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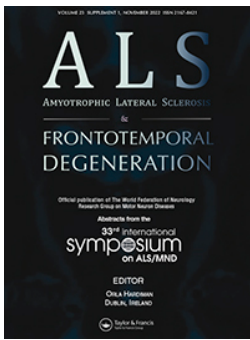
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RESEARCH ARTICLE

Impact of the covid-19 pandemic on amyotrophic lateral sclerosis care in the UK

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Abstract

The Covid-19 pandemic has impacted healthcare. Our aim was to identify how amyotrophic lateral sclerosis (ALS) care in the UK has been affected by the pandemic by exploring the experiences of people living with ALS (plwALS), healthcare professionals (HCPs) working with plwALS, and ALS care centers. Three surveys were carried out to explore the experiences of plwALS, HCPs and ALS care centers during the pandemic. Quantitative data were analyzed using descriptive and inferential statistics and triangulated with the qualitative data which were analyzed thematically. Responses from 53 plwALS, 73 HCPs and 23 ALS care centers were analyzed. Five main themes were identified: keeping safe, losses, negative emotions, delivering care and alternative care delivery in a pandemic. PlwALS and HCPs felt that care was sub-optimal as a result of the pandemic. Changes to care included longer waiting times and face-to-face appointments being canceled or replaced by virtual consultations. While benefits of virtual consultations were reported, concerns were raised about incomplete clinical assessments and the disruption of provision of testing and interventions. ALS care has changed as a result of the pandemic. Patients have had a lack of face-to-face contact with HCPs and have experienced delays to investigations and treatments. PlwALS and HCPs were concerned about the impact of this change, but the long-term implications remain unclear. We propose recommendations for HCPs caring for plwALS, that will promote continuity of evidenced based care in the context of a pandemic.

Keywords: amyotrophic lateral sclerosis, motor neuron disease, Covid-19, healthcare services, thematic analysis


Introduction

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which causes Coronavirus 2019 (Covid-19) disease, has led to a global pandemic (1). As of November 2021, Covid-19 had caused an estimated 5 million deaths (2). The Covid-19 pandemic has affected multiple patient cohorts, including people living with amyotrophic lateral sclerosis (ALS) (plwALS) (3).

Since the emergence of Covid-19, plwALS have been vulnerable to the risk of infection and of complications including pneumonia and respiratory

failure (4). National governments have implemented measures including social restrictions and national lockdowns to control the spread of the virus (5). The UK government introduced the concept of “shielding” whereby vulnerable people were encouraged to remain at home and significantly limit contact with others. The “clinically extremely vulnerable” list was also implemented for vulnerable groups, enabling identification of those requiring additional support and advice. However, this list did not automatically include plwALS meaning that plwALS were not granted protective measures such as priority access to essential deliveries.

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 Supplemental data for this article can be accessed [here](#).

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PlwALS require a wide range of health and social care services and a supportive multidisciplinary team approach (6). In England, care for plwALS is shaped by guidance issued by the National Institute for Clinical Excellence (NICE) (7). Prior to the Covid-19 pandemic, plwALS were usually reviewed in-person every 2–3 months by a range of healthcare professionals (HCPs). The multidisciplinary team would usually include an ALS neurologist, nurse, respiratory physiotherapist, speech and language therapist, dietician, occupational therapist and clinical psychologist (8). Specific care needs would be tailored to the individual patient. Investigations for monitoring purposes such as riluzole safety tests and pulmonary function assessment would be included in regular in-person clinics (9). Complex decision-making such as the consideration of a gastrostomy tube and end of life care would also be discussed with members of the multidisciplinary team (10).

The response to the pandemic has caused major changes in the delivery of multidisciplinary care across all neurological services internationally (11). In-person appointments have been postponed or canceled, causing significant delays and disruptions to ALS specialized care (12). Furthermore, ALS-specific services such as provision of gastrostomy, respiratory function testing and noninvasive ventilation have been reported to be adversely affected (3). Healthcare services for plwALS care have had to adopt new delivery models, with an increase in the use of telehealth and remote monitoring (13).

It is not known how these changes have impacted plwALS, HCPs and ALS care centers (ALS care centers) across the UK. Consequently, we designed three cross-sectional surveys with the following aims: to identify changes in care caused by the Covid-19 pandemic, assess the impact for plwALS and healthcare services, and make recommendations about how best to support plwALS in a pandemic.

Materials and methods

Study design

Three online cross-sectional surveys were undertaken in the UK (see Table 1).

Participants

For survey 1, plwALS were recruited via the Motor Neurone Disease (MND) Association's online forum and support groups. Survey 1 was advertised on the MND Association's research webpage and the news webpage of the UK MND Clinical Studies Group. For survey 2, a convenience sample was obtained (14); HCPs working with plwALS were identified by searching online to identify workplace contact details of HCPs. HCPs were also identified via existing contacts of the research team and were invited to complete the survey via email. Both surveys were also posted on social media (e.g. Twitter and Facebook) to reach a wider audience. This included information on the research team's pages as well as charity and professional network pages. Survey 3 participants were care center coordinators from the MND Association care center directory (15).

Data collection

Surveys used a combination of open-ended and closed questions (see Table 1 and Appendices C, D and E) and were collated using the Qualtrics (16) and the Google Forms platforms (17). Data collection spanned June–December 2020. Survey 1 (plwALS) included the validated Amyotrophic Lateral Sclerosis-Functional Rating Scale-Revised questionnaire (18) and was piloted with a local public involvement group.

Data analysis

Quantitative data from closed questions were analyzed using descriptive and inferential statistics using SPSS (19). A p value of <0.05 indicated statistical significance. Qualitative data from open-ended questions were analyzed using thematic analysis aided by NVivo (20,21). This involved coding the qualitative data and identifying repeated patterns that could be grouped into relevant themes (20). Overall themes were then defined, reviewed and refined.

RG and MC completed the thematic analysis for survey 1 (plwALS) and LM and EB conducted the thematic analysis for survey 2 (HCPs). Data

Table 1. Study design for surveys 1, 2 and 3.

	Target population	Eligibility criteria	Time period of questioning	Survey distribution period	Questions	Data
Survey 1	plwALS	>18 years ALS Diagnosis	03/2020 – 12/2020	September 2020 –December 2020 (12 weeks)	Open and Closed	Quantitative and qualitative
Survey 2	HCP	HCP supporting plwALS in the UK	07/2020 – 10/2020	October 2020 (2.5 weeks)	Open and Closed	Quantitative and qualitative
Survey 3	ALS Care Center	Care center representative	03/2020 – 06/2020	June2020–August 2020 (6 weeks)	Closed	Quantitative

from all three surveys were triangulated and thematic codes were applied to data from surveys 1 and 2.

Quantitative findings from each survey were compared to themes identified from qualitative data for surveys 1 and 2. Triangulation was used to deepen the understanding of the phenomenon under investigation, and to help improve the study's credibility (22). As well as conducting data triangulation, investigator triangulation was used to reduce bias (23). LM and AC independently completed this process, discussed discrepancies and agreed on categorisations, which were then agreed with the rest of the team.

Ethical approval

Participants consented by completing a consent form and submitting the survey. Data were anonymised and kept confidential. Surveys 1 (plwALS) and 2 (HCPs) received ethical approval from the University of East Anglia (Ref. 2020-1036-001982) and University of Sheffield (Ref. 036408), respectively. Ethical approval was not required for survey 3 (ALS care centers) as this was an audit of service provision.

Results

Demographics

Survey 1 (plwALS): Fifty-three plwALS (51% females), with a mean age of 66.6 years (SD = 11.3), participated. The mean (self-completed) ALSFRS-R score was 28.7 out of 48 (SD = 9.4). A total of 29 (55%) plwALS had experienced symptoms 1–5 years and ten (19%) for 6–10 years. Although the survey was available for all plwALS across the UK, 92% of respondents resided in England. Survey 2 (HCPs): Seventy-four HCPs from thirteen separate vocations participated. One set of responses was discounted as the participant was not working in the UK. The most common roles were nurses ($n = 22/73$, 30.1%) and doctors ($n = 18/73$, 24.7%). Survey 3 (ALS care centers): Twenty-three ALS care centers across the UK participated, with individual representatives completing the questions on behalf of each center.

Responses from all three surveys were grouped into five main themes including keeping safe, negative emotions, losses, delivering care, and alternative care delivery in a pandemic. Relevant quantitative and qualitative data with key quotations have been highlighted within each theme with further information seen in [Table 2](#), [Appendix A and B](#). The findings were also used to generate a set of recommendations in relation to how we can best support plwALS in the context of a pandemic, as shown in [Table 3](#).

Keeping safe. PlwALS described the importance of being careful and minimizing contact with others to reduce the risk of infection, even after the end of the shielding period. One plwALS explained “after the shielding period finished, I did not want to leave the house.” Survey 1 findings highlighted that forty-six (88%) plwALS shielded, with thirty-six (69%) formally identified as “clinically extremely vulnerable” by a HCP. Feelings of vulnerability and difficulties associated with keeping safe were also expressed: “The Community Nurse visits once or twice a week and it is not possible to socially distance.” Seventeen (33%) plwALS reported difficulty in being able to adequately socially distance themselves from others, although only one plwALS (1.8%) tested positive for Covid-19. HCPs recognized the challenges faced by plwALS and the need for protection from infection.

Negative emotions. Survey 1 respondents described feeling isolated, low in mood or worried regarding the Covid-19 pandemic and its impact on their mental health. One participant highlighted “Just feel so isolated”. Forty-six (92%) plwALS described feeling specifically worried about contracting Covid-19 infection. Survey 2 responses described concerns about patients’ inability to plan for the future and a consequent loss of control. Both plwALS and HCPs reported a lack of adequate psychological and pastoral support for plwALS during the pandemic.

Losses. The majority of plwALS described negative impacts on quality of life arising from pandemic-related social restrictions. PlwALS reported difficulties maintaining relationships, meeting friends and family, attending social events and gyms, all of which negatively impacted on their mental health. One respondent explained “It has affected my ability to live as full a life as possible. It has reduced my ability to travel and see family, thus reducing my quality of life.” HCPs described the pandemic’s effects on the psychological well-being of their colleagues and the importance of support for staff working from home. “Staff support when working in isolation is very important.”

Delivering care. HCPs described delays and changes to appointments having adverse effects on ALS care. Changes to ALS services included disruptions to gastrostomy support, which were highlighted in all three surveys (see [Appendix A](#)). Two participants (17%) from survey 1 reported delayed gastrostomy insertion. Twenty-two respondents (30.1%) from Survey 2 could only offer virtual appointments for gastrostomy care. Gastrostomies were postponed in eleven (55%) ALS care centers, causing a mean delay of 6.4 weeks (SD = 3.9).

HCPs described the difficulties in carrying out specific assessments without face-to-face contact,

Table 2. Summary findings from surveys 1 and 2.

		Quantitative	Qualitative
Keeping safe	PlwALS	A large proportion of patients opted to Shield ($n = 46$, 88%).	PlwALS reported that they had been avoiding public places even after the end of the shielding period. Some plwALS explained that it was not always possible to socially distance, especially if they were dependent on carers.
	HCPs	HCPs highlighted that face-to-face clinical appointments were avoided in order to minimize risk of infection for plwALS ($n = 33$, 56.9%)	HCPs reported that they had minimized contact with patients to reduce potential transmission of Covid-19. PlwALS were also described as reluctant to see HCPs face-to-face both at their home and in public spaces (e.g. hospitals).
Negative emotions	PlwALS	The majority of plwALS felt worried about contracting Covid19 ($n = 46$, 92%).	PlwALS expressed fear toward the Covid-19 virus and described feeling isolated, angry and frustrated because of the lack of social contact.
	HCPs	N/A	HCPs described being concerned about the impact that Covid-19 has had on service provision (e.g. delaying tests) and worrying about the negative impact on patient care.
Losses	PlwALS	N/A	PlwALS reported that they had lost or missed activities, people and opportunities due to the pandemic which had resulted in them feeling like they are not living their life to the full.
	HCPs	N/A	HCPs reported that because patients were reluctant to come to hospital, they were missing out on opportunities such as having clinical tests (e.g. respiratory function tests) and specialist consultations.
Delivering care	PlwALS	The most significant changes were face-to-face appointments, which were largely replaced with remote consultations including telephone ($n = 31$, 69%) and video ($n = 13$, 29%). ALS-related appointments were also disrupted or disrupted such as breathing tests ($n = 13$, 42%), respiratory support ($n = 2$, 12%) and gastrostomy procedures ($n = 2$, 17%).	PlwALS reported that they had experienced disrupted care as a result of the COVID-19 pandemic. The disturbances included longer waiting times, not being able to see HCPs face-to-face and delayed diagnosis. PlwALS reported that it was easier to communicate in person, especially if they had communication difficulties such as dysarthria. Furthermore, remote consultations could be challenging when patients were not familiar with technology or had trouble with internet connection.
	HCPs	Reports of delays and changes to appointments were reported in the HCP survey. E.g. Some HCPs could only offer virtual appointments for gastrostomy care ($n = 22$, 30.1%).	HCPs reported feeling worried about the impact of Covid-19 on the delivery of care for plwALS. HCPs reported that it was easier to communicate in person and telephone consultations are not appropriate for patients with communication difficulties. Furthermore, remote consultations could be challenging with regards to use of technology. HCPs stressed the importance of having an adequate supply of PPE and guidelines in order to deliver good care during the pandemic.
Alternative care delivery in a pandemic	PlwALS	Patient respondents reported communication with healthcare professionals in relation to their ALS during the pandemic. Contact with an MND specialist/neurologist ($n = 30$, 67%), occupational therapist ($n = 30$, 64%) and GP ($n = 28$, 62%) were most frequently reported.	PlwALS expressed a need for more frequent contact from HCPs to provide reassurance. Respondents described a preference toward in-patient services, face-to-face contact and home visits for optimal care.
	HCPs	Only a small number of HCPs were provided additional training to care for plwALS during the pandemic ($n = 5$, 6.8%)	HCPs thought alternative modes of communication should be used to accommodate people's needs and preferences. Respondents stressed the importance of being able to adopt new service models and to have adequate funding to enable services to provide best care. HCPs also highlighted the need to have an adequate supply of PPE.

Table 3. Recommendations; lessons learnt for promoting effective ALS care provision during a pandemic.

Theme	Recommendations	Potential solutions
Keeping safe	HCPs/services should identify plwALS who may be clinically vulnerable e.g. those with respiratory impairment and advise how to minimize risk.	Services should conduct a review of all cases and identify those at specific additional risk due to a pandemic and contact the patient, wider multidisciplinary and primary care teams about the risk and mitigations to be taken. As part of the multidisciplinary team discussion a plan to ensure continuity of ALS care should be agreed.
Negative emotions and losses	HCPs/services should support plwALS regarding their concerns about safety risk and their care by providing detailed information and reassurance about the pandemic and the care they will continue to receive.	HCPs/services should develop and proactively provide ALS patient-centered information with signposting details to support services when restrictions are in place.
Delivering care	There is a need for bespoke services and adapting to the needs of each individual patient. Consequently, HCPs/services should use additional modes of communication when appropriate to support the needs of plwALS. HCPs/services should offer face-to-face consultations when a patient needs testing that cannot be done at home.	Make use of user-centered telehealth software. During video consultations, use the chat function. Consider using drive through testing (blood tests, respiratory gases etc) to avoid plwALS having to go into hospital. Conduct risk/benefit analysis of face to face encounters in the context of a pandemic.
Alternative care delivery in a pandemic	HCPs should receive appropriate training to ensure there are adequate numbers of trained staff caring for plwALS who are confident and competent caring for plwALS during a pandemic. HCPs/services should evolve and adopt new service delivery models and resources to accommodate changing healthcare and unprecedented situations. HCPs/services should allow home visits when necessary so they can pick up on physical issues without patients needing to attend the hospital. Services should receive adequate funding to accommodate the need for more trained staff and for home visits etc. HCPs/services should have an adequate supply of personal protective equipment and guidelines in order to deliver good care. HCPs/services should use a multidisciplinary approach to provide optimal care for plwALS.	Services should develop online courses, webinars and websites in order to provide additional training to HCPs (e.g. on using remote technologies, supporting plwALS at home). Services should focus on developments such as remote pulmonary function testing which can help to monitor plwALS remotely and safely. Services should also consider adopting domiciliary or drive through testing services (e.g. blood tests and respiratory gases) to avoid the need for plwALS to attend hospital for these tests. HCPs/services should offer home visits when necessary whilst wearing full personal protective equipment. Services should be commissioned appropriately. Services should provide correct personal protective equipment and clear guidelines for staff caring for plwALS. HCPs should have regular multidisciplinary team meetings (virtual or face-to-face) and provide email/ phone support to other HCPs.

HCPs: Healthcare professionals; PlwALS: people living with amyotrophic lateral sclerosis.

such as respiratory assessments and NIV support. “Delay in face-to-face appointments when symptoms can be assessed and respiratory function tests undertaken. This can delay recognition of respiratory failure and initiation of NIV when indicated.” Thirteen plwALS (42%) described their

appointments for breathing tests as either delayed or canceled. Ten (48%) ALS care centers were unable to carry out any breathing tests. Breathing support such as noninvasive ventilation (NIV) was delayed for two plwALS (12%), although thirteen respondents (76%) reported no change.

Other aspects of ALS care were identified. In survey 1, plwALS described home adaptations and delivery of equipment as mostly unaffected, with no changes for seventeen (68%) and twenty-three (74%) plwALS, respectively. Survey 3 identified delays in the prescription of riluzole in twelve (60%) centers. Neurophysiological testing such as electromyography and nerve conduction studies was avoided or delayed in ten (47.6%) centers. Survey 3 also demonstrated that clinical research was affected. Over two thirds of ALS care centers had an average of 5.2 (SD = 4.5) recruiting clinical trials of investigational medicinal products. Face-to-face follow-up was continued for only one of these trials. The remaining trials adopted remote monitoring methods. Despite the pandemic, new non-Covid-19 related studies of ALS were developed in seven (35%) centers, although delays in obtaining approvals were reported in two thirds of cases ($n=6$, 66.7%). [Supplementary material D](#) provides a summary of the quantitative findings.

Face-to-face appointments were modified to telephone consultations for thirty-one plwALS (69%), and to video call appointments for thirteen (29%). Survey 2 highlighted similar changes, with thirty-three (56.9%) HCPs reporting a decrease in face-to-face consultations and 40% of consultation time taking place via telephone. Survey 3 identified 872 (68.5%) follow-up appointments conducted via telephone, with a total of 232 appointments (18.3%) carried out using video call. Interestingly, many plwALS reported satisfaction with this form of communication. Twenty-one (67%) plwALS felt satisfied or very satisfied with telephone appointments, and eight (62%) with video calls. The advantages included protection from infection and avoidance of travel.

Conversely, plwALS and HCPs also explained the challenges with telephone appointments. “My speech problems make telephone calls difficult. I prefer face to face contact.”

HCPs also identified issues with telephone communication, such as the difficulty of delivering diagnosis over the telephone and also the need to communicate via relatives for patients with dysarthria “Phone calls not appropriate for patients with communication difficulties - usually end up talking with relative instead which has not been fair on the person living with ALS.” In addition, some plwALS and HCPs highlighted the challenges associated with technology and internet connections for video appointments. HCPs also described feeling worried about missing important or relevant clinical details when carrying out remote consultations. “Identify more issues from clinical assessment of patient when face to face rather than over the phone.”

Alternative care delivery in a pandemic.

PlwALS explained the need for more frequent contact from HCPs, including advice and reassurance. PlwALS stated clearly “Please can you talk to us” and a request for “more frequent contact from NHS neurologist.”

Most plwALS reported being satisfied with telephone appointments if there were no concerns. However, if a patient experienced a decline or had a particular worry, face-to-face consultations were preferred. Seventeen (46%) plwALS stated a preference for face-to-face consultations while fifteen (41%) preferred a hybrid model (involving in-person and remote appointments). HCPs explained the need to design and adopt new service delivery models using lessons learnt from the first wave of infections. Suggestions included having adequate supplies of personal protective equipment (PPE), adequate numbers of trained staff, continuing a multidisciplinary approach and allowing home visits to enable close monitoring of patients. The findings were used to generate a set of recommendations in relation to how we can best support plwALS in the context of a pandemic, as shown in [Table 2](#).

Discussion

PlwALS made direct attempts to keep themselves safe (e.g. choosing to shield) and changes were made to services to protect patients from contracting Covid-19. Relating to these changes, plwALS described increased feelings of isolation, worry and depression with a need for further contact and reassurance from HCPs. Similar reports of anxiety and loneliness in response to the pandemic restrictions have been described by plwALS in Italy (24,25), as well as worsening self-perceived health status (26).

PlwALS and HCPs shared worries and concerns about plwALS not receiving optimal care, which could have long-term implications for quality of life and survival. Face-to-face appointments were often canceled or changed to virtual consultations. Although telephone appointments were generally regarded positively amongst plwALS, some concerns were raised by plwALS and HCPs about the suitability of these for patients with bulbar dysfunction or communication difficulties, and a fear of missing ALS-related symptoms requiring urgent treatment. ALS guidelines recommend that consultations are tailored to the patient’s needs, and alternative modes of communication used where necessary (7). A balance should be sought between encouraging remote appointments to keep people safe and being able to adequately assess and monitor symptoms. We recommend that HCPs advocate patient choice regarding the type of consultation they receive, particularly for patients

with dysarthria, with the option of home visits where possible. We recommend that services consider drive-through testing (e.g. phlebotomy and respiratory blood gases) to avoid patients coming into hospital for these tests. However, we do recommend that patients be offered face-to-face appointments at hospital when they need testing that cannot be done at home or via a drive-through service. We also recommend that telemedicine and telehealth be considered when face-to-face consultations are not feasible (27).

PlwALS and HCPs reported longer waiting times for appointments and provision of testing, while treatments such as riluzole and interventions such as NIV and gastrostomy were delayed or disrupted. These findings replicate reports from Scotland (3) and the United States (28). This is concerning given that ALS guidelines recommend patients be seen without delays (7). For example, it is recommended that patients with an arterial partial pressure of carbon dioxide greater than 6 kPa be referred urgently to a respiratory ventilation service and be seen within one week (7). Evidence also highlights the importance of earlier initiation of interventions such as NIV because late initiation is associated with poorer outcomes (e.g. reduced survival) (29,30). We recommend that services plan and adopt new service delivery models and resources to maintain key services when lockdown restrictions are in place. Developments such as remote respiratory function testing could be part of redesigned services (31).

The importance of a multidisciplinary approach for providing good care was emphasized by HCPs. This is not surprising given that centralized multidisciplinary care is associated with improved survival in ALS (32) and is recommended in international guidelines (7,33). However, plwALS had less access to multidisciplinary services such as physiotherapy, nutrition support and speech and language therapy during the pandemic. To ensure that a multidisciplinary approach can continue, we recommend that HCPs have regular virtual multidisciplinary team meetings and provide email, telephone, or virtual support to other services to facilitate coordinated multidisciplinary care.

HCPs reported not receiving additional training to support them in their adapted role, with many being concerned about the lack of funding, particularly for hospice services, as well as being concerned about a lack of PPE and staff redeployment. Some also expressed a lack of confidence in being able to care for plwALS during the pandemic. We therefore recommend that HCPs receive training in pandemic ALS care, particularly on how to do perform remote consultations and how to deliver and coordinate care for those being seen in nontraditional settings (e.g. the patient's home).

Limitations

There are a number of limitations to be taken into consideration with regards to our findings. The total number of responses we received from Survey 1 did not produce a large sample and consequently the responses across the three surveys were not evenly distributed. Consequently, it is unlikely we have gathered a truly representative sample. Furthermore, the majority of participants were White/White British, who resided in England, and so the results cannot be generalized to a broader population. Our recruitment approach was pragmatic given the ongoing pandemic and by choosing the simpler and faster University Ethics procedures we clearly have limited our sample size as we were not being permitted to recruit using NHS processes. However, we were able to capture the responses from seventy-three HCPs over a short period of time despite the ongoing challenges of the pandemic.

Online questionnaires place limitations on the generalizability of the findings given that we were only able to capture the experiences of plwALS and HCPs who were able to complete these. Furthermore, the ALSFRS-R scores were self-reported which we acknowledge may have affected reliability. However, online self-reported assessments have been shown to correlate well with paper-based clinician interviews (34). We used cross-sectional surveys that examined different time periods, which places limitations on the interpretation of the findings. The cross-sectional nature of the surveys precluded us from evaluating the long-term implications of the disruption in ALS care. Future research would be useful to assess this.

Finally, we used both closed questions and open-ended questions to allow participants to elaborate on answers which provided us with richer data than quantitative data alone. However, the survey approach can prevent more in-depth exploration of unexpected themes that arise than alternative methods such as semi- or unstructured interviews or focus groups (35).

Conclusion

The unprecedented nature of the Covid-19 pandemic meant that services needed to adopt new delivery models to maintain patient safety while coping with the pressures on healthcare services. ALS care has changed and been disrupted as a result of the pandemic. In particular, patients have had a lack of face-to-face contact with HCPs, and delays to investigations and evidenced based interventions. It remains unclear whether these changes will have any long-term implications. Some changes that were reported are not in line with international and national ALS guidelines (e.g.

timing of investigations and evidence-based treatments) (7,33). It is clear that services will need to continue to adapt and evolve in light of learning from this pandemic. A blended model of face-to-face contact and remote consultations will likely remain for the foreseeable future to suit the preferences of plwALS while keeping patients safe and being able to deliver good care. HCPs and services should maintain high standards of care and abide by clinical guidelines to ensure plwALS receive maximum benefits from the care and treatments they receive. We propose recommendations that may be helpful for HCPs and services to ensure continuity of care for plwALS in the context of a pandemic.

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Declaration of interest

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this article.

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