification number as required by the strict data management protocols of the AMSLS.

The 2020QoL also gathered sociodemographic and clinical data, including age, sex, MS phenotype (relapsing remitting MS; secondary progressive MS; progressive relapsing MS; unsure), number of MS relapses and the Patient Determined Disease Steps (PDDS) for the calculation of disability severity levels (see the Quantitative analysis section regarding disability severity calculation). Education level was sourced from AMSLS Disease Course surveys for 2019 and 2020 and classified as follows: secondary or less, occupation certificate or diploma, bachelor's degree and postgraduate degree.

### Quantitative analysis

We present categorical sociodemographic and clinical variables using frequencies and percentages and continuous variables using means and standard deviations (SD). We used NVivo software<sup>17</sup> to analyse the word frequencies in the free-text data, both in the total sample and within disability severity groups. The weighted frequency proportion for the word frequency count was calculated using the frequency of the word relative to the total words counted where 500/5 was selected as the most frequent/minimum length for exact matches for the word.<sup>17</sup>

Disability level was calculated using the PDDS and was mapped onto the Expanded Disability Status Scale (EDSS) based on the system developed by Kobelt *et al.*<sup>18</sup> Disability severity was ranked as follows: PDDS of 1=no disability, PDDS of 2 or 3=mild, PDDS of 4 or 5=moderate and PDDS

of 6 through 8=severe. Participants reporting a PDDS of 9, indicating substantial and debilitating sensory, rather than ambulatory, symptoms were categorised as having mild disability level.

### Qualitative analysis

Qualitative content analysis of the free-text data was conducted by two authors (JAC and SBC) and common themes were discussed with the broader coauthorship team. More specifically, the first and senior authors discussed the emerging themes and notes were kept to inform further coding and exploration of the data, taking into account the pre-existing academic backgrounds of the two authors (economics, natural science, epidemiology and nursing) including wide-ranging research in MS. In regard to the broader authorship team, discussions regarding emergent themes were explored at weekly group meetings to develop a deeper understanding and nuance to the emerging themes also taking into account the academic background of the broader authorship team and meeting colleagues (neurology, epidemiology, genomics, health economics, nursing, psychology), and their personal experiences including caring and supporting people with complex and chronic disease and some PwMS.

More specifically, the deidentified free-text data were analysed verbatim with the assistance of NVivo software.<sup>17</sup> We conducted inductive and deductive thematic analysis underpinned by sophisticated grounded theory, where data are repeatedly tested against pre-existing theories<sup>19–22</sup> More specifically, we used a combination of inductive and deductive qualitative theory building, where themes emerge from the data influenced by pre-existing theory. The process of theory-building involves an ongoing dialogue between data and pre-existing theory in which theories are repeatedly tested against the data.<sup>3</sup> The concept of externalities<sup>23</sup> was adopted for the pre-existing theory, including employment impacts and social isolation impacts due to the pandemic.

For the first phase of analysis, common themes were identified for each disability level. For the second phase of the analysis, we compared the common themes within each disability level to investigate similarities and differences for people with no or mild disability compared with those with moderate or severe disability. Finally, we also triangulated qualitative data with word frequencies to provide a deeper contextualisation and nuance to the emergent themes.

## RESULTS

### Flow of participants into the study

Figure 1 illustrates the flow of participants into this study. The 2020QoL was distributed to 2513 active AMSLS participants (1882 online and 631 paper-based), 1683 people responded to the survey and of these, 509 PwMS provided relevant free-text data regarding their lived experience of COVID-19. Of these, we could generate a disability level for 501 participants. Online supplemental table 2 provides comments from PwMS for whom we could not generate a disability level (n=8).

### Participant characteristics

Table 1 provides participant characteristics. We found some differences between PwMS who provided optional free-text data regarding their lived experience of the COVID-19 pandemic and those who did not. Those who provided free-text data were more likely to be exposed to lockdowns (+9.9%), more likely

to be female (+8.0%) and were more likely to have relapsing onset MS (+7.9%) (table 1). They also had a higher education level, were more likely to be employed and were more likely to experience a moderate disability level.

### Word frequencies

The 509 PwMS with free-text data provided 22 563 words for analysis. The number of words were provided by participants at each disability level closely reflected the group size: PwMS with no disability (23.2% of the group with free-text data) provided 21% (4758) of the words; PwMS with mild disability (22.2%) provided 26% (5795) of the words; PwMS with moderate disability (36%) provided 36% (8184) of the words and PwMS with severe disability (17.1%) provided 17% (3826) of the words.

Table 2 provides the word frequency rated scores and rankings by disability level. The top 12 word frequencies (excluding 'COVID-19' and 'pandemic' to examine the top 10) differed somewhat between people with no, mild or moderate disability compared with people with severe disability. The word 'working' (related to employment status) was in the top 10 words used by people with no, mild or moderate disability, but did not score for people with severe disability. Additionally, the words 'support' and 'isolated' rated in the top 10 words for people with severe disability but not for people with no, mild or moderate disability. However, there were similarities as well. The words 'family' and 'friends' scored in the top 10 weighted word frequency scores for all disability categories (table 2).

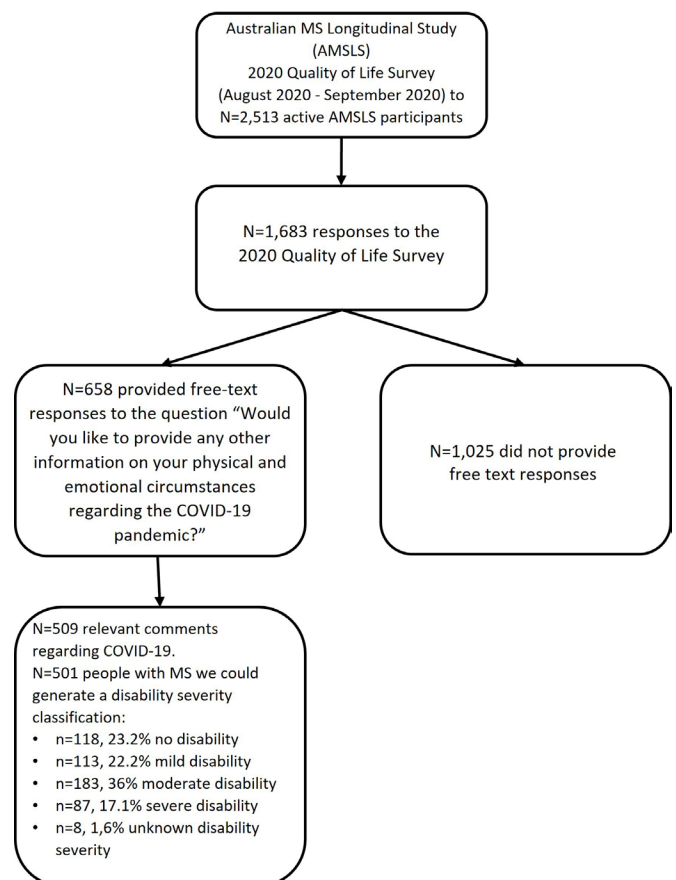


Figure 1 Flow of participants living with MS into the study according to their disability severity classifications. MS, multiple sclerosis.

**Table 1** Participant characteristics of people who provided qualitative free-text data regarding COVID-19 compared with people who did not provide qualitative free-text data regarding COVID-19

	Provided qualitative data	Did not provide qualitative data
Total participants, N (% of total)	509 (20.3)	2004 (79.7)
Mean age, years (SD)	58.2 (11.5)	57.9 (11.6)
Sex (female), n (% of subgroup)	436 (85.7)	1557 (77.7)
Employment status, n (% of subgroup)		
Employed	161 (31.6)	511 (25.5)
Unemployed	250 (49.1)	822 (41.0)
Unknown	98 (19.3)	671 (33.5)
MS phenotype, n (% of subgroup)		
Progressive onset	119 (23.4)	455 (22.7)
Relapsing onset	341 (67.0)	1185 (59.1)
Unknown	49 (9.6)	364 (18.2)
Education, n (% of subgroup)		
Secondary or less	105 (20.6)	491 (24.5)
Occupational certificate/diploma	187 (36.7)	589 (29.4)
Bachelor's degree	101 (19.8)	408 (20.4)
Postgraduate degree	114 (22.4)	290 (14.5)
Unknown	2 (0.4)	226 (11.3)
Disability severity, n (% of subgroup)		
Nil	118 (23.2)	434 (21.7)
Mild	113 (22.2)	455 (22.7)
Moderate	183 (36.0)	581 (29.0)
Severe	87 (17.1)	309 (15.4)
Unknown	8 (1.6)	225 (11.2)
SEIFA, n (% of subgroup)		
Quartile 1	120 (23.6)	522 (26.0)
Quartile 2	124 (24.4)	511 (25.5)
Quartile 3	142 (27.9)	497 (24.8)
Quartile 4	120 (23.6)	465 (23.2)
Unknown	3 (0.6)	9 (0.4)
Exposed to lockdown, n (% of subgroup)	144 (28.3)	369 (18.4)

MS, multiple sclerosis; SEIFA, Socio-economic indexes for areas.

### Qualitative analysis of emergent themes

Table 3 provides a selection of verbatim quotes from the thematic analysis that identified themes around employment, multitasking, emotions, finances and social isolation. In summary, our thematic analysis found that there were differences between disability levels around the issues raised, how frequently an issue was raised, and some of the perceived 'positive aspects' of COVID-19 regarding social distancing and lockdown that were observed. For example, comments regarding a change in routine, including the routine of employment and the concomitant multitasking with young children at home and/or negative financial impacts, were more prevalent in those with no disability, compared with those with a severe disability. On the other hand, social isolation was a common theme in those with moderate and severe disability compared with those with no disability or mild disability. Social isolation encompassed both increasing isolation and the maintenance of pre-existing social isolation. For the milder disability groups, social isolation was largely related to missing family and friends. Another common theme was negative emotions, including sadness, isolation and anxiety, about the lack of face-to-face contact with immediate and extended family, and friends. Another common theme across all disability levels was being worse

off financially, including some PwMS forced to take salary reductions and others needing to access superannuation. More people in the milder disability categories indicated that salary cuts were detrimental. Due to government supplementation of their income, some people in the mild, moderate and severe disability levels indicated that they were better off in the short term; this was not evident for PwMS with no disability.

Participants also described some positive impacts. Some people indicated that they had improved fatigue levels as a result of working from home (WFH) and not needing to commute to work. This was more relevant for those with no, mild or moderate disability levels. The next sections provide additional detail regarding these summarised findings.

### Employment and multitasking for people with lower disability levels

The main theme that emerged for PwMS with no disability was managing changes in established routine, particularly in relation to employment and/or child-rearing (essentially multitasking), and not being able to have face-to-face contact with family and friends. Regarding employment, 30.5% of people with no disability mentioned employment as an issue compared with 4.5% of people with severe disability (also supported by the word frequency data (table 2), with many PwMS in the no disability category dealing with WFH and either home-schooling children or not having childcare support for non-school aged children. Most PwMS with no disability who raised this said that they found this multitasking stressful. To illustrate, one person said that:

Both my husband and I are working full time. He leaves the house and I am here trying to keep 3 kids motivated during home schooling. It has been very stressful for all. Worried about my job, working too long to try and make sure I don't lose my job and feeling terrible that I can't help the kids do their lessons more. Becoming totally overwhelming for all. (female, no disability)

Similarly, another PwMS in the no disability category mentioned the 'emotional drain' from multitasking with work and children at home:

Emotional drain from home schooling kids while also working 40+ hours at home with little support. (female, no disability)

Where multitasking was not required, benefits were observed regarding WFH, including increased time in the day and the alleviated pressures of commuting leading to reduction in fatigue levels. Some PwMS in the no to moderate disability levels said:

Better able to manage fatigue without the pressures of commuting. (female, no disability)

It has been convenient to work from home in terms of less travel time needed. I feel that this has had a positive impact on my fatigue levels. (female, mild disability)

Flexible working arrangements have allowed me to better manage my sleep and not having to commute leaves me with more energy for other tasks. (female, moderate disability)

### Social isolation for people with higher disability levels

The common theme for PwMS with more severe disability was managing increased feelings of social isolation and this was supported by the word frequency data with the word 'isolated' only ranking in the top 10 for people with severe disability which led us to explore this in detail in the thematic analysis (table 2). Almost 50% of people with moderate and severe disability reported this, compared with just over 30% of people with no or mild disability (table 3). People

**Table 2** Top 10 word frequency rated scores and rankings for people with MS classified with the Expanded Status Disability Scale disability severity categories of no disability (n=118), mild disability (n=113), moderate disability (n=183) and severe disability (n=87)

Word	No disability weighted score	No disability rank	Mild disability weighted score	Mild disability rank	Moderate disability weighted score	Moderate disability rank	Severe disability weighted score	Severe disability rank
covid	1.65	1	2.00	1	1.72	1	1.95	1
family	1.09	2	0.95	2	0.78	2	1.32	2
working	0.95	3	0.43	12	0.45	9	–	–
people	0.78	4	0.49	11	0.71	3	0.58	5
impact	0.61	5	–	–	–	–	–	–
social	0.61	6	0.53	9	0.48	6	–	–
emotional	0.56	7	–	–	–	–	–	–
friends	0.56	8	0.67	3	0.58	5	0.47	8
lockdown	0.56	9	–	–	–	–	0.58	4
pandemic	0.56	10	0.53	7	0.45	7	0.68	3
visit	0.56	11	–	–	–	–	–	–
going	0.52	12	–	–	–	–	–	–
health	–	–	0.63	4	0.43	11	0.53	7
income	–	–	0.63	5	–	–	0.42	10
difficult	–	–	0.53	6	–	–	–	–
physical	–	–	0.53	8	–	–	–	–
children	–	–	0.49	10	–	–	–	–
unable	–	–	–	–	0.68	4	–	–
still	–	–	–	–	0.45	8	–	–
activities	–	–	–	–	0.43	10	–	–
husband	–	–	–	–	0.43	12	–	–
support	–	–	–	–	–	–	0.58	6
closed	–	–	–	–	–	–	0.37	11
isolated	–	–	–	–	–	–	0.37	12

Not included represented as a hyphen '–'.  
MS, multiple sclerosis.

with moderate and severe disability discussed feelings of 'social isolation', 'loneliness' and 'depression'. To illustrate these PwMS with severe disability levels said:

Lonely and isolated at home. Very depressing. (female, severe disability)  
You become used to being alone, with not as many pop ins other than paid housekeepers. My daughter and son have small children and I do miss them. So the complaint is it's a little lonely because of COVID-19 pandemic! (female, severe disability)  
A negative impact on social contact I really hate computer talk like zoom etc. makes me feel tired and stressed. (female, severe disability)

On the other hand, some people with more severe disability levels said that they found the experience of not being expected to socialise positive, including the impact on their fatigue levels.

Lock down was divine as I cut down on lots of social contact which was exhausting. When lock down ceased I was negatively impacted as I had to venture back out again. Have been anxious. (female, severe disability)  
COVID situation has lessened pressure to attend social activities when I didn't feel up to it. Also I didn't have to deal with guilt of cancelling something I'd already agreed to. COVID has slowed the world down to a pace I can deal with. (female, moderate disability)

Some people with severe disability also said they felt like 'everybody' was in the same situation of social isolation, not just PwMS:

I felt happy during initial lockdown, because everyone was just as isolated as I usually am. I had a level of expertise in handling it. (female, severe disability)  
"I've been confined to my room for the last 2 years so no change. I live alone, my only visitors are my carers and neighbours, so I've been practising social isolation well before the virus arrived. I have been out

twice in the past 18 months to my optometrist and to my bank." (male, severe disability)

There were also many comments regarding the emotional impact of the COVID-19 pandemic and the link with social isolation. The concept of isolation was more related to changes in routine and missing family and friends for the lower disability groups compared with those with a higher disability level. However, we also established that negative feelings (including sadness, isolation and anxiety) about the lack of face-to-face contact with immediate and extended family, and friends was a common theme across all disability levels.

### Financial impacts

There were many comments about the negative financial impacts of the COVID-19 pandemic across all disability levels, with only a few people saying that the impact was positive. For people who were employed, particularly in the milder disability groups, comments were made regarding wage decreases. For example, one person said that there was an enforced salary decrease of 20%.

My employer [removed] has forced a 20% pay reduction on all staff from 1 April 2020 to 1 October 2020. (female, no disability)

### DISCUSSION

Our mixed-methods study that adopted qualitative research methods to collect and analyse rich free-text data, sought to understand the thoughts and feelings of a large cohort of PwMS with differing

**Table 3** Numbers and proportions of comments, and a selection of these verbatim comments from participants according to their disability level and classified by an emergent theme

Disability severity level		Mild disability (n=113; 22.2%)	Moderate disability (n=183; 36%)	Severe disability (n=87; 17.1%)
<b>Theme</b>				
<b>Employment</b>		20 individual comments (17.6% of the cohort) "I clean other people's houses for a small cash amount weekly. I have had to let 3 of my 4 jobs go as they were elderly or had children (thinking of their health) so it has impacted me quite a bit financially. I am not eligible for any of the government monies though, during this time! Feeling resentful!" ... "I am an essential worker. My managers often pushed me to work longer hours. I was then looked at differently when I said I was high risk and needed to limit my work only to the hours I was contracted."	16 individual comments (8.7% of the cohort) "Finding new employment is tough. New/potential employers are already asking to confirm any illness." "I work in the hospitality sector, our industry is is yet to come. I have been unemployed for over four months and it does not look good for the future. I am worried about things I have no control over"	4 individual comments (4.5% of the cohort) "I am working from home and feel a bit isolated from work mates." "My ex-employer refused to put me on job keeper even though I was eligible. I was a casual employee who was on a long term 12 month contract for the last seven years and went on a month's holiday then came back sick from the holiday and had to isolate due to the start of COVID-19. As such I was unable to work and my ex-employer terminated my contract. This was emotionally upsetting and totally unexpected"
Subtheme—working from home				
<b>Multitasking: in particular working from home and child rearing</b>	8 individual comments (6.7% of the cohort) "Was a stressful time due to home schooling and running my business. Very hard time but we got through it with financial issues" "Requirement to remote teach children while working has also been a challenge of COVID" "During lockdown, closure of childcare and homeschooling had a significant impact on well-being, anxiety and stress." "Struggle concentrating on work, mainly due to having to juggle work with 8 yo & 5 yo children at home with us every day for last 6 months!"	2 individual comments (0.02% of the cohort) "While my income has not changed my work role/time has been impacted by trying to support my two children who have been schooling from home" "Remote learning for my kids causes difficulties focusing on work and causes frustration"	1 individual comment (0.5% of the cohort) "Being at home as a single mother of 4 school aged children has affected my mental health severely. Having no family support makes things very difficult and losing my main income due to COVID has been devastating. I don't know how much longer I can cope with this situation"	No comments
<b>Financial: negative and positive</b>	6 individual comments (5% of the cohort) "Our income has obviously decreased. All these things plus the need to physically distance from everyone is taking its toll on my physical and emotional well-being" "I have taken a 10% decrease in salary." No comments	6 individual comments (5% of the cohort) "I work as a travel agent and my income has been halved" Positive 5 individual comments (4% of the cohort) "I was able to access \$10,000 Superannuation which has greatly eased financial pressure and improved life - paid debts, paid rent in advance, new bed, outdoor setting, linen, etc" "I benefitted greatly from the COVID financial bonus, paid by Centrelink"	12 individual comments (6.5% of the cohort) "I lost my job because of COVID. My work were trying to force me to go into the office and when I gave a doctors certificate to say that couldn't, they said that the funding for my position had been lost anyway. They could only offer me one day a week but it had to be in the office. I was unable to do that because I am on heavy immunosuppressants (Ocrevus) so they said I should just work till my contract ended, which was on June 30" Positive 1 individual comment "The COVID-19 pandemic has had no real impact on my daily living. Previous income I received was the NEWSTART allowance which left me with no money to socialize . . . The extra income from the COVID-19 supplement payment has reduced some financial stress"	4 individual comments (4.6% of the cohort) "My ex-employer refused to put me on job keeper even though I was eligible. I was a casual employee who was on a long term 12 month contract for the last seven years and went on a months holiday then came back sick from the holiday and had to isolate due to the start of COVID-19. As such I was unable to work and my ex-employer terminated my contract. This was emotionally upsetting and totally unexpected" "Not just income influenced by COVID but finances are affected negatively with increase in power usage and inability to shop selectively at cheaper shops" Positive 1 individual comment "I do freelance editing from home and the available work has increased, if anything"

Continued

**Table 3** Continued

Theme	Disability severity level		
	No disability (n=118; 23.2%)	Mild disability (n=113; 22.2%)	Moderate disability (n=183; 36%)
<b>Emotions</b> Subtheme—fear/worry of infections and/or immunosuppression Subtheme: same as everyone else for moderate and severe disability	Emotions 39 individual comments (33% of the cohort) "I have noticed feeling more anxious than I normally would and concentration levels not as high" "COVID has meant I cannot attend external exercise classes which normally assist in my mental and physical wellbeing, as well as taking away my social interaction with friends" "Being isolated from family, and worrying about their circumstances and how they are coping continues to impact my thinking and wellbeing" "I live by myself and this virus hasn't caused too much on my emotional side of things as I try and think positive all of the time and my family ring me every day to make sure I am ok" Fear/worry "Obviously worries me as I am on drugs that hinder my immunity" Same as everyone else "COVID-19 has had a significant impact on people's lives both emotionally and financially but I have been battling MS for 16 years so these current challenges I have been facing for 16 years. I have remained positive in spite of the challenges"	Emotions 31 individual comments (27.4% of the cohort) "Victoria, Stage 3 again! Very hard not being able to see friends, extended family/no social connections/community involvement. Limits on types of physical activities permitted leads to negative impact on fitness, muscle strength etc. Can't run due to physical limitations, walking is the only option. No gym, no pool etc. Feelings of sadness for people who have lost their jobs/loved ones" "It has been hard emotionally as we are unable to see family members or do much at all" "My physical health has declined as my gym has closed and I don't exercise half as much as I should. I normally exercise before work to get me going. Now I struggle to go for a walk. This also affects me emotionally. I feel down most of the time and a lot less motivated to do anything" Fear/worry "Having to work in healthcare is a bit anxiety provoking. My neuro wants me to go on Aubagio but I am scared it will decrease my immunity. My symptoms appear to be coming a bit more frequently" "I stopped my treatment (copaxone) for 2 months at the start of the pandemic, until I learned that Covid was highly contagious anyway. I was concerned about affecting (decreasing) my immune system" Same as everyone else "Covid has allowed me to feel 'normal' when, for example grocery shopping & you're always asked 'what are you doing for the rest of the day' or 'how's your day's been'. Now my answer will be the same as most others"	Emotions 17 individual comment (9.3% of the cohort) "Increased worry that I could get COVID and that I would be more affected than a healthy person. Also worried about my UK parents" "Social isolation has had the biggest impact on me. Not being able to get out and socialise with friends over lunch or a cup of coffee has made me more depressed. Being at home with a spouse 24/7 with nothing new to talk about was frustrating and annoying. While I still see my child on a weekly basis I miss the interaction I had previously" "All of my stress and anxiety from the pandemic has stemmed from worry over not being able to get my medications, the issue of the factories closing down or supply stopping, the effect of me going off my medications worry me greatly. I have been very well over the last 5 yrs or so and I think it's due to the therapy I am on" Fear/worry "The pandemic has forced me to make a decision of ceasing my immunosuppressant as my treatment for MS. I have ceased Gilenya this last week. I am would rather die WITH MS than FROM COVID. I am extremely terrified of contracting the virus" "Fear of other people not doing the right thing that may cause me to become infected, especially in shops and other places where other people do not socially distance as required"
<b>Social isolation and social connection</b> Subtheme: missing family and friends and feelings of sadness	22 individual comments (18.6% of the cohort) "Limited social interaction and activities outside the home has made me feel socially isolated. Sadness re inability to visit children in same state and overseas" "Most of the sadness I noticed I mentioned in this survey is due to COVID-19 and its effect on my ability to attend social activities and visit family members" "Not going out has impacted on many aspects of daily life such as energy, strength, and social connection. Working out at home isn't the same as I don't push as hard and I miss the social aspect of meeting friends and chatting at the gym. I typically go 5 times per week so I really miss it when I'm not going"	16 individual comments (14.2% of the cohort) "Victoria, Stage 3 lockdown again! Very hard not being able to see friends, extended family/no social connections/community involvement" "COVID-19 has had a negative impact on my wellbeing due to self isolating as much as possible, not being able to attend my regular gym classes and the lack of social interaction with family and friends" "I also feel that socially my friendship group is fading away as I have not had regular contact with them"	23 individual comments (26.4% of the cohort) "I am 24/7 wheelchair/scooter reliant and COVID-19 did affect my interaction with several clubs I am involved in ... missed the interaction with friends due to restrictions" "Due to Covid lockdowns(removed*) as they live outside the border bubble that I am in. I am therefore on my own for the duration of the lockdown"

Notes: minor grammatical errors were adjusted for consistency.  
\*Denotes text removed to avoid identifying the participant.

disability levels during the COVID-19 pandemic. When examining differences by disability level, we found that the word ‘working’ was important for people with no or mild disability, whereas ‘isolated’ and ‘support’ were important for PwMS with severe disability. Importantly, we found that multitasking was particularly challenging for people with no disability who were dealing with the additional pressures of meeting employment expectations along with caring for and/or home-schooling young children. Triangulation of the word frequency data with the emerging theme of social isolation also led us to understand the concept in our thematic analysis and we also found that social isolation held a different meaning for different disability levels. Social isolation was particularly challenging for people with higher disability levels. However, some of these PwMS also indicated that they felt that their lived experience with social isolation had not changed and that there was some sense of COVID-19 making everyone else in the community more isolated, and therefore more like themselves.

### Multitasking and WFH

Our study established that multitasking was challenging for people with lower MS-related disability who were required to manage the concomitant pressures of meeting employment outcomes and caring for or home-schooling children. There are few, if any, qualitative studies regarding WFH during the pandemic (or more broadly) for PwMS and there are few studies regarding people with chronic disease and disability. One study that investigated the effect of COVID-19 on employment among people with disabilities and chronic health conditions found that COVID-19 is accentuating pre-existing structural disadvantages and inequalities.<sup>24</sup> More specifically, this study found that the pandemic has not only affected whether or not people with disabilities and chronic health conditions will enter or exit the labour market, but it has also fundamentally reshaped the nature of their jobs. The study observed that some have taken on part-time or freelance work that only provides a fraction of the income and security that they were used to or expecting, others saw no interruptions in their income, either because they are essential workers or because they are working remotely. This study also found clear evidence that occupations matter—those in secure professional jobs were less likely to see income disruptions and also expressed a greater sense of financial security.<sup>24</sup> The intersection of these structural advantages and disadvantages was also established in our study that investigated the lived experience of PwMS during the COVID-19 pandemic. We found that WFH and multitasking were challenging for some people, but that for others the reduction in stress resulting from the reduced commuting to work ameliorated MS-related fatigue. Our study also aligns with another international study regarding the impact of the COVID-19 pandemic that used a mixed-methods approach where a few verbatim quotes were used to supplement quantitative findings and established that WFH for PwMS during the pandemic generally had a positive impact on physical symptoms.<sup>10</sup>

### Social isolation

Our findings regarding the impact of social isolation for PwMS during the pandemic can be used to supplement quantitative findings to provide a context of the ‘how and why’ to the ‘how many’ and ‘how much’.<sup>3</sup> To illustrate, our results can provide some contextualisation to the results of a community-based case-control online questionnaire study that included 2010 PwMS from the UK MS Register and 380 people without MS.<sup>25</sup> Like our study, the cross-sectional component of the UK MS Register study was also conducted early in the pandemic. The publication reported quantitative cross-sectional findings on the mental health of PwMS, its determinants and their general health during the outbreak. The authors found that PwMS

were more likely to feel lonely than controls, but they did not give reasons why PwMS felt lonely or isolated. Similarly, the study showed that PwMS were more likely to experience a worsening of their social support than their controls, yet again there is no contextualisation to this finding.<sup>25</sup> Our study provides insights into these feelings of social isolation, where PwMS with more severe levels of disability identified social isolation as a common theme, yet one of the differing factors for some of these people was that they already felt socially isolated prior to the COVID-19 pandemic.

A potential solution for the problem of social isolation was explored by a small qualitative study in the UK early in the pandemic and before lockdowns<sup>11</sup> that explored the concept of ACP for people living with severe MS-related disability (EDSS>6.0). The study’s findings supported the need for a whole of system strategic approach where information about the potential benefits of ACP in all its forms can be shared with PwMS. Moreover, they highlight the need for health professionals to be skilled and trained in engaging in ACP discussions and where information is contemporaneously and seamlessly shared across services. We suggest that the detailed findings of our study regarding social isolation as a key issue for people with severe disability both inside and outside of the pandemic environment, that well-informed and targeted planning through ACP could provide a solution. We suggest that this could be a subject of further research.

### Strengths and limitations

Strengths of this study include the large sample size of PwMS for a qualitative research methods study, with a representative distribution across levels of disability. Another strength is the rich qualitative data (22 563 words) that specifically addressed the targeted question regarding impacts of COVID-19 for PwMS.

A potential weakness is that the PwMS who completed the qualitative question were different to those who did not. Those who provided free-text data more likely to be female, in COVID-19-related lockdown, have relapsing remitting MS, more highly educated and employed. Age categories were similar between those who responded and those who did not, on average, both groups were middle-aged. Notably, these sociodemographic trends align with other qualitative studies of people during the pandemic where a free-text question has been asked after a large quantitative study. For example, a large study in the USA of older adults who completed the COVID-19 Coping Study were asked an open-ended question where they could provide a free-text response. The sociodemographic profile of this study cohort was two-thirds female, 80% had a college education, and for this older cohort where 50% were retired, almost 40% remained in employment.<sup>26</sup> Importantly for our study, there was also a representative distribution across the disability severity classifications—the key subject of this study.

Finally, another weakness could be the use of free-text data where the data are not elicited with qualitative research methods that include focus groups and interviews. There is one school of thought that has suggested free-text qualitative data are in fact not qualitative, particularly if it is sourced from an open-ended question such as ‘any other comments’.<sup>27</sup> However, we note that our qualitative data were elicited from an appropriately contextualised question at the end of the survey following on the background of a detailed Participant Information Sheet provided to our AMSLS participants. In addition, many leading qualitative researchers<sup>4</sup> use this type of data in their qualitative studies to explore the lived experience of their subjects.<sup>28</sup> We also note that our study followed the criteria for qualitative quality as outlined in the Big Tent Criteria<sup>13</sup> and the Standards for Reporting Qualitative Research.<sup>12</sup> For example, our research is marked by thick description.<sup>12 13</sup>



## CONCLUSION

Early in the COVID-19 pandemic particularly during the first wave of outbreaks and COVID-19-related lockdowns, we found many negative impacts and some beneficial impacts for PwMS regarding the social distancing and lockdown measures of the pandemic. We recommend that additional resourcing be provided to PwMS in the early stages of future COVID-19-related outbreaks and future pandemics, including targeted child-care relief for PwMS and interventions to reduce social isolation. We also recommend that WFH for PwMS be further investigated now that COVID-19 restrictions have eased, and as the nature of work has been reshaped for some sectors due to the flexible working arrangements negotiated during the pandemic. We also recommend that the pre-existing nature of social isolation that has been highlighted in our study for people with severe MS-related disability be addressed now with additional policies and programmes to address this endemic problem for these PwMS. To address these recommendations, we suggest that the concept of advanced care planning could be a fruitful avenue of future research. Another area of future research includes flexible working arrangements for PwMS and childcare arrangements for PwMS during the pandemic that perhaps parallel the same types of arrangements as front-line workers.

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## REFERENCES

- Zarghami A, Hussain MA, Campbell JA, et al. Psychological impacts of COVID-19 pandemic on individuals living with multiple sclerosis: a rapid systematic review. *Mult Scler Relat Disord* 2022;59:103562.
- Andreu-Caravaca L, Ramos-Campo DJ, Chung LH, et al. The impact of COVID-19 home confinement on neuromuscular performance, functional capacity, and psychological state in Spanish people with multiple sclerosis. *Mult Scler Relat Dis* 2021;53:103047.
- Campbell JA, Ezzy D, Neil A, et al. A qualitative investigation of the health economic impacts of Bariatric surgery for obesity and implications for improved practice in health economics. *Health Econ* 2018;27:1300–18.
- Greenhalgh T, Annandale E, Ashcroft R, et al. An open letter to the BMJ editors on qualitative research. *BMJ* 2016;352:i563.
- Weiner BJ, Amick HR, Lund JL, et al. Use of qualitative methods in published health services and management research: a 10-year review. *Med Care Res Rev* 2011;68:3–33.
- Woolcock K. Value based health care: setting the scene for Australia; 2019. Deebie Institute for health policy research, Canberra (2019)
- Campbell JA, Simpson S Jr, Ahmad H, et al. Change in multiple sclerosis prevalence over time in Australia 2010–2017 Utilising disease-modifying therapy prescription data. *Mult Scler* 2020;26:1315–28.
- Multiple Sclerosis International Federation. Atlas of MS. 2020. Available: <https://www.atlasofms.org/map/global/epidemiology/number-of-people-with-ms>
- Parkinson A, Drew J, Hall Dykgraaf S, et al. They're getting a taste of our world': A qualitative study of people with multiple sclerosis' experiences of Accessing health care during the COVID-19 pandemic in the Australian capital territory. *Health Expect* 2021;24:1607–17.
- Morris-Bankole H, Ho AK. The COVID-19 pandemic experience in multiple sclerosis: the good, the bad and the neutral. *Neurol Ther* 2021;10:279–91.
- Koffman J, Penfold C, Cottrell L, et al. I wanna live and not think about the future" What place for advance care planning for people living with severe multiple sclerosis and their families? A qualitative study. *PLoS One* 2022;17:e0265861.
- O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.
- Tracy SJ, Hinrichs MM. n.d. Big tent criteria for qualitative quality. *The International Encyclopedia of Communication Research Methods*;2017:1–10.
- Taylor BV, Palmer A, Simpson S Jr, et al. Assessing possible selection bias in a national voluntary MS longitudinal study in Australia. *Mult Scler* 2013;19:1627–31.
- Thompson AJ, Banwell BL, Barkhof F, et al. Diagnosis of multiple sclerosis: 2017 revisions of the McDonald criteria. *Lancet Neurol* 2018;17:162–73.
- Campbell JA, Ahmad H, Chen G, et al. Validation of the EQ-5D-5L and Psychosocial bolt-ons in a large cohort of people living with multiple sclerosis in Australia. *Qual Life Res* 2023;32:553–68.
- QSR International, Available: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home?msclkid=4c9a6be5c05711eca9467ca57575582e>
- Kobelt G, Berg J, Lindgren P, et al. Costs and quality of life of patients with multiple sclerosis in Europe. *J Neurol Neurosurg Psychiatry* 2006;77:918–26.
- Strauss A, Corbin J. *Basics of qualitative research*. Newbury Park, CA: Sage, 1990.
- Strauss A, Corbin J. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage Publications, Inc, 1998.
- Liamputtong P, Ezzy D. *Qualitative research methods*. second edition. Melbourne Oxford University Press; 2005.
- Ezzy D. *Qualitative analysis*. Routledge, 2013.
- Culyer AJ. *Encyclopedia of health economics*. Newnes, 2014.
- Guaifoli G, Tochev T. Do Localised Lockdowns cause labour market Externalities? *Covid Economics* 2021:46–86.
- Garjani A, Hunter R, Law GR, et al. Mental health of people with multiple sclerosis during the COVID-19 outbreak: A prospective cohort and cross-sectional case-control study of the UK MS register. *Mult Scler* 2022;28:1060–71.
- Finlay JM, Kler JS, O'Shea BQ, et al. Coping during the COVID-19 pandemic: a qualitative study of older adults across the United States. *Front Public Health* 2021;9:643807.
- O'Cathain A, Thomas KJ. "any other comments?" open questions on questionnaires - a bane or a bonus to research? *BMC Med Res Methodol* 2004;4:25.
- Boynton PM, Greenhalgh T. Selecting, designing, and developing your questionnaire. *BMJ* 2004;328:1312–5.