UK clinical approaches to address post-stroke fatigue: findings from The Nottingham Fatigue after Stroke study

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Abstract

Background/Aims: Although post-stroke is common and debilitating, there is little published research on how it is managed by clinicians. Therefore the aim of this study was to document UK management of post-stroke fatigue and ascertain whether there are any differences in its management compared to fatigue arising from other conditions.

Methods A cross-sectional survey was given to allied health professionals, psychologists, doctors and nurses working clinically in hospitals, the community or both, who routinely provided information, management or treatment to patients with fatigue. Questionnaires were designed and underwent pilot testing. Recruitment was conducted using healthcare professional networks, professional and condition special interest groups and social media, snowballing and personal emails targeting key professional experts.

Results A total of 305 questionnaires were analysed; the majority were from occupational therapists (56%, *n*=171). Although there were different opinions about whether post-stroke fatigue was the same as fatigue resulting from other conditions, the strategies suggested for both were similar. Post-stroke management included pacing (67%, *n*=204), which is spreading activities out during the day or week, keeping a fatigue diary (39%, *n*=119) and education (38%, *n*=117). There were variations in how support was offered, and marked variations in length of follow up; some services were flexible and could retain patients for up to 18 months, while others offered one session and no follow up.

Conclusions People with post-stroke fatigue and fatigue arising from other conditions experience different levels of support to manage their fatigue, but the main strategies used in management are similar.

Keywords

Allied health professional, Fatigue, Fatigue management, Post-stroke fatigue, Survey methodology

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Introduction

Post-stroke fatigue is common (Hinkle et al, 2017), affects all aspects of daily life (Worthington et al, 2017), is linked to poor clinical outcomes (Lerdal and Gay, 2017) and increases carer burden (Mandliya et al, 2016). It is generally defined as an ‘overwhelming feeling of exhaustion or tiredness’, which is not related to exertion and does not typically improve with rest (De Groot et al, 2003). The management of post-stroke fatigue is recognised as an ongoing research priority, both nationally and internationally (Norrving et al, 2018) and by people with post-stroke fatigue (Pollock et al, 2012).

Despite an increasing interest in the topic, there is little evidence to strongly support particular interventions for post-stroke fatigue. Possible explanations could relate to the lack of universal agreement about the definition of post-stroke fatigue (Hinkle et al, 2017) or because despite ongoing research, post-stroke fatigue mechanisms remain unclear (Hinkle et al, 2017; De Doncker et al, 2018; Aali et al, 2020). Several comprehensive reviews (Hinkle et al, 2017; Aali et al, 2020) and Cochrane systematic reviews (Wu et al, 2015; Kennedy and Kidd, 2018) have attempted to provide evidence-based guidance on management but have been unable to do so, largely because of inconsistencies in case definitions and sample sizes. Consequently, clinical national and international practice guidelines rely on low levels of evidence, such as clinical expert consensus, to make recommendations for post-stroke fatigue.

In the absence of definitive guidance and with an incomplete evidence base, the overall aim was to conduct a study to develop a comprehensive fatigue management programme for stroke survivors with post-stroke fatigue. As part of this wider study, Nottingham Fatigue Stroke Study (NotFAST2), which sought to examine the management of post-stroke fatigue pragmatically (Drummond et al 2020) the authors first needed to understand and document clinical management of post-stroke fatigue in the UK. Although the focus was on stroke, the authors wanted to examine interventions used in other conditions where fatigue is also a key symptom, for example in multiple sclerosis (Braley and Chervin, 2010) and rheumatoid arthritis (van Steenbergen et al, 2015) in order to ascertain any differences and similarities that might be of value in future research endeavors. Thus, the research question was ‘how do clinicians manage their patients with post-stroke fatigue, and ‘other’ fatigue?’ Specifically, the objectives were to understand:

- Whether there are differences in healthcare professionals’ perceptions of the management of fatigue following stroke, compared to the management of fatigue in other conditions
- The healthcare conditions with associated fatigue that are commonly referred or treated
- The format and content of interventions offered and whether people with fatigue are followed up
- Whether fatigue assessments are routinely used
- The confidence of healthcare professionals in managing fatigue.

Methods

Ethical approval

The study received ethical approval from the University of Nottingham Faculty of Medicine Research Ethics Committee (Reference 480-2001: 10 March 2020). Participant consent was taken electronically, respondents had to tick a box to confirm consent. The survey was designed so that participants were not able to answer questions if they did not complete the section on providing informed consent.

Study design

This was a cross-sectional survey of UK-based allied healthcare professionals, psychologists, medical doctors and nurses. Participants were eligible if they were currently working clinically in either a hospital or a community setting, or were working across both and routinely provided information, management or treatment to any patient with fatigue.

Instrument

A questionnaire was developed by the authors with input from the study steering group (full text available from the authors). The steering group consisted of the authors, occupational therapists, physiotherapists and patient and public involvement members, with lived experience of managing fatigue. Key relevant literature was used, notably that of Hinkle et al (2017) and Aali et al (2020) to guide the content. The survey was designed to collect data specifically on the following:

- Participant details (profession, clinical setting, geographical location) and confidence in managing fatigue in stroke and other conditions
- Conditions treated and referral methods
- Assessments used and interventions used
- Number of sessions offered and timescale; use of follow up and review
- Whether post-stroke fatigue was perceived as different to other fatigue
- Participants' rating of their confidence in managing people with fatigue and specifically with post-stroke fatigue, using a 10-point Likert scale (1: not very confident, 10: very confident).

The survey included a total of 23 questions and used a combination of single response, multiple choice and free-text response options. For example, the question regarding professional group was multiple choice, allowing a single response, followed by a free-text answer where further explanation could be provided if relevant. Similarly, the question 'do you think post-stroke fatigue is different to other fatigue?' was a single response, multiple choice answer followed by a free text answer to provide further explanation. The two questions, relating to clinicians' confidence in the management of people with post-stroke fatigue and fatigue, used a Likert-response scale. The questions were designed to examine attitudes, knowledge and beliefs about fatigue management.

The survey was initially pilot tested by the study steering group members, several of whom were practising clinically and working with patients with fatigue, who were asked to complete the survey assuming the role of a potential participant. When the content of this was agreed, the survey was transferred onto an online platform, providing the option for either postal or online completion. Research colleagues were then asked to provide overall feedback on ease of completion. Following this, minor amendments were made to resolve any technical issues with online completion.

At this point, the survey was pilot-tested with eight clinicians (three 'stroke' nurse consultants, four clinical occupational therapists and one physiotherapist). They completed the survey and provided feedback and comments regarding the clarity of the questions, whether they felt any key issues had been overlooked and their experiences of the online form. Consequently, some further changes were made, this included clarification around the wording of workplace settings, wording regarding 'routine provision' was amended to include 'before COVID-19' in order to understand practice before short-term changes in practice because of COVID-19. Further minor technical points were addressed to allow greater fluidity in moving around the survey and the wording was again scrutinised to ensure it was in plain English. The data collected in the pilot phases were not included in the final analysis.

Procedure

The survey was launched on 20 July 2020 and was open for 3 months, closing on 31 October 2020. Recruitment was conducted through targeting professional networks, such as the UK Stroke Forum and the Specialist Section of Occupational Therapists interested in Neurology, professional and condition-specific special interest groups and via Twitter. A snowballing method (Heckathorn, 2011) was also used; the research team used professional contacts to share information and colleagues were asked to forward details of the survey to others with an interest in fatigue. Key prominent professionals who had published on fatigue or who were part of clinical advisory panels across the UK were emailed directly.

Analysis

Descriptive statistics were used to examine the numbers of participants who responded to single response, multiple choice questions in relation to whether post-stroke fatigue is different to fatigue, the assessments and interventions used for managing fatigue and post-stroke fatigue, the format of interventions, the assessment of fatigue and routine follow up. Descriptive statistics were also used to examine participant clinical backgrounds including numbers reporting on the Likert scale for participant perceived confidence in supporting fatigue management of their patients with fatigue in general and stroke survivors with post-stroke fatigue. Free text responses were then explored for broad, overarching themes that provided further explanations for ‘closed questions’. JA and AD read the sample of free-text responses and independently created themes and codes under each question heading. These themes and codes were then discussed with the wider research team. As the codes were applied to the data, commonality between codes was noted, as was when a new code was required. These were again discussed with the research team to ensure agreement with regard to the final themes and codes in relation to the responses.

Results

Responses were received from 306 participants. Of these, one was excluded as they were from outside the UK; therefore, 305 responses were included in the analysis. Responses were received from across the UK (***Table 1***). The largest response was from the southeast of England (*n*=75, 25%), followed by Scotland (*n*=49, 16.1%) and Yorkshire and the Humber (*n*=34, 11%). Responses were received from a range of professions, with the majority from occupational therapists (*n*=171, 56%) and physiotherapists (*n*=65, 21%). Participants were alerted to the survey via Twitter (*n*=130, 42.6%), their professional network (*n*=98, 32.1%), colleagues (*n*=15, 24.6%) or ‘other’ methods (*n*=15, 4.9%). Some participants were informed by more than one source.

Table 1. Geographical spread of respondents

	Occupational therapist		**Physiotherapist**		**Nurse**		**Psychologist**		**Medical doctor**		**Other***		**Total**	
	n	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***	***n***	***(%)***
South east	47	(15.41)	16	(5.24)	1	(0.33)	4	(1.31)	3	(0.99)	4	(1.31)	75	(24.59)
Scotland	20	(6.55)	12	(3.93)	10	(3.28)	0		4	(1.31)	3	(0.99)	49	(16.06)
Yorkshire And the Humber	17	(5.58)	4	(1.31)	11	(3.61)	2	(0.65)	0		1	(0.33)	34	(11.48)
South West	17	(5.58)	11	(3.61)	2	(0.65)	0		0		3	(0.99)	33	(10.82)
East Midlands	10	(3.28)	4	(1.31)	5	(1.64)	5	(1.64)	2	(0.65)	0		26	(8.53)
North west	21	(6.88)	3	(0.99)	0		2	(0.65)	0		0		26	(8.52)
Wales	11	(3.61)	4	(1.31)	1	(0.33)	0		0		0		16	(5.24)
North east	8	(2.62)	4	(1.31)	0		0		1	(0.33)	2	(0.66)	15	(4.92)
East of England	8	(2.62)	5	(1.64)	0		0		0		0		13	(4.26)
West Midlands	9	(2.95)	1	(0.33)	0		0		0		0		10	(3.28)
Northern Ireland	2	(0.65)	1	(0.33)	0		1	(0.33)	1				5	(1.64)
Isle of Man	0		0		1	(0.33)	0		0		0		1	(0.33)
UK Region Not Stated	1	(0.33)	0		0		0		0		0		1	(0.33)
Total	171	(56.06)	65	(21.31)	31	(10.17)	14	(4.60)	11	(3.60)	13	(4.26)	305	(100)

*For example: dietitians, speech and language therapists.

Clinical settings, conditions treated and methods of referral

Respondents worked in a wide range of locations, across a range of settings and with a diverse population of patients: there were respondents working in the community and in primary care, in hospitals, working between both of these sectors, employed by charities and as independent practitioners. Although the majority worked within a team or rehabilitation unit, some worked alone. Even when respondents worked with one key group, the range of settings listed was also diverse, for example, those working with patients with stroke were employed in stroke units, general neurological teams (including neuropsychology teams), outpatients, outreach teams, specific clinics, such as transient ischaemic attack and minor stroke clinics, 6-month review clinics, worked in early supported discharge teams, general community rehabilitation teams or community neurorehabilitation teams.

The range of conditions listed was diverse, and while some respondents worked with people from only one group, such as stroke, multiple sclerosis or traumatic brain injury, others worked across generic areas, including neurology, rheumatology, oncology, or were employed in a fatigue-specific service that treated people with a range of conditions. However, the majority of respondents worked with stroke survivors (*n*=260, 85.2%), those with multiple sclerosis (*n*=119, 39%), Parkinson’s disease (*n*=108, 35.4%), chronic fatigue syndrome (*n*=58, 19%) and arthritis (*n*=40, 13.1%). The list of the ‘other’ (*n*=133, 43.6%) key conditions or groups of conditions identified (ie those listed by more than ten respondents) was extensive and included cancer, cerebral palsy, Guillain Barré Syndrome, motor neurone disease, respiratory conditions, COVID-19 and post viral fatigue.

Of the 305 participants, the majority (*n*=234, 76.7%) did not treat post-stroke fatigue within a generic fatigue service, while 71 participants (23.3%) did. Participants reported that the majority of their patients were referred by (another) occupational therapist or physiotherapist (*n*=211, 69.2%), although there were a notable number of self-referrals (*n*=133, 43.6%) (*Table 2).*

Table 2. Method of referral for fatigue management

Source of referral	***n* (%)**
Occupational therapists and physiotherapists	211 (69.2)
Medical doctors	208 (68.2)
Nurses	155 (50.8)
Self-referral	133 (43.6)
Carers/family	81 (26.6)
Psychologists	80 (26.2)
Paid carers	32 (10.5)
Other*	61 (20)

*Included social workers and case managers.

Is post-stroke fatigue different from other fatigue?

While almost half of respondents believed that post-stroke fatigue was different to fatigue in other conditions (*n*=154, 50.5%), just over a third were not sure (*n*=124, 40.7%), and others felt it was the same (*n*=31, 10.2%). Those who believed post-stroke fatigue was different from fatigue in other conditions, and from any other fatigue experienced, said:

> ‘There are some similarities to other neuro conditions but primary fatigue as result of stroke is specific to post stroke.’
>
> ‘Post-stroke fatigue can improve and lessen, whereas often fatigue associated with conditions such as multiple sclerosis progress in the same way as the condition.’
>
> ‘Patients state that it [post-stroke fatigue] does not feel like any other tiredness/fatigue that they have experienced.’
>
> ‘It [post-stroke fatigue] appears to be all consuming and more debilitating that normal fatigue.’
>
> ‘[Post-stroke fatigue] tends to be more related to physical/cognitive problems and more responsive to rehab[ilitation].’

Of those who were not sure or did not know whether there was a difference in fatigue, some cited their own lack of experience with fatigue in other conditions, in stroke, or commented on the individual nature of fatigue:

> ‘I work within stroke services and have not worked with other [types of] fatigue.’
>
> ‘I have some understanding of post-stroke fatigue but not so much of other types of fatigue’.
>
> ‘Don't have knowledge re post stroke fatigue’.
>
> ‘Not worked in post stroke clinical setting’.
>
> ‘I don’t think we fully understand the underlying mechanisms of fatigue and whether they differ across conditions.’

> ‘Each person is different, and this seems to be the basis of a treatment approach. People describe mental/cognitive fatigue but also physical fatigue post stroke.’

> ‘The mechanisms may all be different but the experience to the patient may be similar’.

> ‘Many reasons for fatigue in both stroke and non-stroke; [we] have to unlock each individual’s problem.’

Those who felt there were no differences suggested:

> ‘I think the same physiological response occurs with all types of fatigue.’

> ‘I think the impact is the same but I'm not sure about the mechanisms.’

> ‘Never thought of it as different.’

Some respondents underlined their belief that there were differences in physical and cognitive fatigue:

> ‘I do think cognitive fatigue adds a different angle.’

Interventions for managing fatigue and post-stroke fatigue

Participants were asked to list the top three interventions that they used with their patients to manage fatigue generally and specifically for post-stroke fatigue. These can be seen in ***Table 3***. The most commonly cited was ‘pacing’, which is where patients are advised to spread out their activities and intersperse these with rest periods. This was followed by keeping a diary (some called this a fatigue diary and some an activity diary) so individuals could understand their patterns of fatigue plus their daily and weekly activities and education, which included education of the individual about how fatigue was a common symptom and how to manage it, and educating family members and carers. However, there were a wide range of suggestions.

Table 3. Top suggestions of respondents to manage fatigue

	Post-stroke fatigue	**All fatigue**
Top interventions	**Total responses** **_n_ (%)**	**Total responses** **_n_ (%)**
Pacing	204 (66.88)	275 (90.16)
Diary	119 (39.1)	121 (39.67)
Education – patient/care/family	117 (38.36)	139 (45.57)
Exercise	48 (15.73)	61 (20)
Sleep hygiene	41 (13.44)	49 (16.06)
Resting eg after lunch, early evening	37 (12.13)	34 (11.14)
Graded activity	27 (8.85)	0 (0)

Information: written or web	26 (8.52)	20 (6.55)
Psychological therapy (eg acceptance and commitment therapy or cognitive behaviour therapy)	19 (6.22)	19 (6.22)
Assessment	17 (5.57)	28 (9.18)
Relaxation	17 (5.57)	24 (7.86)
Goal setting	16 (5.24)	18 (5.9)
Nutrition	11 (3.6)	19 (6.23)
Formal fatigue management programme	11 (3.6)	0 (0)
Specialist referral onwards	8 (2.62)	21 (6.88)
Environment modification	0 (0)	15 (4.91)
Self-management	0 (0)	10 (3.27)
N/A (ie not treating this group)	38 (12.45)	0 (0)

Format of interventions

Before COVID-19, participants reported that they were most likely to provide rehabilitation one-to-one, face-to-face (*n*=264, 87%) or to provide written information (*n*=239, 78%) and to do this by telephone (*n*=154, 51%), in a group (*n*=70, 23%) or a combination of both groups and individual sessions (*n*=75, 25%). Many respondents set (what they referred to as) ‘homework’ tasks, for example, to keep an activity diary (*n*=259, 86%), and directing people to web resources (*n*=139, 46%) and apps (*n*=89, 29%). The web resources cited were all condition-specific including the Stroke Association (*n*=54, 18%), Multiple Sclerosis Society (*n*=18, 6%), and Headway (for people with traumatic brain injury; *n*=19, 6%). General relaxation/mindfulness apps were recommended, as well as specific relaxation or mindfulness apps, such as Headspace (*n*=38, 12.4%), Calm (*n*=17, 5.57%). A generic pacing app was cited by two participants but details were not given.

Assessing fatigue

The majority of respondents did not use a standardised assessment tool to assess fatigue; 66% (*n*=201) for post-stroke fatigue, and 71% (*n*=216) for fatigue arising from other conditions. Of the participants that used a standardised assessment for fatigue, the most frequently cited were the Modified Fatigue Impact Scale (Heckathorn, 2011) (*n*=31) and the Fatigue Severity Scale (Larson, 2013) (*n*=27). However, 23 participants mentioned one specific ‘other’ assessment tool, for example, ‘in house’ locally devised scales, condition-specific scales, such as the Inflammatory Bowel Disease Fatigue Scale, Bristol Rheumatoid Arthritis Fatigue Scale or cited generic fatigue scales, many of which we could not find or identify (see *Table 4*).

Table 4. Standardised assessments for fatigue

Formal assessment tool or questionnaire	***n (%)***
Fatigue Severity Scale/Fatigue Impact Scale	32 (10.5)
Modified Fatigue Impact Scale (MS)	31 (10.2)
Fatigue Assessment Scale	11 (3.6)
Visual analogue scale – fatigue	5 (1.6)
Chalder Fatigue Scale	3 (1.0)
Multidimensional assessment of fatigue	3 (1.0)
Visual analogue scale – fatigue	3 (1.0)
Barrow Neurological Institute Fatigue Scale	2 (0.6)
Fatigue questionnaire	2 (0.6)
Functional assessment of chronic illness Therapy fatigue scale	2 (0.6)
Canadian Occupational Performance Measure	2 (0.6)

With regard to post-stroke fatigue specifically, the most popular assessment tools used were the Fatigue Severity Scale (*n*=14, 4.6%) and the Modified Fatigue Impact Scale (*n*=15, 4.9%), (which was specifically developed for use with patients with multiple sclerosis). Some (*n*=8, 2.6%) used the Fatigue Assessment Scale and others (*n*=8, 2.6%), reported using a variety of other assessment tools, for example, the mental fatigue questionnaire (*n*=1), scales not specifically validated for stroke and a 'local' scale (*n*=1).

Routine follow up

The majority (*n*=223, 73%) reported that there was no set maximum length of time for the follow up (that is, maintaining clinical contact with people after their initial assessment) of people with fatigue, whereas 82 (27%) reported that there was; however, this could be 'variable'. It was also not clear whether follow up referred to only further reassessment or to offer further rehabilitation. While some supplied exact figures (eg. 2 weeks, 7 weeks, 12 weeks) others provided ranges (eg. 1–2 weeks, 4–8 weeks and 6–10 weeks). Of those who supplied a numerical value, there was a wide range identified, with the lowest being 1 week and the highest being 18 months. Some respondents also noted that they might provide more input initially and taper the sessions off, while others saw the patient regularly weekly or fortnightly. Some had health service agreements, so could not see anyone for longer than 6 weeks (for instance), while others were flexible. Some began their contact with patients while they were in hospital, others only after discharge. Responses were also varied regarding how follow up was determined. Some reported that follow up was based on a locally agreed protocol, others that it was based on their clinical reasoning, and some that it was a combination of both.

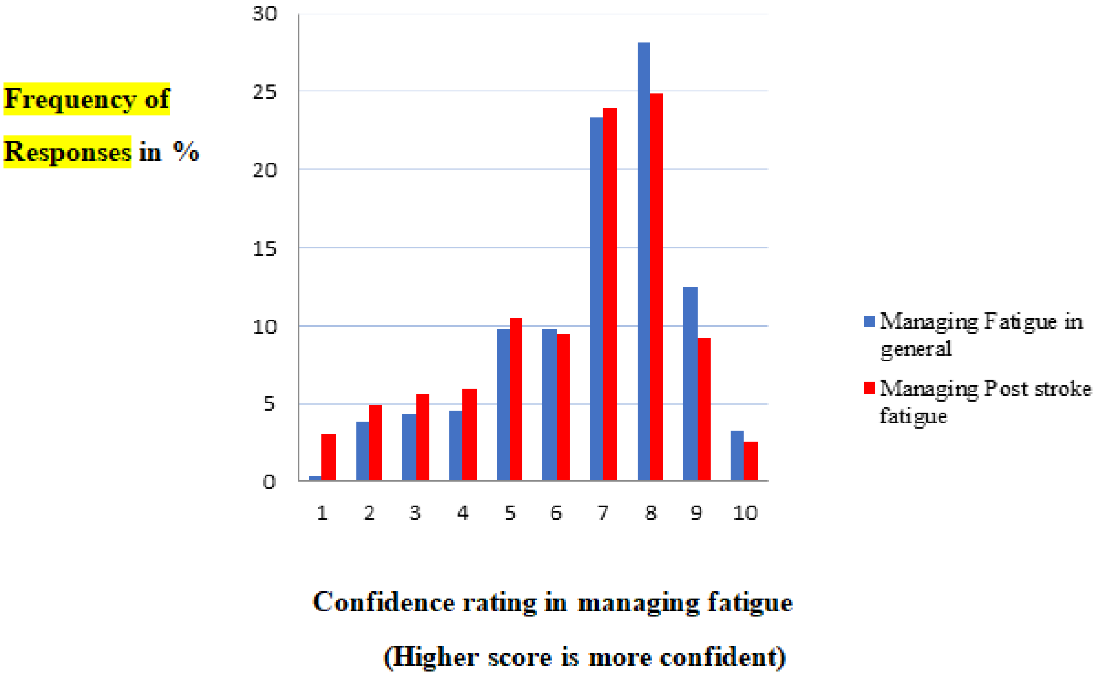
With regards to number of individual sessions, there was also a wide range of responses. Many respondents simply said this was 'variable' or that there was 'no set amount'. Others supplied ranges (eg. 1–2 sessions, 5–10 sessions and 1–20 sessions) or provided a specific number (eg. 3 sessions, 6 sessions, and 12 sessions). The lowest number cited was 1 and the highest was 20 sessions.

Of those who did provide fatigue management treatment or support to people with post-stroke fatigue, 49% (*n*=148) reported that regular follow-up was provided. However, responses were varied; some said this was offered automatically as part of a 6-month review, others offered a telephone contact, or a home visit (before COVID-19) and several respondents reported that follow up was conducted on an individual basis agreed with the patient and as a part of a wider rehabilitation plan.

Confidence in managing people with fatigue and fatigue after stroke

Participants reported similar levels of confidence in managing both fatigue generally and post-stroke fatigue (*Figure 1*). Participants rated their perceived confidence level on a Likert scale (1: not very confident, 10: very confident). Most rated their confidence to be 7 (fatigue generally (*n*=71, 23%), (fatigue after stroke (*n*=73, 24%) or 8 (fatigue generally (*n*=86, 28%), (fatigue after stroke (*n*=76, 25%). There were a number who felt less confident as determined by a score of 1–4 on the Likert scale – 19% (*n*=59) respondents were not confident in managing post-stroke fatigue, while 13% (*n*=40) were not confident with managing other fatigues.

Figure 1. Self-reported confidence in managing fatigue.



Discussion

This was a UK-wide study of fatigue management and a total of 305 questionnaires were analysed. To the best of the authors' knowledge, this is the first survey conducted on this topic. The majority of respondents were occupational therapists but responses were also received from physiotherapists and nurses. In addition, respondents included those who worked with people with post-stroke fatigue and those working with people with fatigue resulting from other conditions, which enabled comparisons to be made. Although there were differences in opinions about whether post-stroke fatigue was different from other types of fatigue, the strategies used to manage both were similar. The most common strategies cited were pacing, keeping an activity diary and education (including both the patient and their family/carers). This is consistent with recommendations in the *UK national clinical guideline for stroke* (Royal College of Physicians, 2016), and in other international guidelines such as the *Canadian Stroke Best Practice Recommendations* (Lanctôt et al, 2020), which have recommended education and information provision. However, it is worth reiterating that these clinical recommendations are largely generated from expert professional consensus rather than from research.

It was notable that the majority of respondents were occupational therapists and there was an impression that in many services, fatigue management is synonymous with this professional group. However, it was not clear whether the focus of occupational therapy on everyday activities makes this profession best suited to providing this care or whether the results reflected less engagement from other groups.

There were marked variations in the input offered to patients, and in the length of follow-up periods. While some services were extremely flexible and could retain patients for up to 18 months, some people received only one session and there were no opportunities for any follow up. There were also differences in respondents' confidence in managing people with fatigue, both with post-stroke fatigue and that arising from other conditions. There were a number who reported that they did not feel confident in managing fatigue, which given its prevalence in the stroke population, merits attention. It was not a study objective to compare or draw particular conclusions about the different professions who manage post-stroke fatigue and therefore the data did not enable an appropriate analysis of whether some professional groups were more confident than others in managing fatigue. However, this could be explored in future research.

The results of this survey are difficult to benchmark more widely. Although there have been extensive systematic reviews, notably Hinkle et al (2017) and Aali et al (2020), these have been conducted on studies that have focused on targeting particular strategies, such as cognitive behavioural therapy (Zedlitz et al, 2012). Until this point, it has not been clear what strategies clinicians in practice have actually used with their patients or how (or if) they have implemented clinical recommendations; a survey by Thomas et al (2019) focused only on post-stroke fatigue, targeted only occupational therapists and physiotherapists and sought to understand how clinicians conceptualise fatigue rather than asking about what they actually did in practice. The authors believe that the findings in the present study are important as they demonstrate what is happening in clinical practice and how healthcare professions manage this aspect of their workload in the face of a weak evidence base.

There were key challenges in analysing the data. It was difficult to categorise some of the data in any meaningful way given the fact that services were set up so differently and that, while some respondents had a caseload with clear demarcations (for example, multiple sclerosis, or those with a neurological diagnosis) others were able to treat anyone who was referred to them with fatigue. It was also clear that while some services had an exact limit on how long a patient could be treated for, or could cite a time frame (for example, 4–8 weeks) other services were very fluid and individuals could access services for as long as they were needed. This meant that it was not possible to calculate any meaningful figures to illustrate time frames. This survey also showed that, contrary to national guidance, there was not a consistent approach to using standardised assessments for fatigue generally or for post-stroke fatigue specifically. However, there was some difficulty noted for many respondents in naming and identifying the assessments they used; some used photocopied forms and were not clear what the original source was. It was also interesting that clinicians used scales for measuring post-stroke fatigue developed and validated for other conditions. Nevertheless, it was noticeable that most respondents did not use any standardised assessment at all despite this being recommended in national guidance. A number of respondents identified conducting an assessment as an intervention in its own right – presumably because the results were used to inform or educate people about their fatigue.

Strengths and limitations

A strength of the study is that respondents were from across the UK, from a range of professions and from those working specifically in post-stroke fatigue and those who were not. Several approaches were used to promote the study and it seemed that using social media and targeting professional networks were the most successful strategies. Respondents were generous in the information they provided and many provided additional details and expanded on their responses.

However, although this was a relatively large survey, there were limitations. It was not possible to determine a response rate which means that, ultimately, it is not known how representative the results are of practice. Most significantly, the survey was conducted during a COVID-19 peak in the UK NHS, which would have affected overall response rates. Equally, it is recognised that those people who responded were very likely to be those professionals with a strong interest in this topic and who felt knowledgeable, as reflected in the ‘confidence’ scores. Another limitation were the difficulties faced in analysing the data. It was challenging to categorise some data in any meaningful way, given the fact that services were set up so differently. These differences in services and in approaches to the rollout of services present clear barriers to collecting research data and to enabling research.

As already acknowledged, two of the key difficulties in conducting research in this topic lie in the absence of an accepted definition of post-stroke fatigue and the lack of proposed mechanisms to explain and underpin it. It may be easier to achieve the first, which would in turn improve the generalisation of results from future research endeavours. However, the second is likely to take much more thought and planning. It is also evident that clinicians rely on evidence from other conditions that have fatigue as a symptom. This research is, itself, often not robust and again, there needs to be consensus around whether fatigue in other conditions is essentially the same.

Conclusions

Although there were differences in opinion about whether post-stroke fatigue was different from other fatigue, the same strategies were used clinically for both. There were marked variations in access to support and management in terms of how much input could be provided, and in terms of whether follow up was routinely offered: only a small number of respondents used standardised tools to assess their patients’ fatigue. In reality, the service provided depended on where people lived and on the protocols in local services, rather than on clinical need. Of key concern, there was a notable absence of conducting formal assessments of fatigue by clinicians.

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