Understanding Post-Stroke Fatigue

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Abstract

Post-Stroke Fatigue is a common and debilitating condition affecting stroke survivors' quality of life, rehabilitation outcomes, mood and life expectancy. There is no widely accepted evidence-based method of assessment, measurement or management of fatigue. Improved knowledge of both stroke survivor and health care practitioner perspectives on post-stroke fatigue could inform care pathways. This thesis addresses four research questions 1) How is post-stroke fatigue perceived? 2) What are the psychometric properties of current fatigue measurement scales? 3) How do healthcare practitioners assess post-stroke fatigue? 4) How is post-stroke fatigue managed?

These four questions were answered through five studies. *Study 1.* A systematic search and literature review of validity, reliability, and acceptability of fatigue specific scales. *Study 2.* Thematic analysis of archived posts on the Stroke Association hosted forum TalkStroke. *Study 3.* Thematic analysis of semi-structured interviews with 25 stroke survivors and supporters investigating the lived experience of post-stroke fatigue. *Study 4.* An online survey of 137 stroke rehabilitation therapists. *Study 5.* Framework analysis of 2 focus groups with healthcare practitioners exploring post-stroke fatigue care pathways.

Study 1. Many outcome measures have been developed for fatigue in chronic conditions, however there is still no gold standard outcome measure for post-stroke fatigue when considering psychometric properties. *Study 2.* Six themes were generated, encapsulating forum users perception that fatigue is a legitimate symptom of stroke which can be coped with and conceptualised in a variety of ways. *Study 3.* The unpredictable and variable nature of fatigue is distressing and acts as a barrier to routine, roles and personal aspirations. *Study 4.* Therapists use a variety of assessment and management strategies in clinical practice, predominantly focused on self-management. Notable variation was found between respondents' definitions and characterisations of post-stroke fatigue. *Study 5.* Approaches to assessment and management varied by profession and setting, often led by one perceived specialist within the clinical team. The resulting lack of standardised approach may affect continuity of care.

Stroke survivors, their supporters and healthcare practitioners find understanding and explaining post-stroke fatigue challenging due to its variable and multi-faceted presentation. Perhaps as a result of its subjective nature, no measurement scales used in a stroke population have been found to have optimal psychometric properties. In the clinical setting, measurement tools are often used as an addition to extensive subjective assessment to enable the healthcare practitioner to assess the impact of fatigue. Management strategies vary dependent on profession and setting, leading to unstandardised care pathways and information provision.

Declaration

I herewith declare, that this dissertation, submitted for the degree of Doctor of Philosophy at the University of Cambridge, is the result of my own work and includes nothing which is the outcome of work done in collaboration except where specifically indicated in the preface and specified in the text It is not substantially the same as any work that has already been submitted before for any degree or other qualification except as declared in the preface or specified in the text.

This dissertation is 66,693 words long and so does not exceed the word limit (excluding figures, references and appendices) set by the degree committee for Clinical Medicine and Clinical Veterinary Medicine.

No part of this dissertation has been submitted for any other qualification.

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Thank you to every stroke survivor, supporter, family member and clinician I have met. Providing your voice and your story will have a bigger effect than you realise and over time I hope will drive changes we all hope for. To those I interviewed, your ongoing strength and determination is amazing, and I will remember many of your stories and faces for the rest of my life.

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List of Publications and Conference Presentations

Publications

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Oral Presentations

Joint European Stroke Organisation and World Stroke Organisation Conference 2020 (Rapid Communication Presentation on Improving Stroke Outcomes)

UK Stroke Forum 2020 (Seat on Fatigue topic panel and invited session presenter)

Society for Academic Primary Care Annual Society Meeting 2018 (Excellent Abstract; chosen for a poster & pitch presentation)

Society for Academic Primary Care 2018 (Excellent Abstract; chosen for a poster & pitch presentation)

Nursing, Midwifery and Allied Health Professions, Cambridge Conference 2018 (Best Abstract award)

National Royal College of Occupational Therapy- Neurological Specialist Section Conference 2018

Poster Presentations

Joint European Stroke Organisation and World Stroke Organisation Conference 2020

Society for Academic Primary Care ASM 2018

Nursing, Midwifery and Allied Health Professions Cambridge Conference 2018

Society for Academic Primary Care Eastern Region Conference 2018 & 2020

Association of Chartered Physiotherapists in Neurology National Conference 2018 & 2020

UK Stroke Forum 2018

In Service Clinical Training Sessions

Addenbrookes Acute Stroke team (Lewin Stroke Ward)

Spire Cambridge Lea Physiotherapy team

Cambridgeshire Stroke Lead Fatigue Workshop

Cambridgeshire and Peterborough Foundation Trust Community Teams

Contents

Section 1

Section 2

Section 3

Section 4

1. Increased visibility of post-stroke fatigue

2. Improved continuity of care and communications between settings

3. Lived experience terminology and education

4. Standardised ‘baseline’ information giving and resources

List of figures

List of tables

List of abbreviations

ACPIN- Association of Physiotherapists in Neurology

AHA- American Heart Association

ESD- Early Supported Discharge Team

FAS- Fatigue Assessment Scale

FSS- Fatigue Severity Score

OT- Occupational Therapist

MBSR- Mindfulness-Based Stress Reduction

MFSI-General- Multidimensional Fatigue Symptom Inventory

MS- Multiple Sclerosis

PROM- Patient Reported Outcome Measure

POMS-Fatigue- Profile of Mood States

PPI- Patient and Public Involvement

PSF- Post-Stroke Fatigue

PT- Physiotherapist

RCOT- Royal College of Occupational Therapy

RCOT-NSS- Royal College of Occupational Therapy Specialist Section- Neurological Practice

SALT- Speech and Language Therapy

SDHS- Secure Data Hosting Service

SS- Stroke Survivor

SU- Supporter

TBI- Traumatic Brain Injury

WHO- World Health Organisation

List of terms

Care giver- A trusted individual who carries out care for a stroke survivor. This may be on a formal basis within a residential or care home environment or be in an informal care capacity as significant other, child or sibling.

Healthcare Practitioner- This term encompasses all qualified allied healthcare professionals, nurses and doctors who play a role in the support of stroke survivors and their supporters.

Patient- An individual receiving active treatment either prior to discharge from an acute setting or receiving support from community healthcare practitioner(s).

Stroke Survivor- An individual over the age of 18 who has been diagnosed with a stroke. No gender or socioeconomic boundaries have been set regarding use of this term.

Supporter- A trusted individual who spends time with a stroke survivor. This term encompasses family members, significant others, children and close friends.

Therapist- An individual registered with the Health & Care Professions Council (HCPC) as an Occupational Therapist or Physiotherapist.

Initials of Study Collaborators

ADS- Anna De Simoni
CG- Chloe Gamlin
CH- Clarissa Hjalmarsson
DM- Donna Malley
JM- Jonathan Mant
RM- Ricky Mullis

Section 1

Chapter 1- Introduction

Lay Summary

Having a stroke is a life-changing experience. Symptoms are individual to each person and include physical, social and mood changes.   Looking at a stroke survivor you may not always know how the stroke has affected them. One ‘hidden’ symptom is fatigue. When you or I feel tired we often adjust our behaviour to help us to recover. This may be by getting an early night's sleep or taking a break from work to read a book. Individuals who experience fatigue after a stroke may sleep for longer periods yet still feel tired. Simply having a short conversation with a family member, even if sitting down, might exhaust a stroke survivor.

Research has shown that fatigue is one of the most commonly occurring un-met needs following a stroke and often it leaves the person affected feeling isolated and misunderstood by their family and friends. In some cases, individuals have been unable to explain to relatives the difference between their tiredness before and after the stroke. This may lead to it being interpreted as normal. Fatigue after stroke is not yet fully understood by researchers and healthcare practitioners. We are still working out what exactly fatigue after stroke is and how we can explain and measure it.

If we could better understand what fatigue after stroke is, what causes it and what strategies could be used to help people who have it then we could potentially improve many individuals’ quality of life and independence.

Section 1. Introduction

-The problem

-What is currently known about post-stroke fatigue?

-Defining fatigue

-How common is post-stroke fatigue?

-Measuring Fatigue

-Mechanisms of Post-Stroke Fatigue

-The Natural Course of Post-Stroke Fatigue

-Factors associated with Post-Stroke Fatigue

-Assessment and Management of fatigue in other conditions

-Assessment and Management of Post-Stroke Fatigue

Chapter 2 -Aims and Objectives of the Thesis

Section 2. Methods (by study)
Section 3. Results (by research question)
Section 4. Discussion and conclusions

1.1 The problem

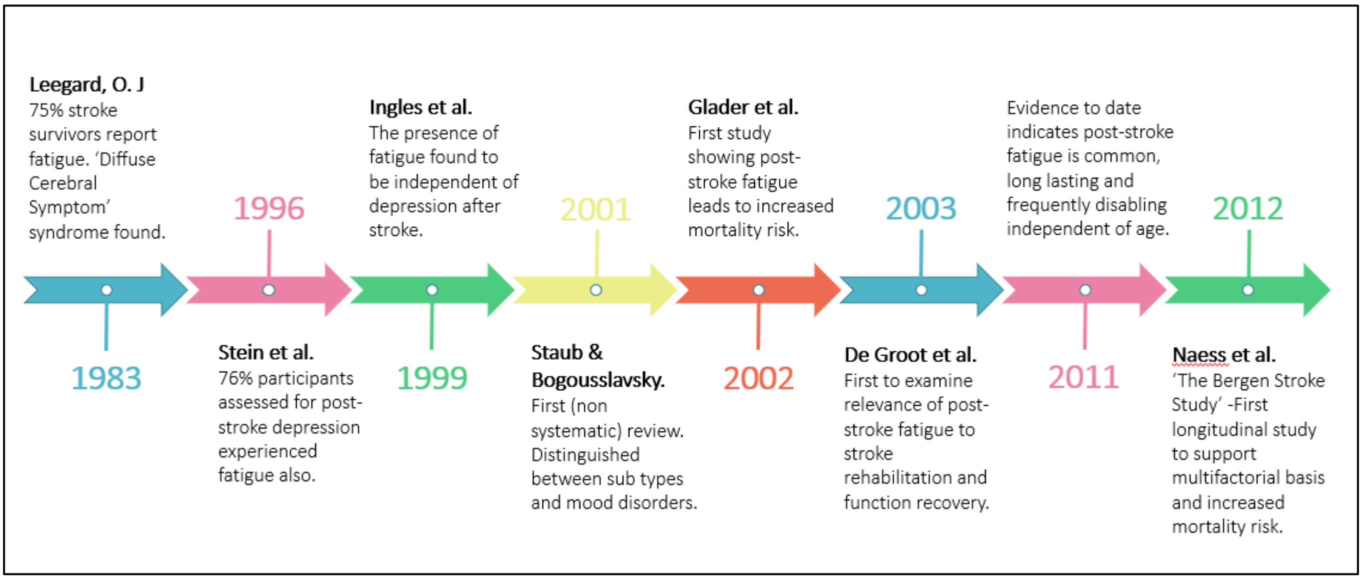
In the United Kingdom (UK), over 100,000 strokes occurred in 2018, with the number of diagnosed stroke survivors predicted to increase by over 123 percent by 2035 (Stroke Association, 2018). Worldwide, stroke is the second most common cause of death and stroke-related disability is set to double over the next 15 years (WHO, 2017; Feigin et al, 2016). A stroke event is caused by an artery blockage, termed an ischemic stroke, or a burst blood vessel, known as a haemorrhagic stroke. The majority of strokes that occur are ischemic, however haemorrhagic strokes often lead to higher rates of disability and mortality (Mant & Walker, 2011). Many risk factors have been identified, including raised blood pressure, diabetes, and blood vessel diseases. Primary prevention, including identification and treatment of modifiable risk factors, has progressed considerably o An international study carried out in 2016 found 10 modifiable risk factors to be associated with stroke, independent of gender and age group (O’Donnell et al, 2016). Variation in importance of each risk factor was identified dependent on geographical region and stroke event characteristics. Due to the need for timely assessment and treatment, a clear knowledge of the symptoms of stroke is in the public interest. The Department of Health led the first UK stroke awareness ‘Act FAST’ campaign in 2009. This highlighted several of the most common stroke symptoms, which are numbness or weakness on one side of the body and face with confusion or trouble speaking. There are many physical and cognitive effects of stroke. The most common, according to a 2018 Stroke Association survey, are fatigue (86%), memory (83%), balance problems (82%), concentration (80%) and mobility issues (75%). Despite nine out of ten UK stroke survivors experiencing at least one cognitive effect, stroke is most commonly known for causing physical difficulties.

Currently, it is estimated that the cost of stroke to the UK society is £5.3 billion a year, within a wider economic cost of £26 billion. This is likely to increase as the population ages (Stroke Association, 2018). Acute management of stroke in the UK has changed dramatically in recent years, with an increasing and reliable evidence base highlighting the benefit of effective stroke unit care for improved patient outcomes (Young and Forster, 2007), and evidence based acute treatments such as thrombolysis and thrombectomy (National Audit Office, 2010).

Fatigue can worsen the impact of neurological conditions, leading to greater handicap and lower life satisfaction (Levine and Greenwald, 2009). Post-stroke fatigue is a common and debilitating problem for stroke survivors (Murray et al, 2003; Cumming et al, 2016). It adversely affects individuals' quality of life, social participation, return to work and mortality (Eilertsen et al, 2012; Balasooriya-Smeekens et al, 2016; Glader et al, 2002; Naess et al, 2006). These findings occur independently of stroke severity (Choi-Kwon and Kim, 2011). Stroke survivors who experience good clinical recovery are often prevented from returning to work by fatigue, which can affect mental health and have economic implications (Andersen et al, 2012). Currently there is not a widely adopted definition, a gold standard stroke-specific outcome measure or well-evidenced therapeutic options available for the management of post-stroke fatigue (McGeough et al, 2017; Acciarresi et al, 2014).

This PhD aims to contribute evidence to inform the fatigue management pathway, through the use of a number of studies involving perspectives of stroke survivors, their support networks and healthcare practitioners.

1.2 What is currently known about post-stroke fatigue?



Leegard, O. J
75% stroke survivors report fatigue. 'Diffuse Cerebral Symptom' syndrome found.

Stein et al.
76% participants assessed for post-stroke depression experienced fatigue also.

Ingles et al.
The presence of fatigue found to be independent of depression after stroke.

Staub & Bogousslavsky.
First (non systematic) review. Distinguished between sub types and mood disorders.

Glader et al.
First study showing post-stroke fatigue leads to increased mortality risk.

De Groot et al.
First to examine relevance of post-stroke fatigue to stroke rehabilitation and function recovery.

Evidence to date indicates post-stroke fatigue is common, long lasting and frequently disabling independent of age.

Naess et al.
'The Bergen Stroke Study' -First longitudinal study to support multifactorial basis and increased mortality risk.

Figure 1. A timeline depicting major advancements in the literature from 1980-2015.

Post-stroke fatigue first emerged within academia in 1983, when Leegard and colleagues proposed fatigue as a component of the "Diffuse Cerebral Symptom" Syndrome (Figure 1, Page 4). Alongside fatigue, the syndrome was thought to encompass emotional lability, poor memory and reduced concentration following stroke. The authors believed this syndrome occurred due to an adjustment reaction caused by inadequate coping (Leegard et al, 1983). Little research was carried out over the following decade until 1996 when an investigation of the discriminative properties of post-stroke depression found a significant link between post-stroke fatigue and depression. 76 percent of the study's participants assessed for post-stroke depression also experienced fatigue (Stein et al, 1996). Fatigue being a constituent symptom of post-stroke depression was the accepted view until Ingles and colleagues found the presence of fatigue to be independent of depression following stroke (Ingles et al, 2001). In 2001, Staub and Bogousslavsky published the first large review on post-stroke fatigue. Within this, the authors suggest the presence of primary and secondary fatigue, where 'primary' fatigue was thought to develop in the absence of cognitive post-stroke changes and result from subcortical damage caused by the stroke event. Additionally, the importance of co-existing factors and the effect coping ability may have on fatigue impact was considered within the paper (Staub and Bogousslavsky, 2001). Kuppuswamys' mechanistic model proposed in 2015 further supported the presence of independent mechanisms occurring in early and persisting fatigue (Kuppuswamy et al, 2015). Following Staub and Bogousslavskys' review, the number of studies investigating post-stroke fatigue began to grow. Evidence emerged of an association of post-stroke fatigue with increased mortality and poorer rehabilitation outcomes, further clarifying its clinical importance (Glader et al, 2002; De Groot et al, 2003).

Until 2012, no large-scale longitudinal studies had been carried out, investigating post-stroke fatigue (Wu et al, 2015). The Bergen Stroke Study was the first longitudinal study to evidence the multifactorial nature of fatigue and increased mortality risk associated with post-stroke fatigue 1 year after the stroke event (Naess et al, 2012). Forty-two percent of participants who returned the study questionnaire reported fatigue, supporting the consensus that post-stroke fatigue is a common occurrence after stroke. This finding was comparable with the frequencies reported in other shorter duration studies (Glader et al, 2002). Over time, researchers have speculated on the mechanisms underlying post-stroke fatigue (Kuppuswamy, 2017; De Doncker et al, 2017). Amongst these, Kuppuswamy proposed that pathological fatigue occurs due to the perception that daily motor tasks are more effortful as a result of poor sensory attenuation. This is defined as a phenomenon where the intensity of sensation caused by self-generated movement is reduced. De Donckers' work centred around increased pro-inflammatory responses caused by the stroke event (Kuppuswamy, 2017; De Doncker et al, 2017). These proposals are discussed in greater detail within Section 1.5.

1.3 Defining fatigue

The term ‘fatigue’ is generally agreed to represent a multifactorial, subjective experience independent of the associated condition (Duncan et al, 2015; Malley et al, 2014). In 1891, Mosso delineated two clear aspects of generalised pathological fatigue, distinguishing the diminution of muscular force and the sensation of fatigue. Mosso split fatigue into physical fatigue, which is readily measurable, and a more elusive psychological element (Mosso et al, 1891; Giulio et al, 2006).

In 1971, McFarland stated that ‘fatigue’ was one of the most used and yet most poorly understood words in the English language (McFarland et al, 1971). Irrespective of the sharp increase in the published literature on fatigue over the last 30 years, and on post-stroke fatigue specifically in the past 2 decades, this insight appears to still hold true. Pathological fatigue is a common complication in many illnesses and is highly subjective, affects mood and reduces performance in every-day tasks. De Groot and colleagues defined pathological fatigue as a constant state of weariness that is unrelated to activity levels and is usually not improved by rest (De Groot et al, 2003). This points towards pathological fatigue being present in both the acute and chronic stages of illness.

Initial background literature reading was carried out in the early stages of the PhD project (Table 1, Page 8). Within this, a search was carried out on definitions of pathological and neurological fatigue. Commonly occurring terms in the definitions were the term “weariness” and reference to the feeling of a lack of energy. Some examples are as follows:

Definition	Author
“A subjective lack of physical or mental energy (or both) that is perceived by the individual to interfere with usual or desired activities”	Guidelines, Multiple Sclerosis Clinical Practice, 1998
“A feeling of early exhaustion with weariness, lack of energy and aversion to effort that develops during physical or mental activity and not ameliorated by rest”	Staub and Bogousslavsky, 2001
“A feeling of physical tiredness and lack of energy that is described as pathological, abnormal, excessive, chronic, persistent or problematic”	De Groot et al, 2003
“Since their stroke, the patient has experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day. This fatigue has led to difficulty taking part in everyday activities”	Lynch et al, 2007
“A feeling of weariness, tiredness, and lack of energy that is pathologic and chronic”	Kwon and Kim, 2011
“A constant weariness unrelated to previous exertion levels and not usually ameliorated by rest”	Egerton et al, 2012

Table 1: Examples of fatigue definitions captured during background literature reading.

Of the above definitions, only the statement included in the 1998 Multiple Sclerosis Guidelines included mental fatigue. Mental fatigue has been found to be a common and debilitating characteristic of post-stroke fatigue (Johansson and Ronnback, 2014). However, the term lacks specificity and no studies have proposed how to measure it objectively. Mental fatigue can be broken down into constituent symptoms including fatigability accompanied by the feeling of exhaustion and a long recovery time to restore energy (Johansson et al, 2012). In the Stroke Associations’ recent Lived Experience of Stroke report, fatigue was classified as a cognitive after effect of stroke, adding to the complexity of the condition (Stroke Association, 2019). Qualitative studies investigating post-stroke fatigue have supported the notion that fatigue is related to cognition (Eilertsen et al, 2012; Salter et al, 2008; Pedersen et al, 2019).

Staub and Bogousslavsky proposed a definition of post-stroke fatigue in their 2001 review; "*A feeling of early exhaustion with weariness, lack of energy and aversion to effort that develops during physical or mental activity and not ameliorated by rest*". To overcome limitations arising from using subjective definition, Lynch and colleagues proposed two case-definitions; one for hospital patients and one for community-based patients. The following case definition for community-based stroke survivors was proposed:

"*Since their stroke, the patient has experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day. This fatigue has led to difficulty taking part in everyday activities*". (Lynch et al, 2007)

The Lynch et al definition has been tested for reliability and validity. Concurrent validity was displayed through use of four scales (MFSI-General, FAS, POMS-Fatigue subscale, SF-36) to measure fatigue severity. Each score was related to case definition fulfilment and individuals rating higher levels of fatigue on the definition also had substantially higher scores on all 4 scales (p<.001 on the Mann-Whitney *U* test). Almost 40% of participants fulfilled the definition, which is in line with other literature in the field (Lynch et al, 2007; Naess et al, 2012; Glader et al, 2007). However, the majority of the study participants in Lynch and colleagues investigation were inpatients and due to the changeable nature of post-stroke fatigue, this may not be representative of stroke survivors based in the community with a chronic presentation. The definition provides several objectively measurable markers. However, it does not include markers of fatigue impact or psychosocial symptoms of fatigue that have been shown to be relevant (Eilertsen et al, 2013).

A meta-synthesis of qualitative post-stroke fatigue studies was carried out by Eilertsen and colleagues in 2013, highlighting the limited experience-based narrative research in the field. The authors found that the core characteristics of fatigue were influenced by two main factors. Firstly, acknowledgement by the stroke survivor and their significant others affected how fatigue was experienced and the perceived legitimacy of the condition. Secondly, two main coping ability styles were evidenced; taking fatigue into account and struggling to cope. Eilertsen's review demonstrated that individuals perceive and experience fatigue in a variety of different ways.

Therefore, it is difficult to create one definition which accounts for every post-stroke fatigue sufferer. In the absence of an accepted definition, the use of interchangeable terminology makes understanding fatigue challenging for stroke survivors, clinicians, and researchers alike (Kuppuswamy, 2017; Wu et al, 2015). For the purpose of this thesis, the definition which will be used will be Lynch’s case definition ‘Since their stroke, the patient has experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day. This fatigue has led to difficulty taking part in everyday activities’. The thesis will inform the reader on the suitability of this definition for future projects on post-stroke fatigue.

1.4 How common is Post-Stroke Fatigue?

Lynch attempted to provide a way to quantify post-stroke fatigue, which in turn would make measurement and assessment less challenging. Without a standardised or agreed measure available, estimates of the prevalence of post-stroke fatigue in stroke survivors have been highly variable ranging from 23% to 75% (Naess et al, 2005; van der Werf et al, 2001; Park et al, 2009). Ponchel and colleagues systematic review outlined several other factors that affect this figure; the use of unidimensional and multidimensional conceptual frameworks, lack of a consensual definition and variation in stroke survivor age, stroke type, severity, and presence of comorbidities (Ponchel et al, 2015). The use of patient-reported outcome measures could also have excluded patients with greater neurological deficits unable to engage with this form of fatigue assessment, who may have also suffered from fatigue (Snaphaan et al, 2010). This should be considered when interpreting the figures presented as it could have led to an underestimation.

In addition to post-stroke fatigue being a common post-stroke problem, the largest survey to be conducted on stroke survivors long-term needs found that over half of the 1251 participants reported fatigue as a problem and 43% of those individuals felt that it was an un-met need (McKevitt et al, 2011). This finding was supported by Crosby and colleagues who found that although post-stroke fatigue was a commonly occurring problem, few patients in their audit study had discussed fatigue with a healthcare practitioner (Crosby et al, 2012).

1.5 Measuring fatigue

Measurement tools are also needed to assess or evaluate the most efficacious management strategies. Before 2012, no stroke-specific fatigue measures had been developed. Several general multi-dimensional fatigue measurement scales have been used by researchers and clinicians. The validity of these scales was reviewed in relation to post-stroke fatigue by Mead and colleagues who noted that all the scales used to measure and assess post-stroke fatigue were originally developed for other conditions and ask questions that could be confusing or misleading to stroke survivors such as “Do you feel weak?” (Mead et al, 2007). Following a stroke, this question may be considered in the context of residual hemiparesis. Scales that lacked face validity were excluded from the systematic review. Four scales were found by Mead to be valid and feasible for measurement of post-stroke fatigue, namely the

Profile of Mood States (POMS-Fatigue), Fatigue Assessment Scale (FAS), Multidimensional Fatigue Symptom Inventory (MFSI-General) and the vitality subscale of the SF-36v2 (McNair et al, 1971; Michielsen et al, 2004; Stein et al, 1998; Ware et al, 1992). The Fatigue Assessment Scale was recommended for measurement of post-stroke fatigue in Meads review due to its feasibility, high test-retest reliability (within 95% limits of agreement) and high construct validity (p=0.001 when tested against POMS). However, the scale had a low internal consistency (Table 18). The Fatigue Severity Scale was found to be the most commonly used scale to measure fatigue after stroke in the literature, followed by the Fatigue Visual Analogue Scale (Lerdal et al, 2009). The Fatigue Severity Scale is recommended by the AHA, who justified their choice due to it being the most commonly used scale. (Hinkle et al, 2017). The UK National Clinical Guidelines for Stroke do not provide a recommendation but do suggest that fatigue can be routinely assessed by structured assessment scales. (Intercollegiate Stroke Working Party, 2016).

In 2019, the Norwegian Study of Fatigue After Stroke group carried out a mixed-method content analysis of fatigue measures to assess scale acceptability for stroke survivors (Skogestad et al, 2019). The study provided valuable insight into whether the available measurement scales truly analyse the impact of stroke specific fatigue, and not pathological fatigue in general. They concluded that no measurement scales which have been utilised in a stroke population address all aspects of post-stroke fatigue. This echoes Mead and colleagues' finding in 2007 that poor face validity was a problem across most fatigue scales used to measure post-stroke fatigue, with the authors deciding 5 out of 52 identified fatigue scales exhibited adequate face validity. Despite this, the 2019 review identified 11 measures used to evaluate post-stroke fatigue as a primary outcome of a study on more than five occasions per measure as compared to no studies being found in Meads' 2007 review when employing the same criteria. Three of the measures were developed specifically for post-stroke fatigue. Thus, new scales are being developed including condition-specific ones. The variety of outcome measures and the high number of unique items within the measures reflects a continued lack of consensus across the field on how best to assess post-stroke fatigue (Skogestad et al, 2019). Skogestad noted that important aspects of assessment of post-stroke fatigue, such as diurnal variation and pre-stroke fatigue, were not included in any of the existing scales.

Given the variety of measures, the lack of consensus, and the continued developments in this area, a systematic search and literature review of the characteristics and psychometric properties of all fatigue patient-reported outcome measures evaluated in a stroke population forms part of the thesis.

1.6 Mechanisms of Post-Stroke Fatigue

The mechanisms underlying fatigue have been investigated for over a century, with no definitive models emerging. As described previously, Mossos' investigations distinguished between the diminution of muscular force and the sensation of fatigue (Mosso et al, 1891; Giulio et al, 2006). This classification continues to be used to explain a range of possible causative processes for fatigue. However, Mosso focused on non-pathological neuromuscular fatigue as opposed to pathological fatigue which is present in conditions such as stroke. Nevertheless, Mossos' theoretical concepts provide a framework from which to consider the pathophysiological basis of debilitating fatigue (Kuppuswamy et al, 2017). Pathological fatigue can be further divided into central and peripheral fatigue. Post-stroke fatigue is proposed as being associated with central fatigue. Central fatigue is defined as difficulty initiating and sustaining mental and physical tasks in the absence of motor or physical impairments (Levine and Greenwald, 2008).

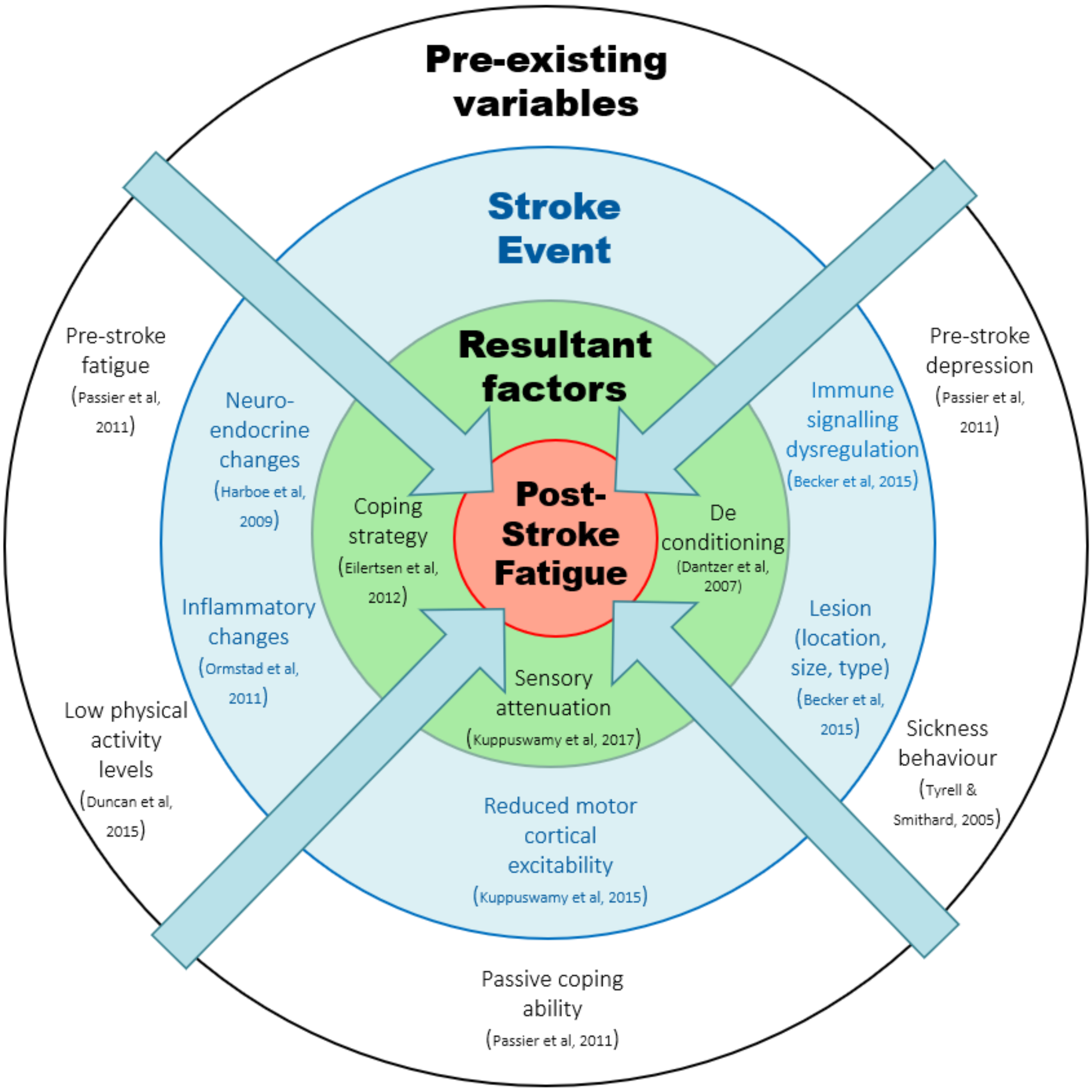


Figure 2. Model depicting proposed mechanisms of post-stroke fatigue in the literature.

Previous work has sought to classify post-stroke fatigue into biological and psychosocial dimensions and to identify primary and secondary aetiology (Maughan et al, 2014). Despite much research in the area, a definite pathophysiological cause has yet to be identified.

Biological data are often not included in post-stroke fatigue mechanistic studies (Kutlubaev et al, 2012). Prominent hypotheses, as shown in Figure 2, Page 14, include post-stroke fatigue being a disorder of sensorimotor attention, immune signalling dysregulation and the product of inflammatory processes (Kuppuswamy et al, 2017; Becker at al, 2015; Ormstad et al, 2011).

In the acute stage, one study found there to be an independent association between post-stroke fatigue and right side thalamic and brainstem lesions (Becker et al, 2015). However, when reviewing the literature more broadly and considering the acute and chronic stages of recovery, no definitive conclusions can be made regarding the link between fatigue severity and the location, aetiology or size of infarct, in part due to the varying methodologies employed (Becker et al, 2015).

Kuppuswamy proposed that *sensory attenuation*, a phenomenon where the intensity of sensation caused by self-generated movement is reduced, could help researchers and clinicians define and understand the pathophysiological basis of post-stroke fatigue and could also be applied to pathological fatigue more broadly (Blakemore et al, 2000; Kuppuswamy et al, 2017). Her aetiological framework suggests that fatigue is an affective symptom. Post-stroke fatigue has often been linked to self-reported high perceived effort during activities of daily living. Sensory attenuation studies have demonstrated daily motor acts being perceived as effortful when sensory pathways are impaired, which is a key component of pathological fatigue (Kuppuswamy et al, 2017). This framework could begin to explain the presence of fatigue in several chronic and neurological conditions. However, this mechanistic theory has not yet been able to explain the presence of fatigue at rest which is an ongoing and debilitating symptom expressed by many sufferers of severe fatigue after stroke.

Pro-inflammatory activation and processes occurring immediately after the stroke event have been considered as a contributing factor to fatigue severity and impact (Mutai et al, 2017; Becker et al, 2015). Following a stroke, it has been shown that there is an inflammatory reaction that spreads to the peripheries of the brain (Wang et al, 2007). This leads to an initial pro-inflammatory response and the activation of immunosuppressive mechanisms (Doncker et al, 2018). Inflammatory signalling and the presence of cytokines can affect the immune response, leading to fatigue (Kuppuswamy et al, 2017). Becker and colleagues investigated a potential genetic influence leading to increased systemic inflammation. They found that the single nucleotide polymorphism in IL1RN and TLR4 were significantly but differentially associated with post-stroke fatigue. The participants who reported higher levels of fatigue had a higher circulating concentration of inflammatory biomarkers (Becker et al, 2015). The sample size was relatively small and so future studies are needed to validate Beckers' findings. Ormstad and colleagues also investigated the association between inflammatory response and post-stroke fatigue (Ormstad et al, 2011). It was suggested that fatigue could be associated with inflammation-induced sickness behaviour, due to the presence of higher IL-1B levels in individuals with post-stroke fatigue.

Multiple small-scale studies have found associations between post-stroke fatigue, inflammatory markers, and neuroendocrine changes (Harboe et al, 2009; Krupp and Christodoulou, 2001; Ramsay and Rothrock, 2010). Several lines of evidence support this association; fatigue commonly occurs in immune-mediated illness (Krupp and Christodoulou, 2001), the administration of pro-inflammatory cytokines leads to higher perceived fatigue levels (Tate et al, 2001) and treatment with cytokine antagonists causes decreased fatigue levels (Tookman et al, 2008).

No work has identified whether markers of inflammatory and biochemical change remain present in chronic post-stroke fatigue. Understanding and investigating the chronic sequelae of fatigue poses many additional challenges due to the behavioural, neurophysiological, and deconditioning effects associated with acute fatigue (Dantzer et al, 2007). These effects mean that identifying the cause and effect of stroke survivors' symptoms can become less straightforward.

Several mechanistic investigations have been carried out to progress understanding on the causes of post-stroke fatigue. Although numerous studies have hinted at pathophysiological mechanisms, one clear answer has not been found. This is unsurprising considering the variability in patient presentations. Figure 2 (Page 14), provides an overview of the multiple different factors that could cause post-stroke fatigue characteristics, including pre-stroke and post-stroke factors and those relating to the stroke itself.

1.7 The Natural Course of Post-Stroke Fatigue

Post-stroke fatigue has been reported to fluctuate and change during its course (Wu et al, 2015). Increased awareness of this changeability has led to different definitions being proposed for post-stroke fatigue in the acute and chronic phases (Lynch et al, 2007).

No clear associations have been found between timeframe and fatigue severity in the literature to date, however the exclusion of severely aphasic stroke survivors in key studies suggest these findings are interpreted with caution (Becker et al, 2014; Hinkle et al, 2017). When fatigue levels are high in the acute phase after stroke, reduced function and activities of daily living have been observed (Lerdal and Gay, 2013). Inflammatory changes significantly associated with post-stroke fatigue were found 12 months post-stroke by Ormstad and colleagues, however, this did not remain the case at 18 months despite fatigue and depression levels not reducing (Ormstad et al, 2011). This suggests that if pro-inflammatory response is important, it is mainly linked to fatigue associated with acute stroke.

Early fatigue has been associated with late fatigue (van Eijsden et al, 2012; Passier et al, 2011). The temporal course of post-stroke fatigue has been modelled in Figure 3, Page 19 (Wu et al, 2015). Despite stating that a variety of biological, psychosocial, and behavioural factors are associated with the course of fatigue, Wu’s 2015 review suggested that the nature of the stroke event may be the strongest determinant of early fatigue, whilst psychological factors had an effect in both early and late fatigue. Comorbidities have been found to be a more important determinant of early fatigue than medication usage, although polypharmacy may lead to increased post-stroke fatigue severity in the initial months post stroke event (Ponchel et al, 2016). Outcome measure studies offer valuable information on the amount of time fatigue symptoms persist. Valko et al’s study suggested that in comparison to neurological symptoms, which may gradually improve following stroke, post-stroke fatigue may persist as a stable complaint, at least during the first two years (Valko et al, 2008). This ‘ongoing’ fatigue has been replicated in recent studies (Skogestad et al, 2019).

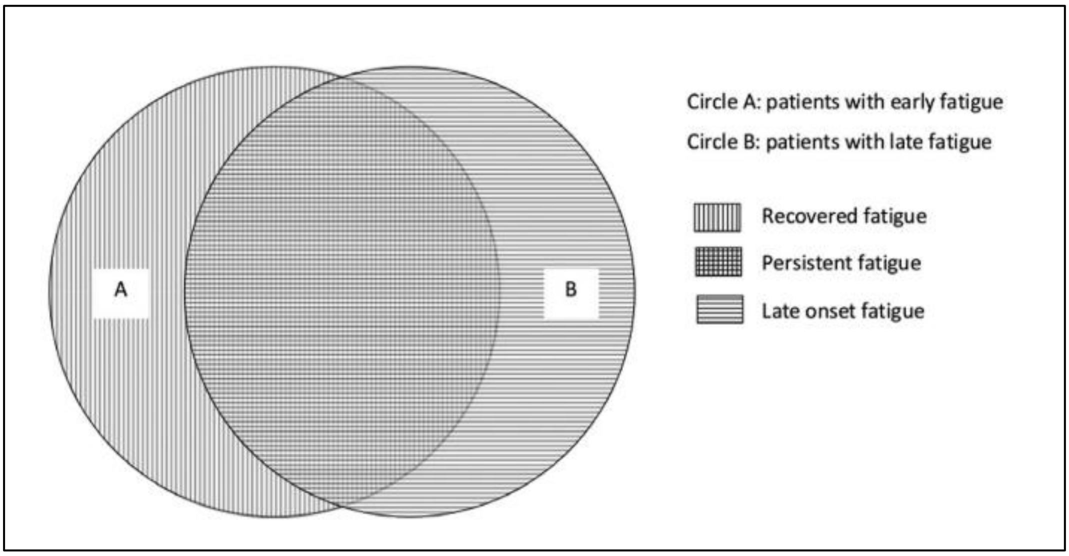


Figure 3. Temporal course of Post-Stroke Fatigue (Wu et al, 2015).

Another study (Staub and Bogousslavsky, 2001) which investigated the evolving characteristics of post-stroke fatigue from acute to chronic presentations found that specific risk factors led to increased severity levels. Chen and Marsh administered the Functional Assessment of Chronic Illness Therapy fatigue scale at several time points post-stroke. It was suggested that early fatigue was largely attributed to the severity of the stroke event whilst chronic fatigue was influenced more heavily by medical comorbidities and medication use (Chen and Marsh, 2016). Drummond found that the prevalence of fatigue in their participants recruited 4-6 weeks post stroke was high (43%) compared to Radman et al. who recruited participants at 6 months post stroke (30%), suggesting that fatigue occurs in the early stages following stroke and could be a key limiting factor when considering the acute rehabilitation potential window (Drummond et al, 2017).

1.8 Factors associated with Post-Stroke Fatigue

As found with fatigue in other chronic conditions, post-stroke fatigue has been described as a multi-factorial condition in qualitative and quantitative investigations (Stokes and Murphy, 2001; Kruithof et al, 2016; Kutlubaev and Mead, 2012). Mechanistic investigations in the field have found several factors to be associated with presence and impact of post-stroke fatigue (Figure 4, Page 20).

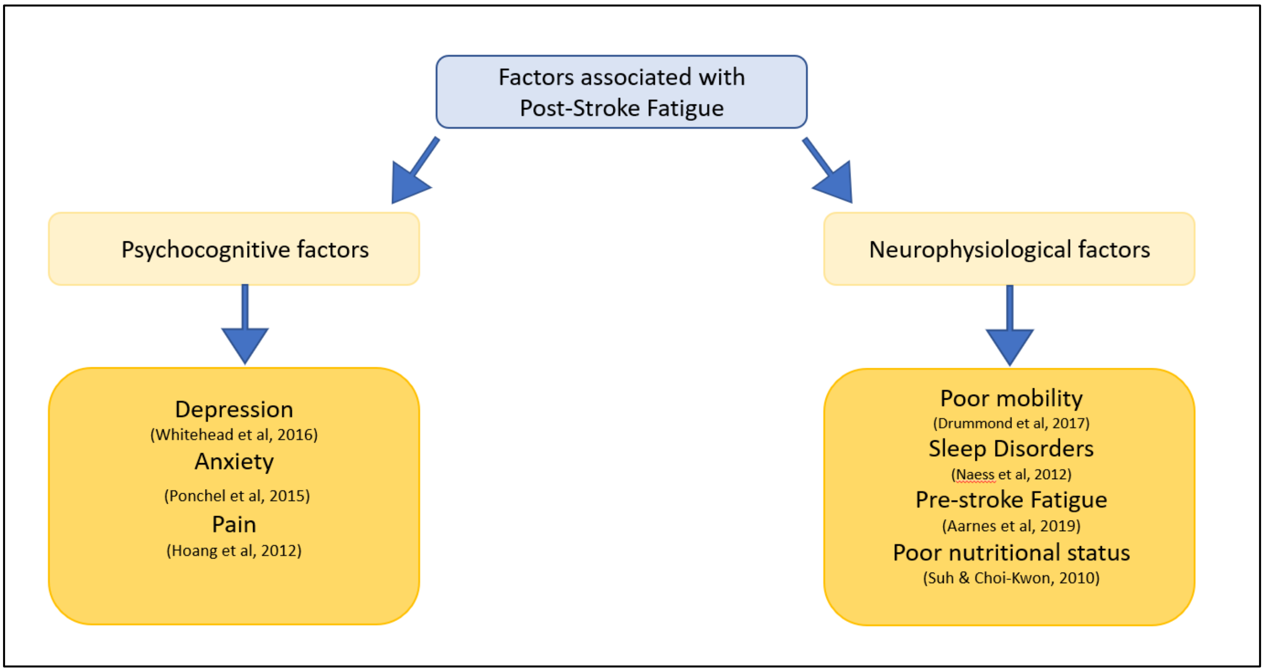


Figure 4. Factors associated with post-stroke fatigue, as reported in the literature.

Aarnes and colleagues carried out a systematic review of the literature which identified several factors associated with fatigue including demographics, emotional health, clinical factors, social factors, and cognitive function (Aarnes et al, 2011). These findings were replicated in Ponchel and colleagues' systematic review in 2015, which together provide an insight into our knowledge to date (Ponchel et al, 2015). Addressing a common limitation of the above reviews, the NotFAST study investigated factors associated with post-stroke fatigue, excluding post-stroke depression (Drummond et al, 2017).

Several associations have been investigated, however only 7 factors have been commonly linked with post-stroke fatigue. Neurophysiological factors included poor functional outcome and presence of physical fatigue which have been demonstrated as associated factors up to 2 years post stroke event (Christensen et al, 2008). The relationship between fatigue and physical deconditioning has been evidenced in the wider fatigue literature due to reduced muscle strength leading to higher effort. This relationship also would support Kuppuswamys' sensory attenuation hypothesis (Ponchel et al, 2015; Kuppuswamy, 2017). The presence of sleep disorders following stroke has been assessed in many studies, due to the frequency of individuals reporting sleep disturbances following stroke. Significant associations have been made in multiple studies, assessed by self-report questionnaire (Naess et al, 2012; Choi-Kwon et al, 2005; Tang et al, 2014). Although not unanimously demonstrated, the majority of studies investigating the relationship between pre- and post-stroke fatigue have found an association (Choi-Kwon et al, 2005; Lerdal et al, 2011; Duncan et al, 2014). Finally, studies assessing for vitality using the SF36-v2 Vitality Subscale found an association between low vitality which is synonymous with higher fatigue and poor nutrition (Suh and Choi-Kwon, 2010; Westergren, 2008).

Several psychocognitive factors have also been strongly associated with post-stroke fatigue. Mood disorders, in particular depression, have been heavily researched in stroke populations and in Ponchels' 2015 systematic review, 45 out of the 48 included studies found a correlation, increasing the generalisability of the conclusion (Ponchel et al, 2015). In Drummond and colleagues NotFAST study, an association with mood disorders was found despite individuals with high levels of depressive symptoms being excluded from the study (Drummond et al, 2017). Although the distinct characteristics separating post-stroke fatigue and depression have now been identified, co-occurrence must be considered alongside each conditions' common risk factors (Ponchel et al, 2015). Fatigue was found to heighten depressive symptom occurrence which could mean there is an indirect relationship between fatigue and cognition, mediated by post-stroke depression (MacIntosh et al, 2017). Other mood disorders link to post-stroke fatigue have not been investigated as frequently, however a consistent relationship has been demonstrated between anxiety and fatigue (Chen et al, 2014; Harbison et al, 2009; Ponchel et al, 2015). Finally, the presence of the subjective symptom of pain has been significantly associated with both the presence and persistence of post-stroke fatigue (Naess et al, 2012).

No clear links have been found between fatigue severity, presentation or location of infarct. One study found that post-stroke fatigue was slightly more common in females and the elderly, however not significantly associated (Van Eijsden et al, 2012). In the NotFAST study, the presence of a significant other led to higher fatigue levels. This conclusion contrasts with previous studies which found no association between fatigue and marital status and so is a factor which warrants further investigation (Drummond et al, 2017; Miller et al, 2013).

In summary, as shown in Figure 4 (Page 20), there are several psychocognitive and neurophysiological factors which have been associated with post-stroke fatigue. Further research is needed to find out if each factor was co-existing with other highlighted factors and to investigate whether treatment would reduce the severity of stroke survivors reported fatigue. In other conditions such as Cancer and Multiple Sclerosis, importance is placed upon detecting and treating associated factors within the clinical assessment (Berger et al, 2015; Braley and Chervin, 2010).

1.9 Assessment and Management of fatigue in other conditions

Fatigue is a commonly reported symptom within a large range of neurological and chronic conditions. It is one of the most frequent complaints in primary care whilst also being one of the most challenging to accurately assess due to the difficulties of objective measurement and varying personal experiences and perceptions (Johansson and Ronnback, 2012).

Similarities across conditions include the unpredictability of fatigue onset, the perception of a "different type of fatigue" distinct from non-pathological fatigue and the sense of a loss of control (Chaudhuri and Behan, 2004). Stroke survivors experiencing severe post-stroke fatigue have also been found to have a comparable psychosocial profile to patients with other chronic conditions, which provides a further rationale for examining assessment and management strategies across chronic diseases (Zedlitz et al, 2011). However, although similarities can be found, there are differences between fatigue in other conditions and that which stroke survivors experience. Further exploration of this literature would be worthwhile to further inform research and practice (Whitehead et al, 2016).

1.9.1 *Multiple Sclerosis*

Multiple Sclerosis (MS) is a progressive disease that results in lesions along the axons of nerve fibres in the Central Nervous System (Motl et al, 2009). As it progresses, it results in functional limitation, disability, and reduced quality of life (Opara et al, 2010). Several characteristics are shared between fatigue sufferers with MS and stroke diagnoses. To guide MS fatigue assessment, a stepwise approach has been published by the Multiple Sclerosis Council for Clinical Practice Guidelines (Fatigue Guidelines Development Panel, 1998). It highlighted the importance of considering associated factors and precipitators when assessing and developing a patient-specific management strategy (Braley and Chervin, 2010). Self-management and lifestyle adaptation are recommended strategies for mild to moderate MS-specific fatigue (Rooney et al, 2019). Conservative rehabilitation such as exercise and educational interventions were found to be more effective at reducing the impact and severity of fatigue as compared to pharmacological intervention, in a meta-analysis of published management interventions (Asano and Finlayson, 2014). Aerobic exercise is an accessible intervention with most studies reporting low attrition rates (Rooney et al, 2019). In progressive MS, exercise was found to reduce the impact of fatigue (Briken et al, 2014).

Although not recommended by MS Clinical Guidelines, several medications have been shown to benefit individuals with Multiple Sclerosis in small-scale studies (Fatigue Guidelines Development Panel, 1998). Notably, Modafinil led to the most pronounced changes when measured using the Fatigue Severity Scale. Bakshi (2003) concluded that selective use of pharmacologic and nonpharmacologic treatment approaches were most likely to lead to substantial improvements in outcome and quality of life for MS sufferers.

1.9.2 *Cancer*

Cancer-related fatigue is common and significantly affects the sufferer's quality of life (Wagner and Cella, 2004). Undertreatment of fatigue has been associated with ineffective assessment and identification (Curt et al, 2000). The National Comprehensive Cancer Network Cancer-Related (NCC-NCR) Fatigue Guidelines recommend a two-step approach (Berger et al, 2015). The first step is to identify and address contributing factors to the individual's fatigue, and then secondly to manage the residual fatigue. The guidelines emphasise the importance of screening at regular intervals and ongoing surveillance and evaluation. Clinical staff working in oncology are advised to use a simple VAS scale for the screening process and to first focus on managing concurrent and contributing symptoms (Berger et al, 2015).

Education, counselling and self-management strategies are recommended as initial non-pharmacological conservative interventions (Bower et al, 2014). No pharmacological interventions are suggested unless there is a need for referral to a specialist care provider. Exercise interventions have been shown to reduce fatigue, often through patient-selected exercise (Kelley and Kelley, 2017). The most investigated pharmacological treatment has been the use of psychostimulants such as patient-controlled methylphenidate and modafinil (Schwartz et al, 2002; Rammohan et al, 2002, Morrow et al, 2003). The National Comprehensive Cancer Network Guidelines reported some evidence supporting the use of psychostimulants in fatigue management however advised that pharmacological treatment should only be considered after ruling out all other potential causes of fatigue (Hanna et al, 2006; Berger et al, 2015).

1.9.3 *Traumatic brain injury*

Similar to post-stroke fatigue, fatigue following traumatic brain injury (TBI) is common. When looking to identify fatigue after TBI, healthcare practitioners assess for prolonged exhaustion which is exacerbated by sensory stimulation or extended cognitive tasks (Cantor et al, 2013). Focus has been placed on the importance of coping ability in brain injury fatigue studies (Ezekiel et al, 2020). Cantor and colleagues proposed a theoretical model similar to that which Leegard proposed in 1983. The “coping hypothesis” theorises that processing speed and attention adversely increases effort which is thought to lead to fatigue (Cantor et al, 2013). Fatigue is thought to describe “different symptom clusters with potentially heterogeneous aetiologies and consequences”, presenting a broader way of considering assessment and management of fatigue.

Self-management, planning and prioritisation of tasks are recommended to achieve a balance between rest and stimulating activities (Levine and Greenwald, 2009). Mental fatigue following TBI has been reduced by mindfulness-based stress reduction program interventions (Johansson et al, 2012). Mindfulness-based stress reduction (MBSR) improves long-term mental fatigue after stroke or traumatic brain injury. Pharmacological neurostimulants such as methylphenidate block dopamine and norepinephrine signalling which increases dopamine activity and is thought to translate to increased concentration and reduced stimulus overload (Johansson et al, 2017). Antidepressant medications and wakefulness agents have also been found to promote wakefulness. Although these pharmacological agents are known to be used, they are not supported by evidence (Levine and Greenwald, 2009).

1.10 Assessment and Management of Post-Stroke Fatigue

Currently, little evidence exists to guide the best clinical practice for the assessment and management of post-stroke fatigue. The AHA Scientific Statement recommends the use of the Fatigue Severity Scale to assess the condition, citing it as the most commonly used measure within the literature (Hinkle et al, 2017). The statement goes on to suggest post-stroke fatigue assessment should occur at the point of discharge from acute care and then reviewed at 3 months, 6 months, and 1-year post-stroke event. Suggestions have been made within the literature that healthcare practitioners should communicate that post-stroke fatigue is a likely consequence of stroke in both primary and secondary care (Colle et al, 2006). Wu's 2015 Cochrane review is the only review to investigate whether any intervention reduces the proportion of individuals experiencing fatigue, fatigue severity or both.

It concluded study methodological quality was poor throughout, and no study had a primary outcome measuring post-stroke fatigue. The conclusions within Wu's review have been reported within established UK stroke care guidelines (Royal College of Physicians, 2012; NICE Guidelines, 2013).

Fatigue is an important determinant of post-stroke disability and for this reason, it needs to be a consideration within stroke rehabilitation programmes (Mandliya et al, 2015). Wu's 2015 Cochrane review looked at interventions that focused on managing the underlying reasons for the fatigue occurring. These included dietary and hydration interventions, re-establishment of activity and exercise, antidepressant usage and effective sleep disorder interventions (Wu et al, 2015).

The pharmaceutical interventions tested included modafinil, fluoxetine, enerion, and citicoline. Fluoxetine and modafinil have received the greatest attention in recent years, with investigators hypothesising that fatigue decreases neurotransmitter availability (Dantzer et al, 2014). Wu concluded that fluoxetine did not lead to a reduction in post-stroke fatigue severity within a trial setting. Modafinil, a wakefulness-promoting agent, has been tested in several small sample studies. The treatment resulted in lower levels of self-reported fatigue and an improved quality of life (Visser et al, 2019). This result may be due to modafinil positively influencing sensory processing and alleviating motivational deficits occurring as a result of post-stroke fatigue. In a separate study, Visser and colleagues found that fronto-striato-thalamic functional connectivity predicted the modafinil response, which is a finding that has been replicated in other neurological populations and as such suggests there could be similar mechanisms across neurological related fatigue (Visser et al, 2019).

Annoni and colleagues found that the side effects of modafinil led to high participant drop out and although fatigue severity outcome measure scores decreased in brain-stem and thalamic strokes, they did not in cortical stroke infarcts. Bivard and colleagues carried out a cross-over trial and found that stroke survivors with non-resolving fatigue reported reduced fatigue levels and improved quality of life following daily modafinil usage (Bivard et al, 2017). Considering the above studies' findings, it could be suggested that characteristics of post-stroke fatigue vary dependent on the site of the lesion and pharmacological treatment may not be suitable for all post-stroke fatigue sufferers. Inflammatory changes have been well-established as a mechanistic factor in fatigue occurring in acute stroke. Becker considered that treatments that lessen inflammation, such as Aspirin, could be reasonably considered to reduce fatigue severity (Becker et al, 2016).

Non-pharmaceutical options that were tested but inconclusive included a fatigue education programme, a mindfulness-based stress reduction programme and continuous positive airway pressure (Clarke et al, 2015; Johansson et al, 2012; Brown et al, 2013). Cognitive behavioural therapy in addition to a graded exercise programme was found to reduce fatigue more than Cognitive Behavioural Therapy (CBT) alone however it was not clear which was the causal factor (Zedlitz et al, 2012). Wu suggested further studies should investigate management interventions focused on psychological interventions and physical training due to the associations between fatigue, mood disorders, and physical fitness.

Following on from the review, a psychological intervention pilot study of 8 participants was conducted by Wu and colleagues which demonstrated acceptability and feasibility utilising a combination of face-to-face and telephone sessions (Wu et al, 2017). Physiotherapy intervention has been found to improve physical endurance in fatigued stroke survivors, however further high-quality research is needed to test if fatigue levels are reduced over time (Alahmari et al, 2019).

Due to the multidimensional nature of post-stroke fatigue, effective management interventions would need to consider biological, psychological and behavioural contributors. Considering the evidence as a whole, it may be concluded that no single treatment strategy has effectively reduced the severity or impact of post-stroke fatigue. Considering the significant impact fatigue has on stroke survivors, it remains an insufficiently addressed consequence of stroke in major guidelines. The guidelines which have sought to provide recommendations have often concluded that the evidence is either not present or not of a high enough quality to guide practice.

Chapter 2

Section 1. Introduction
-The Problem
-What is currently known about post-stroke fatigue?
-Defining fatigue
-How common is post-stroke fatigue?
-Measuring fatigue
-Mechanisms of post-stroke fatigue
-The natural course of post-stroke fatigue
-Factors associated with post-stroke fatigue
-Assessment and management of fatigue in other conditions
-Assessment and management of post-stroke fatigue

Chapter 2. Approach to the thesis

-Aims and objectives

-Thesis development

-Sociological standpoint

-Approach to each thesis research question

Research Question 1: How is post-stroke fatigue perceived?

Research Question 2: What are the psychometric properties of current measurement scales?

Research Question 3: How do healthcare practitioners assess post-stroke fatigue?

Research Question 4: How is post-stroke fatigue managed?

Section 2. Methods (by study)
Section 3. Results (by research question)
Section 4. Discussion and conclusions

2.1 Aims and Objectives of the thesis - Overview

Post-stroke fatigue, similar to fatigue in other chronic conditions, lacks a consensual, clear definition. A pathophysiological basis of post-stroke fatigue is yet to be agreed. There is a paucity of evidence-based recommendations within national and international stroke care guidelines that advise healthcare practitioners on measurement, assessment or management strategies for stroke survivors experiencing fatigue. The most commonly used fatigue measurement scales in stroke care were not originally designed or evaluated for a stroke population. Reviews of post-stroke fatigue management have not been able to make clear recommendations due to the dearth of high-quality evidence.

Given the limited evidence base, and the high prevalence of post-stroke fatigue, it was important as a first step to better understand post-stroke fatigue from different perspectives. Secondly, given that appropriate outcome measurements are needed to evaluate interventions developed to manage post-stroke fatigue, it seemed important to assess the validity of existing measures that are in use. Thirdly, it was important to understand what is currently being done to assess and manage fatigue in clinical practice, given the lack of evidence-based guidance.

2.2 Aims and objectives

Thesis Aim

The thesis aimed to contribute evidence to support improved assessment and management of post-stroke fatigue. This aim has been broken down into four constituent research questions.

The thesis aimed to answer the research questions:

Research Question 1: How is post-stroke fatigue perceived?

Research Question 2: What are the psychometric properties of current measurement scales?

Research Question 3: How do healthcare practitioners assess post-stroke fatigue?

Research Question 4: How is post-stroke fatigue managed?

2.3 Thesis Approach: underlying principles

When approaching the thesis objective, a sociological theory was selected, which informed the creation of a theoretical model to encapsulate the lived experience of post-stroke fatigue. The way an individual makes sense of a situation determines their ongoing behaviour and how they view their 'self'. Both the model and sociological perspective detailed below support the view that knowledge of a patient's lived experience is vital to fully comprehend and make sense of their behaviour. The symbolic interactionism approach is centred around how social situations, different individuals and different perspectives affect the lived experience of illness. This is encapsulated in the importance of sense-making model.

2.3.1 Sociological position statement

Qualitative research allows the investigator to explore the cultural, social, and uniquely personal aspects of living with a condition (Astalin et al, 2013). To further investigate these areas, sociological theory was used to guide the interrogation of the data set. The theory underpinning this thesis will be symbolic interactionism (Charmaz and Belgrave, 2013). The Symbolic Interactionism theory was initially developed from the pragmatist view that human beings adapt in a constantly changing social landscape and this process is made possible due to the individuals' contemplation of a situation. Researchers operating within this paradigm are interested in how meaning arises during social interaction, how individuals present and construct the self and how social situations are defined. Considering health, a patient's lived experience is key to fully comprehend their behaviour. To understand how a stroke survivor and their supporters interact with the healthcare pathway and the practitioners they meet along it, it is important to interpret their experiences as they see them.

2.3.1 The importance of sense- making model

After deciding on the symbolic interactionism theoretical perspective , I worked with Occupational Therapist Donna Malley at the Oliver Zangwill Centre, to develop the *Importance of Sense-Making model* (Figure 5, Page 35). Considering the initial background literature reading highlighted in the introduction section, a different approach was needed to inform the thesis objective. It was hypothesised that progress had been hindered by a lack of in-depth insight into the lived experience of post-stroke fatigue that accounts for all perspectives involved. This hypothesis was supported by research carried out by Young and colleagues which focused on the patient perspective. Taking an interpretive phenomenological approach, the authors concluded that further research was needed to understand the dynamic interrelationships between the complexities of post-stroke fatigue and the unique patient profile. Due to the factors identified, caution was suggested in healthcare practitioners taking simplistic unitary approaches to information provision and management (Young et al, 2013).

We created the *Importance of Sense-Making* model to fit within the social dimensions of professional practice and inform the direction of the thesis (Nixon and Creek, 2006). The model demonstrates how the three perspectives within this thesis project are considered and interlinked, allowing for the symbolic interactionist theory to underpin each of the PhD studies. As the symbolic interactionism theory eludes to, the way an individual makes sense of the construct referred to here as ‘fatigue’ is likely to determine their behaviour towards it. The time post-onset that an individual first experiences fatigue is also a factor which is likely to influence presentation and the expectations of the individuals involved in management. This may change over time when considering how the patient-practitioner relationship adjusts between the acute and community settings. For this reason, a time arrow was added into the model. In the rehabilitation sphere, to foster self-management for a condition which might become chronic, a shared understanding will enable a collaborative approach and support patient-practitioner interaction.

Considering the symbolic interactionist perspective and importance of sense-making model together allows further investigation of the role and effectiveness of social interaction and what is perceived as effective communication between the three perspectives making up this thesis project. Four of the 5 studies within the thesis consider this concept in greater detail by looking at interactions; between stroke survivors and supporters on the TalkStroke forum analysis without the presence of researcher involvement, between stroke survivors and healthcare practitioners in a professional consultation context and between stroke survivor and supporter to assess the value this has when considering lived experience of post-stroke fatigue.

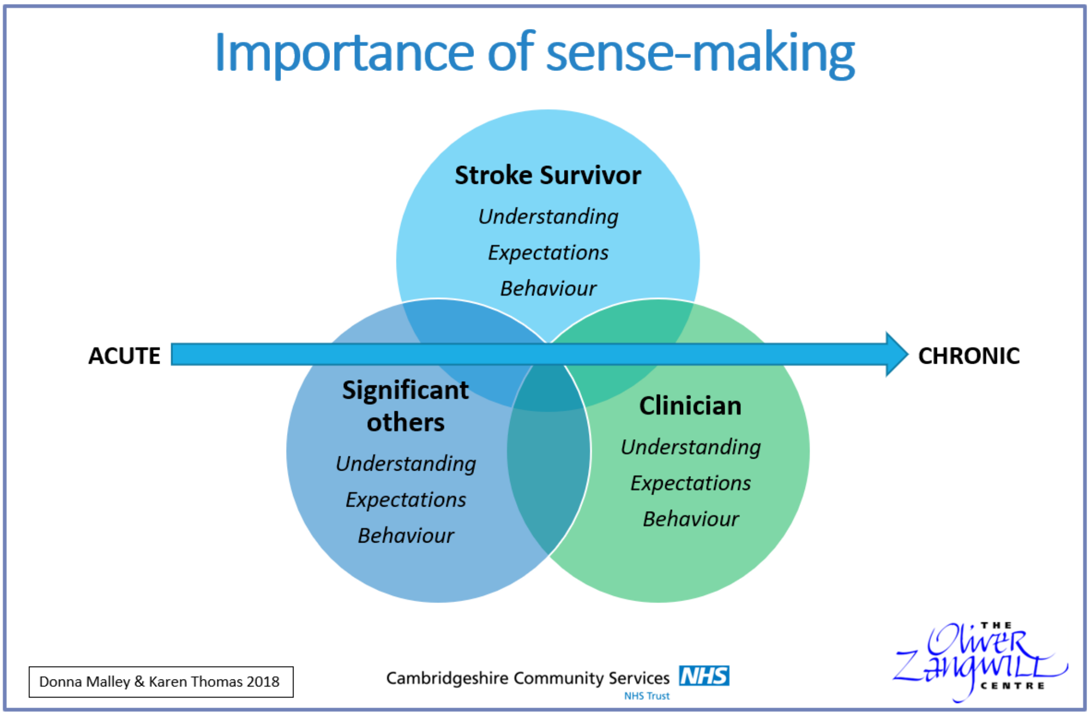


Figure 5: A model depicting the importance of sense-making, incorporating the three perspectives utilised in the PhD project.

The shared-decision making approach is also drawn upon within this thesis, when considering improved patient care for stroke survivors experiencing post-stroke fatigue. There are similarities with the importance of sense-making model; namely the consideration of patients, families and clinicians when considering patient values and preferences alongside medical evidence (Armstrong, 2017). The reason the Importance of Sense-Making model was created for this piece of work was the need to situate these important concepts within the specific condition and chosen theoretical approach.

2.3.3 Lived Experience: The role of Patient and Public Involvement (PPI)

To decide upon the thesis research questions, an initial PPI group was conducted. I visited a Cambridgeshire based stroke group to discuss stroke survivors' perception and experience of post-stroke fatigue and post-stroke care more broadly. Initial research priorities were presented to 18 individuals to determine which aspects were important to the stroke survivor population. The group convened annually to review the goals of the project and test research materials.

2.4 Thesis Approach: Turning the Research Questions into Studies

5 research studies have been developed and carried out to answer the 4 research questions. Considering the sense-making model, each study utilised a key perspective. Several of the studies gained insight on multiple research questions either to obtain a descriptive understanding or to build upon the previous studies findings. To recap, the 4 thesis research questions are:

Research Question 1: How is post-stroke fatigue perceived?

Research Question 2: What are the psychometric properties of current measurement scales?

Research Question 3: How do healthcare practitioners assess post-stroke fatigue?

Research Question 4: How is post-stroke fatigue managed?

An initial literature review was carried out to gain a detailed insight into key studies within the field. Qualitative and quantitative studies and reviews including logical combinations of the search terms ‘stroke’, ‘fatigue’, ‘tiredness’, ‘rehabilitation’ and ‘intracranial haemorrhage’ or ‘subarachnoid haemorrhage’ were explored.

Study 1: A Systematic Search and Literature Review of the psychometric properties of post-stroke fatigue measures

The most recent study to review post-stroke fatigue scales at the point of carrying out the systematic review was published in 2007, which arguably does not reflect the current use and scope of patient-reported outcome measures (PROMs). To inform the PhDs direction, it was important to assess if there was a reliable and valid fatigue scale available for academics investigating management interventions and for clinicians to utilise in clinical practice. The literature review aimed to analyse the psychometric properties of PROMs used to measure post-stroke fatigue and other neurological conditions where applicable.

Study 2: How is poststroke fatigue understood by stroke survivors and carers? A Forum Analysis

Although qualitative research has been increasing, Eilertsens' meta-analysis identified a limited scope of research investigating the lived experience of stroke survivors experiencing post-stroke fatigue. Understanding the stroke survivor perspective was an initial priority due to the lack of a clear and accepted definition for post-stroke fatigue (Mead et al, 2007). Furthermore, no studies considered a research design that eliminated researcher bias. Jamieson and colleagues 2012 study highlighted the benefit of utilising online communities within qualitative research. This was seen as a novel naturalistic method of data collection which could provide additional insight into stroke survivor and supporters experience compared to traditional interview design. For these reasons, a thematic analysis of the Stroke Association hosted TalkStroke online forum was conducted to provide a naturalistic snapshot of how stroke survivors and caregivers perceive and conceptualise post-stroke fatigue.

Responses on the TalkStroke forum were analysed to learn what management and coping strategies stroke survivors and supporters were suggesting to each other, without researcher or clinician input.

Study 3: An interview study investigating lived experiences of post-stroke fatigue

The findings from the TalkStroke Forum analysis were used to inform the topic guide for qualitative interviews with stroke survivors and their supporters. The input of family members and supporters was highlighted in the TalkStroke forum analysis and so all interview participants were given the option to have a supporter present. Interviews with stroke survivors and their supporters provided an opportunity to check whether the responses within the TalkStroke Forum analysis study reflected other stroke survivors' experiences and to recognise choices and barriers surrounding different management strategies.

Study 4: Conceptualising post-stroke fatigue: A cross-sectional survey of UK-based physiotherapists and occupational therapists

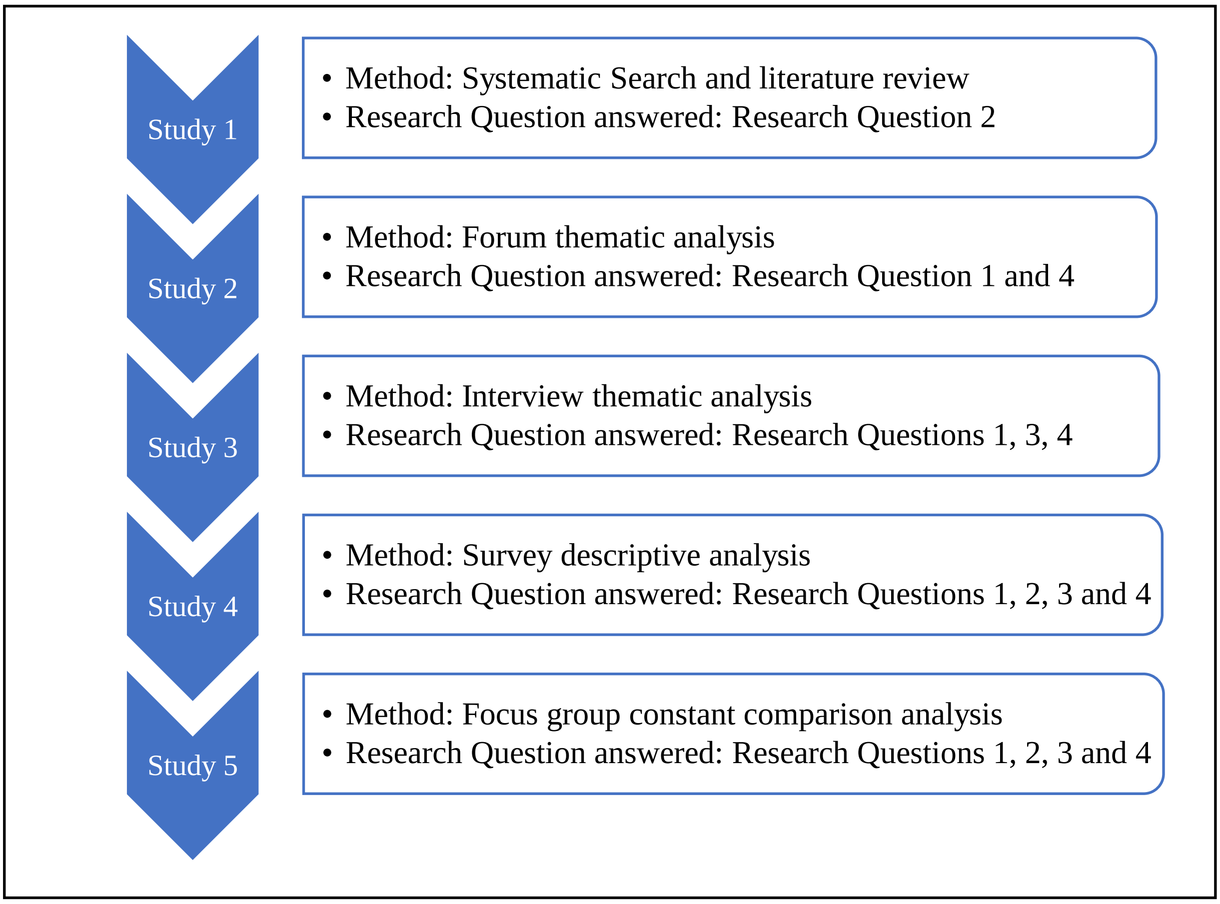
While there have been some studies developing and trialling potential interventions for post-stroke fatigue, the literature describing how the condition is currently managed is sparse. Therefore, it is relevant to undertake a survey of current practice with regard to how fatigue is measured, assessed and understood by healthcare practitioners. Such an approach also enabled more targeted questioning in study 5.

Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue

The findings from the cross-sectional therapist survey and the TalkStroke forum analysis informed the topic guide used for study 5. This study provided an opportunity to understand the findings from the therapist cross-sectional survey. The focus group provided an opportunity to gain an insight into barriers, differences between clinical settings and how different professions tackle management of this clinical problem.

2.5 Summary

As shown in Figure 6 (Page 39), each study incorporated one or more of the thesis' underlying principles to enable detailed insights from the stroke survivor, supporter and healthcare practitioner perspective to be gained. The thesis primarily utilised a qualitative study design which was considered as a justifiable approach when investigating a highly subjective under-researched clinical problem.



Study 1
- Method: Systematic Search and literature review
- Research Question answered: Research Question 2

Study 2
- Method: Forum thematic analysis
- Research Question answered: Research Question 1 and 4

Study 3
- Method: Interview thematic analysis
- Research Question answered: Research Questions 1, 3, 4

Study 4
- Method: Survey descriptive analysis
- Research Question answered: Research Questions 1, 2, 3 and 4

Study 5
- Method: Focus group constant comparison analysis
- Research Question answered: Research Questions 1, 2, 3 and 4

Figure 6. A summary of the methods used within the thesis.

Section 2. Methods

Lay Summary

At the end of the introduction section, a summary of the three approaches taken to answer the thesis research questions was stated. These were; 1) The importance of sense-making, 2) Sociological perspective and 3) The lived experience.

Research can be split into two broad categories which are qualitative study and quantitative study. Essentially, qualitative investigation is a scientific method of observation and discussion to gather non-numerical data and establish meaning. Quantitative investigation aims to answer questions by gathering numerical data to quantify behaviours and variables.

As established in the introduction, post-stroke fatigue is highly subjective which means it is experienced differently depending on the individual. For this reason, the studies within this thesis needed to find out more about how different people experience and perceive fatigue. Understanding different stroke survivors' lived experiences was important. If you were to consider the people you spend most time with, it is likely you would say your partner, family or close friends. This is the same following a stroke and so it was important to talk to the supporters of stroke survivors also. Finally, to understand and improve care on a larger scale, it was important to find out how healthcare practitioners think about, assess and manage post-stroke fatigue on hospital wards and in the community. For these reasons, five studies were designed which used a combination of qualitative and quantitative descriptive methods. They included a review of studies investigating fatigue measurement, interviews and discussions with stroke survivors, supporters and healthcare practitioners and an analysis of an online community used by stroke survivors.

Section 1. Introduction

Section 2.
Chapter 3 Methods (by study)

-Overview

-Study 1: A Systematic Search and Literature Review of the psychometric properties of fatigue measures used in a stroke survivor population

-Study 2: A thematic analysis of the TalkStroke Forum

-Study 3: An interview study investigating lived experiences of post-stroke fatigue

-Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

-Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

-Ethical Considerations

Section 3. Results (by research question)
Section 4. Discussion and conclusions

Chapter 3

3.1 Overview

Each research question drew upon and considered the findings from two or more studies. Likewise, most of the studies carried out for this thesis contributed findings to more than one research question (Figure 6, Page 39). This section describes the methods used for each of the five studies reported. It also states the study specific research questions.

3.2 Study 1: A Systematic Search and Literature Review of the psychometric properties of fatigue measures used in a stroke survivor population

The following section will follow the preferred reporting structure set out by the PRISMA statement, guided by the systematic review checklist (Moher et al, 2009).

3.2.1 Study Research Question

When tested on stroke survivors over the age of 18, how do fatigue measurement scales perform when psychometrically tested for reliability and validity (face validity, concurrent validity, test-retest reliability, internal consistency)? (PICOS Strategy: Methley et al, 2014)

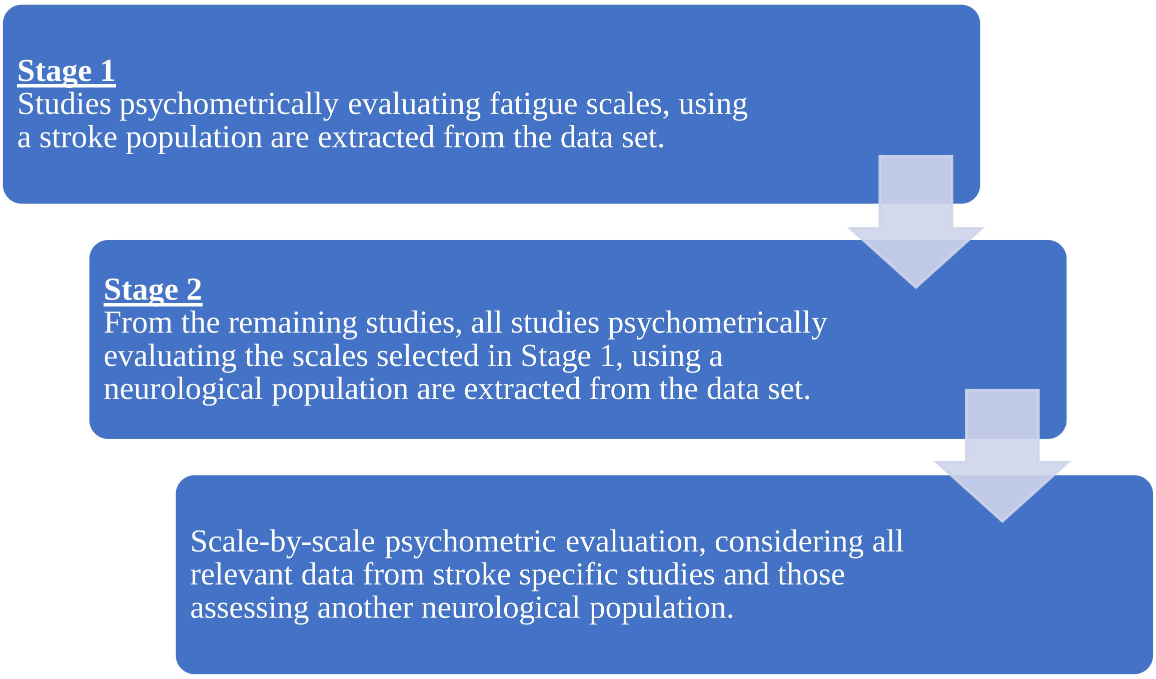
This study relates to Thesis Research Question 2:

(1) Thesis Research Question 2 '**What are the psychometric properties of current measurement scales?**'.

3.2.2 Study eligibility criteria

Due to the anticipated small number of studies primarily investigating post-stroke fatigue, the study eligibility criteria was expanded to draw out similarities and differences between neurological conditions which had a greater evidence base. This was carried out in a two-stage process, shown below in Figure 7, Page 43. In Stage 1, measures were identified which had been tested in a stroke population. In Stage 2, studies were selected that had tested psychometric properties in these scales within neurological conditions more widely.

Studies were included if they investigated the psychometric properties of a scale used for fatigue measurement (Table 2, Page 44). Only full text, English language, peer-reviewed studies were included in the final dataset. No date limits were set. Conference proceedings, review articles and protocol papers were excluded. No restrictions were placed on publication type, design, country, or year of publication. During abstract review, a further exclusion procedure took place to limit publications to those including a neurological population, as defined by the World Health Organisation. To do this, the WHO list of neurological conditions was consulted (WHO, 2016).



Stage 1
Studies psychometrically evaluating fatigue scales, using a stroke population are extracted from the data set.

Stage 2
From the remaining studies, all studies psychometrically evaluating the scales selected in Stage 1, using a neurological population are extracted from the data set.

Scale-by-scale psychometric evaluation, considering all relevant data from stroke specific studies and those assessing another neurological population.

Figure 7. Two-stage process for scale psychometric evaluation.

Inclusion Criteria
• Psychometric evaluation carried out on a fatigue measurement scale. Psychometric properties to be included were face validity, concurrent validity, sensitivity to change, test-retest reliability, internal consistency. • Study participants had a diagnosis of a neurological condition. • Study participants were over the age of 18 years old. • English language texts only. • Published in a peer-reviewed journal and not a review article, protocol paper or result of conference proceedings.

Table 2: Inclusion criteria applied in the Study 1 systematic search and literature review.

3.2.3 Information Sources

Medline was used as the primary information source. Medline is an international database of biomedical research with over 25 million studies from more than 5,200 worldwide journals. Due to its size and subject focus, it was expected that all relevant studies investigating fatigue outcome measurement would be found. The database is often used by other researchers carrying out reviews in the stroke and fatigue fields. Psycnet was considered, however as a stand-alone database its total reach of 4.5 million studies and narrower subject focus on behavioural and social science could have led to studies being missed. The first database search was carried out by one researcher in March 2017 independently. The second search was carried out by two independent researchers on 19th November 2019.

3.2.4 Search

#1

1. Fatigue OR
2. Tiredness

105322 retrieved

#2

1. Outcome measure OR
2. Instrument OR
3. Assessment AND
4. Scale AND
5. Measurement

10476 retrieved

(#1 and #2)

763 retrieved

Box 1. Search strategy conducted in MEDLINE on 12th March 2017 and 6th November 2019.

An initial literature search was carried out to identify common search terms used to assess outcomes measurement and scale usage in clinical populations. Gilbody and colleagues' expansive chapter on outcome measurement in psychiatry detailed a long list of search terms used to identify outcome measures in each of their chosen databases (Gilbody et al, 2003). This strategy was replicated first, however, very few titles were retrieved (n=46). The key search terms from within the list were noted down and compared to Mead's search strategy (Mead et al, 2007). Following this comparison, the search terms within Box 1 were adopted. The terms 'stroke' and 'neurology' were not included in either of the above two strategies and so to replicate the strategy employed in the first post-stroke fatigue measurement review as closely as possible, the terms were not included here. This could be seen as a weakness of the study and will be further discussed in Chapter 5 (Study Limitations Section). When first searched, the boolean operator “OR” was used between each term in search #2. This led to 2434558 abstracts being retrieved, and when combined with search #1, 24871 abstracts were retrieved. From a pragmatic perspective this was considered too large a number for an initial retrieval, and so the boolean operators were adjusted as shown in Box 1, page 45. In Mead and colleagues review in 2007, the terms measurement and scale were both included. This search strategy was replicated, which could have increased the risk of studies being missed through use of the boolean operator ‘AND’ instead of ‘OR’ (Mead et al, 2007).

3.2.5 Study Selection

Publications (N=763) emerged as a result of the search strategy employed (Box 1, page 45). Titles and abstracts were assessed for applicability, as assessed by the inclusion criteria in Table 2 (Page 42), and then imported into reference manager Mendeley. At this stage, any duplicates were removed. All full texts of the retrieved articles were reviewed to ensure relevant references were included. Following analysis of all abstracts and full texts, those without a neurological sample or study aim which included psychometric testing were excluded (Figure 7, Page 43). The same search strategy was used on both occasions. On the second occasion, each researcher independently reviewed all retrieved titles, abstracts and full texts which met the inclusion criteria. Any variations were resolved through discussion.

Each paper was searched for evidence of face validity, content validity, internal consistency, test-retest reliability, convergent validity, construct validity, concurrent validity and sensitivity to change. No studies reported all of the above categories and following Stage 1 data extraction a narrower primary set of variables were decided upon which the majority of studies had analysed. Reliability evaluation was also assessed through a search for internal consistency and test-retest reliability.

3.2.6 Data collection and data items

The following details were extracted from the data set and tabulated in their reported form in a Microsoft Excel workbook.

1) First author

2) Year published

3) Study title

4) Study design

5) Participant characteristics including diagnosis and intervention groups

6) Sample size

7) Outcome measure used to include item number, response format, and content

8) Inclusion criteria when stated

9) Psychometric evaluation

3.2.7 Risk of bias in individual studies

Assessment of the primary data sources included in the systematic review is important to consider the overall review bias. The Cochrane risk of bias tool was used to assess potential sources of bias in the included studies (Higgins et al, 2011). It is a domain-based critical assessment, which has been recommended due to its clear interpretability and reliable measurement (Higgins and Green, 2011). Although the review was investigating psychometric properties of the included scales, it was important to consider the possible biases introduced as a result of the study methods. Seven categories were tested and reported on for each study. Selection bias was assessed firstly through assessing if random sequence generation was employed, and secondly if any condition allocations were concealed.

Performance bias was assessed by presence of participant and research team blinding. Detection bias was indicated by the blinding of outcome measurement., which was the fourth variable assessed. Attrition bias was the fifth assessment variable, assessed by considering if the outcome data was incomplete. Finally, each study was viewed for selective reporting and other biases present. Each category was rated as low (red), high (green) or unclear (yellow).

3.2.8 Summary Measures

Firstly, studies were searched for internal consistency assessment. Internal consistency tests how reliably a measure or scale actually measures what it was designed to measure. The Cronbach's Alpha test is often carried out to provide an objective marker of internal consistency. It was created to check the reliability of likert scale tests, which is a design most fatigue scales use. As it is a commonly used measure, interpretation advice is available. An alpha above 0.80 is considered good and an alpha below 0.6 is considered poor. There are variables which must be considered when interpreting scores however, as likert scales with more items lead to a larger alpha score. Poor interrelatedness between questions can lead to a lower alpha, which may be an issue in fatigue due to its multi-faceted nature and impact.

The second reliability score checked for in the systematic review was test-retest reliability. The objective scoring of this is between 0 and 1, testing the consistency of the scale or measure over a period of time. Similar to Cronbach's alpha, 0.8 to 1 signifies good reliability and a score below 0.6 signifies poor reliability. Often, intraclass correlation (ICC) is calculated and it is viewed as the most accurate for a range of sample sizes. Test-retest reliability scores can become biased due to the patient or participant potentially understanding the task better the second time they complete it or receiving feedback after the first test.

Validity measures varied across the included studies. Face validity was the first psychometric property considered. Although it does not have a quantitative test associated with it, it is an important validity measure to consider as it assesses whether the scale appears to measure what it is supposed to measure. In studies assessing outcome measures, face validity may be assessed through a qualitative component to the study, finding out if the patient or respondent felt the scale included all the elements of the condition or symptom being measured.

Secondly, concurrent validity was assessed. This is a form of criterion validity and assesses the primary scale or test against another variable which may be another test or on a different population. As there are very few outcome measures designed to assess post-stroke fatigue severity or impact, it is valuable to compare newly evaluated tests to more well-established tests and also compare to other similar conditions. It is tested by working out if there is a significant difference between the two groups being evaluated and if the result is not statistically significant, concurrent validity will have been achieved.

3.2.9 Synthesis of results

The same psychometric variables were extracted from each study, where possible. This allowed for assessment of reliability and validity across and between measures to assess overall psychometric strength of each scale included in the analysis. The details of each measure were put into a Microsoft Excel data extraction sheet and then transferred across to Microsoft Word, where they were tabulated by scale and by population (stroke or neurological population). No formal statistical synthesis of the results of individual studies was performed.

3.2.10 Risk of bias across studies

The categories reported on within the individual study risk of bias assessment matrix were considered to assess the overall systematic review risk of bias. Assessing overall risk is important when interpreting the review findings and conclusions. Guided by Yavchitz and colleagues, three main categories were considered (Yavchitz et al, 2016). Firstly, misleading reporting was reviewed on an individual study level by assessing reporting bias. Secondly, misleading interpretation was reviewed. This could have been present when interpreting quantitative reliability and validity values and categorising them as excellent, good or poor. Finally, all studies and overall systematic review findings were checked to ensure no inappropriate extrapolation occurred. For example, studies which assessed an outcome measurement or scale with a parkinsons or multiple sclerosis population could not be applied to the primary population of stroke survivors.

3.3 Study 2: A thematic analysis of the TalkStroke Forum

3.3.1 Study Research Question

This study provides data relevant to two of the thesis research questions:

(1) Thesis Research Question 1 '**How is post-stroke fatigue perceived?**'

(2) Thesis Research Question 4 '**How is post-stroke fatigue managed?**'

When considering how forum users perceived post-stroke fatigue, the thesis working definition "“*Since their stroke, the patient has experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day. This fatigue has led to difficulty taking part in everyday activities”* was considered, to compare and contrast key features of the definition and perceived lived experience.

3.3.2 Setting

The moderated TalkStroke forum comprised 22,173 unique posts, written by 2583 unique users. It was a UK-based online community hosted by the Stroke Association charity from 2001 to 2012. The forum was open access to all individuals who registered. To register, users needed to provide a username and reason for accessing a Stroke Association resource, for example being a stroke survivor or supporting a stroke survivor. This meant a range of individuals accessed and used the forum over the period it was online including stroke survivors, family members, healthcare practitioners, and academics. In 2012 it was withdrawn and changed to an online resource covering all aspects of post-stroke recovery and aftercare. For this study, the archived posts from 2004 to 2011 were used.

3.3.3 Design

This study employed a thematic analysis of posts relating to post-stroke fatigue written by stroke survivors and supporters on the archived online Talkstroke Forum. For this study, the term supporter was used as an umbrella term for a spouse, family member or friend fulfilling an assistive role for a stroke survivor. Archived forum posts written between 2004-2011 which included the primary search term “tiredness” and related terms “fatigue”, “tired”, “weary” and “weariness” were identified. All demographic data of the forum participants were captured through information provided on forum posts. No information was taken from the individual forum registration process. The symbolic interactionist theory was used when deciding the study research questions and study design.

3.3.3.1 Design Justification

As the largest and most well-known UK based charity for stroke, Stroke Association resources are used widely amongst stroke survivors and healthcare practitioner populations.

Simoni and colleagues further justified the use of this study design, suggesting that by drawing upon the large online community, a broad sample of stroke survivors and caregivers could be identified (Simoni et al, 2014). Comparison of data taken from the Talkstroke forum with data from interviews with stroke survivors and caregivers showed that similar themes emerged from both sources (Jamieson et al, 2018). This was true despite key differences in methods of data collection and the lack of verification of forum participants' identity and stroke diagnosis. This highlighted that an online stroke forum can be considered a rich source of data for qualitative research on patients' and caregivers' issues. Forum data offered additional insights due to the inclusion of a younger and computer literate population, along with the opportunity of online discussions between survivors and caregivers (Jamieson et al, 2018). When deciding on the most appropriate study design and setting, analysis of social interactions on an online forum was felt to align with the symbolic interactionist theory, employed throughout the PhD. By considering the discussions taking place on the forum, conversational interactions between users could be analysed to form a deeper understanding of how stroke survivors and their supporters made sense of the lived experience of fatigue. This extra theoretical depth was necessary for this study to gain insight into how the condition and associated healthcare environment were perceived or experienced.

Thematic analysis is a popular process used to encode qualitative information (Roulston, 2001). Its flexible nature as an approach that fits into both essentialist and constructionist paradigms provides freedom whilst also allowing a rich yet complex analysis (Braun and Clarke, 2002). This form of analysis allows for social and psychological interpretations and can be used effectively to summarise features of a large data set, which is often the case in qualitative healthcare studies.

3.3.4 Data Selection

Two investigators searched the complete forum archives between 2004 and 2011 for the following search terms: “tiredness”, “tired”, “fatigue”, “weary” and “weariness”. Repeated and irrelevant posts were removed, as agreed by both investigators through the use of two rounds of coding and discussion. Irrelevant posts were agreed to be posts with a cursory mention of fatigue because of a primary post-stroke complication or medication. Further, posts citing fatigue in relation to depression, pain or sleep disorders were excluded, as they were not related to fatigue as a direct consequence of stroke. Posts written by individuals under the age of 18 or by a parent figure describing their child were also removed since the focus of the study was adult stroke. These posts were identified during data familiarisation and cross-checked with the second investigator or through the use of the demographic dataset provided by researcher Anna De Simoni, collated during an earlier investigation (Simoni et al, 2014). These posts were again screened by both investigators to assess their relevance to the research questions and discussed until agreement was reached.

3.3.5 Data Analysis

The process for data selection and analysis is summarised in Figure 7 and 8, Page 54 and 55.

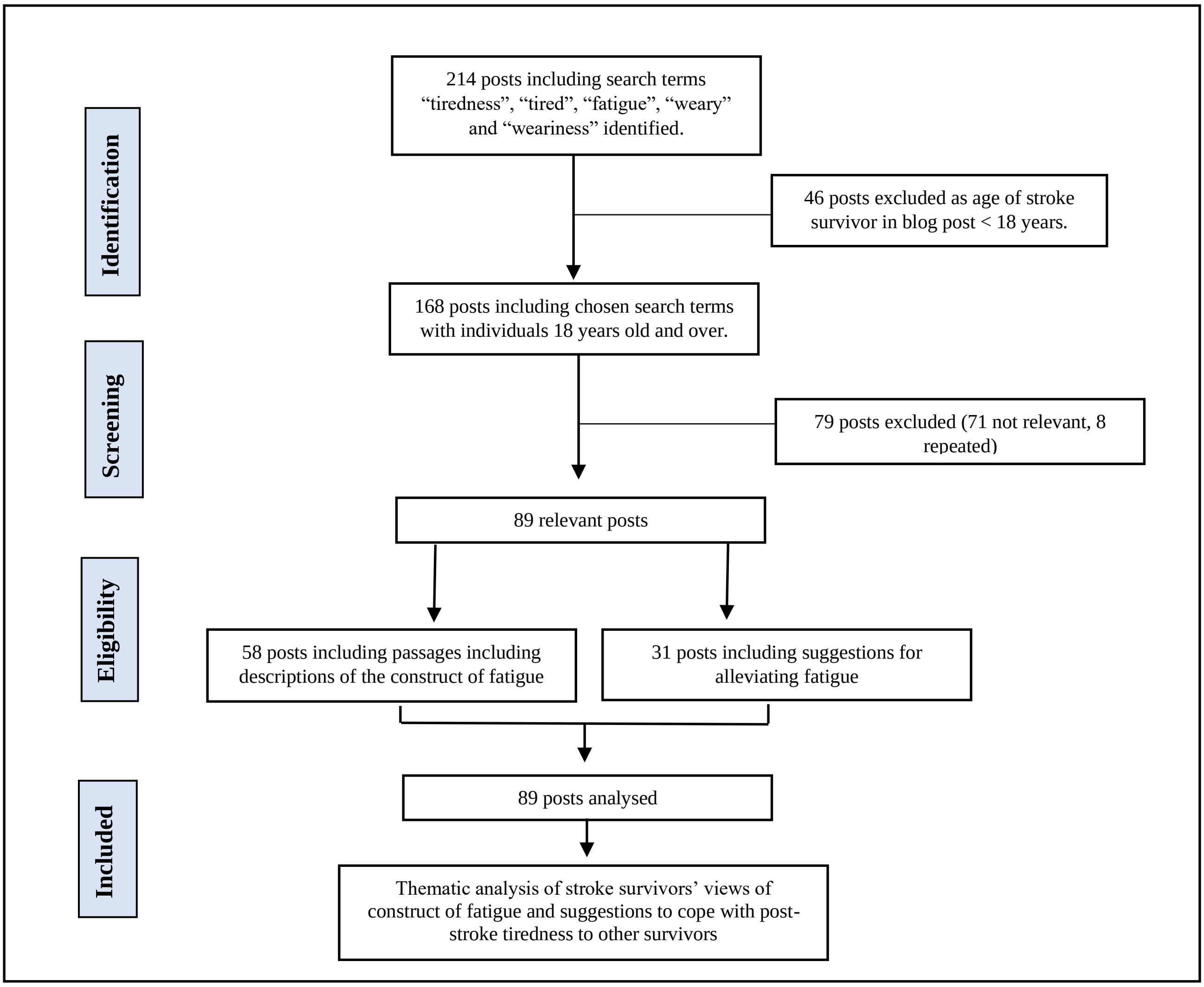


Figure 8. Flowchart of the process for data selection and analysis.

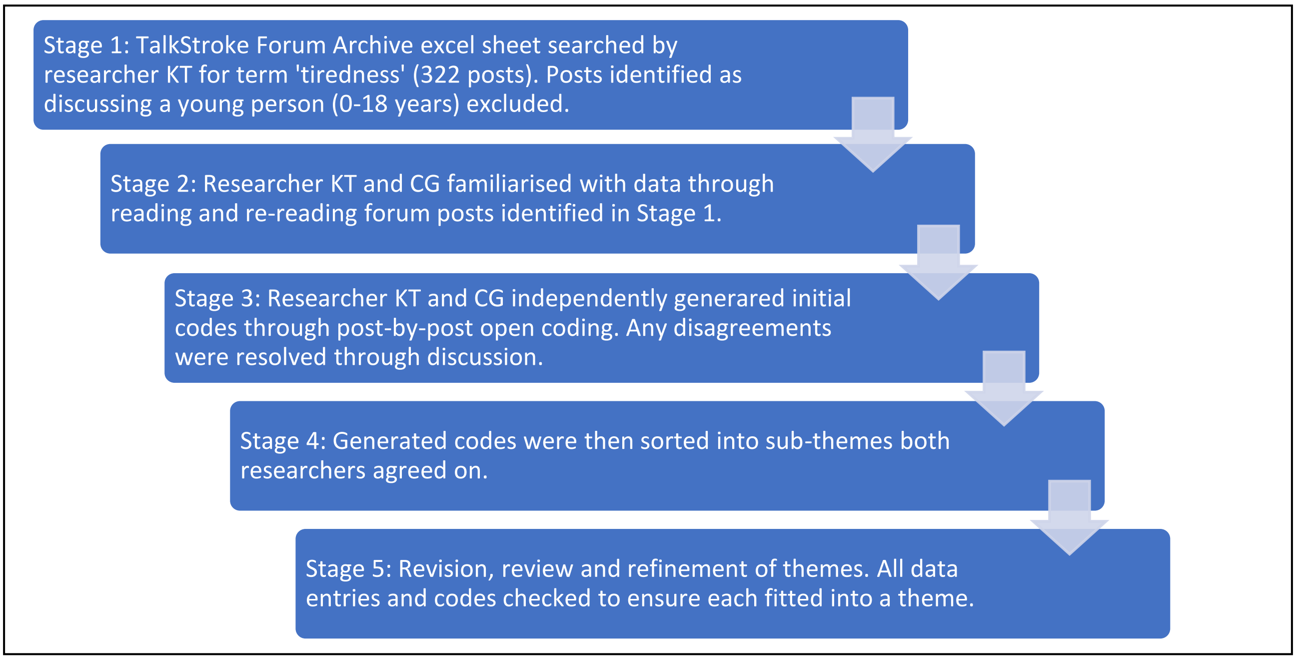


Figure 9. Flowchart detailing the Forum Analysis Procedure.

As shown in Appendix 1, after reading all posts in the final data set to ensure familiarisation with the content, both investigators carried out thematic analysis to generate and refine emerging issues, using methods described by Braun and Clarke (Braun and Clarke, 2006). Posts were coded to answer the two research questions by identifying the defining characteristics of post-stroke fatigue and coping strategies. Both researchers considered the two questions: (1) How is post-stroke fatigue described by people who write posts on the forum? (2) What coping strategies are suggested to target post-stroke fatigue?

Five percent of posts (n=5) were coded by both researchers to establish a consistent, systematic coding approach was being used. Sixty-five percent of posts (n=57) were coded by the first investigator. The remaining 30 percent of posts (n=27) by the second investigator. Coding was discussed until agreement was reached for all 89 included posts to identify pertinent key themes. These codes were aggregated into several broader themes; potential subthemes and relationships between subthemes were considered. During this process, both researchers revisited all extracts independently and then together to ensure the suggested themes incorporated all data entries and that the final themes truly represented the complete data set.

3.4 Study 3: An interview study investigating lived experiences of post-stroke fatigue

3.4.1 Study Research Questions

This study relates to the thesis research questions 1 3 and 4:

(1) Thesis Research Question 1 ‘**How is post-stroke fatigue perceived?**’

(2) Thesis Research Question 1 ‘**How do healthcare practitioners assess post-stroke fatigue?**’

(3) Thesis Research Question 4 ‘**How is post-stroke fatigue managed?**’

3.4.2 Study Design

Qualitative semi-structured interviews were conducted with stroke survivors and supporters living in the East of England.

3.4.2.1 Design Justification

A semi-structured qualitative interview design was selected for several reasons. Firstly, this form of data collection allows a broad focus to be placed on human experience to generate more generalisable and applicable conclusions (Holloway and Galvin, 2016). In addition to this, interviews provide the opportunity to collect a rich and detailed dataset. This was seen as pertinent, as the study sought to gain additional depth and insight to the findings from the TalkStroke survey analysis. Qualitative research also allows the investigator to explore the cultural, social and uniquely personal aspects of living with a condition (Alasuutari, 1996). This enables analysis from a symbolic interactionist perspective. Finally, a flexible topic guide was chosen so questions asked could be adjusted throughout the process of data collection dependent on early developing themes and supporter input.

3.4.2.2 Topic Guide Justification

Study 3 Topic Guide
How do stroke survivors and their supporters understand and experience post-stroke fatigue?
Suggested Questions Can you tell me your story? When you had the stroke? How would you like us to refer to the tiredness you have experienced after the stroke? What word? Can you tell me about your tiredness since having the stroke? Can you describe how it feels? Did you experience fatigue before your stroke? How is this different? If you were asked to explain to me what post-stroke fatigue is, what would you say? How does your tiredness affect your day to day life?

Study 3 Topic Guide
What management strategies do stroke survivors and supporters use to cope with post-stroke fatigue?
Suggested Questions What do you do to ease/cope with the tiredness? Have you heard of any other effective strategies from other stroke survivors? Have you ever been to a community stroke group or thought about using one?
What multidisciplinary medical team input do stroke survivors and caregivers receive in the community setting?
Suggested Questions How often do you see a medical professional? Have you discussed your tiredness/fatigue with anyone? Can you tell me more about that? If you were invited to a fatigue management programme made up of sessions in a community location do you feel like this is something you would want to be part of? A question around what they feel the 'role' of the medical team is with their fatigue i.e. is it more for education and guidance than an intervention or the latter? (Asked in an open unleading manner)
What would stroke survivors and caregivers want an intervention aiming to help them cope with post-stroke fatigue to consist of?
This final research question will be answered implicitly through responses to the above questions. If the researcher feels like it has not, they may ask some further specific questions here.
Interview Close - Is there something else you wish to discuss today? Thank you for your time and sharing your experiences with us today.

Table 3. Study 3 Interview Topic Guide.

The topic guide (Table 3, Page 57) was created in line with findings from the TalkStroke forum analysis first carried out. The themes from the TalkStroke forum analysis that were considered when creating the interview topic guide were; medicalisation of post-stroke fatigue and a tiredness like no other when asking how participants understand and experience post-stroke fatigue, acceptance and conversely fighting post-stroke fatigue when asking about current management strategies. The array of data drawn from the theme how stroke survivors cope with post-stroke fatigue informed two questions within the topic guide relating to current management strategies and the medical team input participants received.

The insight from these studies was further supplemented by ongoing reading of the literature. Due to the multitude of different ways that stroke survivors and their supporters perceive the experience of fatigue, several questions were included in the first section of the topic guide which aimed to gain the same information but approached the question of understanding fatigue from different angles. During the data collection period, it became clear which questions engaged the participants best and provided more detailed answers. This meant the structure of each interview changed as more interviews were carried out. One example of this was an increase in the number of questions asking the supporters present about their experiences to provide a clearer overall picture of the participants' characters, daily routine, and feelings towards fatigue.

3.4.3 Inclusion criteria

Inclusion Criteria
Stroke Survivor Participants • Was on a stroke register and has been diagnosed as having had a stroke event • Was under the care of community clinicians at time of recruitment • Had the capacity to give informed consent • Was over the age of 18 years old. • Had experienced post-stroke fatigue, judged by the answer to response form questions Supporter Participants • Supported or provided care to a stroke survivor participant • Had the capacity to give informed consent

Table 4. Inclusion Criteria for Study 3; A stroke survivor and supporter interview study.

3.4.4 Recruitment

25 participants were recruited through primary care services. Recent qualitative studies within the field have recruited between 15 and 25 participants; the higher sample size enabled sufficient themes to be identified to adequately reflect the transcribed interview data whilst the lower number was seen as a major study limitation (Barbour and Mead, 2012; Drummond et al, 2017).

Four primary care practices across Cambridgeshire and Thetford were contacted, as shown in Figure 10 on page 61, following the study protocol (Appendix 6). Practices were approached through their allocated gatekeeper (usually the practice manager), with the first Cambridgeshire practice treated as a pilot recruitment site (Figure 9, Page 58). Individuals on the stroke register were identified by the staff member in charge of research recruitment. A random sample was selected using a free online resource which randomly generates a number order (www.randomizer.org). Each practice generated a random number order from 0 to the total number of patients on the practice stroke register. At this point, the first 25 percent of the total number on the stroke register were taken and any duplicates were discarded. If participant demographics varied significantly from the national average in regard to gender, age, social support and presence of other post-stroke complexities, a stratified sampling approach would have been carried out (Stroke Association, 2018). This was reviewed following recruitment of 10 participants and again at 15 participants. The selected individuals were sent a recruitment pack which included a letter, participant and supporter information booklets and response form (Appendix 7-9). Take up from the Cambridgeshire based pilot site was used to decide how many invitation packs were sent out at each of the following three recruitment sites. The two locations were chosen due to the difference in socioeconomic status between the two areas to increase the generalisability of the study findings. The population of Cambridge has 20 percent more high and intermediate managerial, administrative, or professional households than the national average compared to Thetford which sits 20 percent below. Cambridge has a higher level of residents than the national average with a higher education qualification, whilst Thetford has a high level of residents with either no qualifications or qualifications equal to 1 or more GCSE at grade D or below.

The response form asked stroke survivors to identify if they had experienced post-stroke fatigue and whether they wished to take part. To identify whether a prospective participant had experienced post-stroke fatigue, the thesis working definition was used; "*Since their stroke, the patient has experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day. This fatigue has led to difficulty taking part in everyday activities.* This case definition formed the two questions individuals had to respond 'Yes' to. The two questions were:

1. Over the past month, has there been at least a 2-week period where you have experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day?
2. If you answered yes to the above question, has this led to difficulty taking part in everyday activities?

This form was returned to me, the chief investigator. The participant identified at this stage if they had a supporter they wished to be present for the interview. Respondents were contacted to arrange a suitable interview time and location, on receipt of their response form. This process continued until 25 stroke survivors were recruited. Potential participants were informed in the Participant Information Booklet that they may not receive a response from the research team if 25 individuals had been recruited already.

Although the focus of the interview study was on stroke survivors' lived experience of post-stroke fatigue, many qualitative studies have identified caregivers and significant others as an important part of their recovery following stroke (Elf et al, 2016; Pederson et al, 2019). This justified the inclusion of supporters within the study. Due to the communication difficulties faced by individuals with aphasia, I did not anticipate receiving many response forms from this population. However, this did not prove to be a deterrent to participation, with several aphasic stroke survivors taking part in the study, supported by family members or care staff.

Figure 10. Recruitment map showing the locations the four General Practices cover.

3.4.5 Data Collection

All study participants were given the choice of being interviewed at their own home or at an alternative suitable University of Cambridge research location. On arrival, participants and their supporters (where applicable) were asked to complete a consent form and reminded that they could withdraw or stop the interview at any time (Appendix 10). The interview was carried out by one researcher and recorded using an audio device, which was shown to the participant(s). The full process, including initial introductions and clarification of any questions before beginning the interview, lasted no longer than ninety minutes. Participants were offered a report summarising the study findings.

3.4.6 Interview approach

All the interviews were semi-structured. The primary focus for myself as the interviewer was to gain a clearer picture of what each participants' personal experiences were in each of the areas. Each set of questions asked was slightly different, to accommodate for the tone of the interview and ease of information retrieval. The dynamics between myself and the participant, as well as the added dynamic of supporter participants, were important to consider. For interviews where the supporter quickly took the lead in discussion, I made sure to keep the stroke survivor included and asked each question to them personally before gaining greater detail from the supporter. There were several different dynamics between the stroke survivor and supporter participants. However, the vast majority exhibited body and verbal language suggestive of them being a team when it came to the stroke recovery.

Use of Audio Device

Following introductions, the use of an audio recording device was explained and the participants were given the opportunity to look and hold the device. This allowed them to ask questions before signing the consent form. No participants expressed feeling uneasy or uncomfortable due to the presence of the recording device. Also, participants were asked to refrain from using names where possible during the interview. The recorder was positioned between the interviewer and interviewee in full view in all interviews. During sixteen of the interviews, participants used a name and then quickly expressed regret as they remembered the audio device was recording. This highlighted the participants feeling at ease and engaging in ‘normal’ conversation in the presence of the device.

Use of field notes

Following each interview, I briefly reflected on the visit noting down observations, thoughts, and feelings. This helped me distinguish each interview when I came to data analysis and enabled a deeper reflection. An example of a field note I made was “The participant had been looking forward to the visit and hadn’t had anyone come round for quite some time- themes of isolation. Opened up more as the interview progressed. Room dark and chairs positioned next to the window- he frequently looked out during the visit”.

3.4.7 Myself as the interviewer

Due to the subjective nature of qualitative data collection and the personal setting of interviews carried out at individuals’ homes, how participants perceived my role warrants consideration. Although I am a qualified physiotherapist, I did not mention this role in any documentation or during the interviews. There were several occasions where a participant recounted past negative experiences with therapists, which they may not have felt comfortable including in the interview if they had known about my clinical background. Most participants assumed I had a subject-specific knowledge, as usually I needed no clarification when medications were listed or technical terms were used. If I felt I needed clarification, I asked further questions as necessary. On some occasions during the data collection period, I found it personally difficult to listen to participants who became upset or distressed discussing feelings of isolation or anxiety, and as in other settings I would be inclined to signpost or try to help.

3.4.8 Data Analysis

Thematic analysis was chosen for this study. This form of qualitative analysis was most suited to the aims of the investigation, due to its non-prescriptive flexible nature (Braun &

Clarke, 2006). A deductive approach was taken to create the topic guide used, considering themes from the previous TalkStroke study. Initial coding was mapped onto the topic guide question. Due to the flexible nature of thematic analysis, unlike other analytical techniques such as framework analysis and grounded theory, an inductive approach to coding was used. This allowed analysis to follow new themes which were added to the initial theoretical base.

All recordings were anonymised and 19 (75%) were sent to an external transcription company. Six (25%) were transcribed independently by myself as chief investigator to allow familiarisation with the data set. All transcriptions carried out by the external company were checked whilst listening to the recordings. Transcriptions did not include notations for changes in tone or speed to ensure a focus on the wording used. Spider diagrams were created following familiarisation, for each secondary research question. From this point, formal analysis began on NVivo and codes were identified (Bazeley and Jackson, 2013). Using the symbolic interactionist perspective allowed a deeper insight into the participants' lived experience of post-stroke fatigue.

3.5 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

3.5.1 Study Research Questions

This study relates to the thesis research questions 1 3 and 4:

(1) Thesis Research Question 1 ‘**How is post-stroke fatigue perceived?**’

(2) Thesis Research Question 1 ‘**How do healthcare practitioners assess post-stroke fatigue?**’

(3) Thesis Research Question 4 ‘**How is post-stroke fatigue managed?**’

3.5.2 Design

A cross-sectional survey was created and answered electronically using Qualtrics software, an online survey creation and analysis site licensed to the University of Cambridge (https://eu.qualitrics.com). The software was chosen due to its high-level security and GDPR compliance, with all data stored within the EU.

3.5.2.1 Design Justification

The purpose of carrying out a cross-sectional survey is to gather descriptive information on a chosen subject (Kelley et al, 2003). Descriptive analysis is an important first step to gaining greater insight into under-researched fields, which is why it was the most suitable design for this investigation. Carrying out a more thorough qualitative investigation at this stage, such as semi-structured interviews or focus groups, was considered. However, due to the paucity of evidence prior to the study, justification of a novel topic guide would have been weak.

A national online survey design was chosen to capture a broad and generalisable data set. It was felt that therapists would be more likely to fill out an online survey than one in a postal format. As there was no evidence before the study, collecting descriptive data at this early stage of the PhD allowed me to choose the most appropriate design for the following studies. Surveys are a frequently used study design in healthcare research owing to their convenience, cost-effectiveness and low commitment required from participants (Fricker and Schonlau, 2002). During the design process, the research team aimed to create a survey that would take under ten minutes to complete. Shorter length questionnaires have a higher response rate and so 10 short-answer questions were included (Deutskens et al., 2004). This influenced the question wording and if open, closed, or multiple-choice questions were asked in the survey.

The use of a remote survey allowed respondents to participate from far-reaching geographical locations and removed the variable influence of an interviewer on responses. By choosing an online survey, the study was cost-effective for both the research team and therapists participating. The study duration for participants was significantly shorter than it would have been through a postal or face-to-face survey.

3.5.2.2 Survey Content Justification

By collecting descriptive data on post-stroke fatigue, important factors and associations within clinical practice could be uncovered and built upon. Within the initial PPI group, stroke survivors were asked who they thought would help explain and manage their fatigue. The majority of individuals who answered named a therapist role. I confirmed this perspective by posing the same question to the Cambridgeshire and Peterborough Trust Clinical Manager. She also highlighted the therapist teams. For this reason, I consulted the specialist neurological sections of the Chartered Society of Physiotherapy and the Royal College of Occupational Therapy. The thesis working definition was considered when creating Question 5, to assess whether therapists would draw upon the definition when describing post-stroke fatigue to another individual.

3.5.3 Survey Content: Development and Refinement

In collaboration with specialist occupational therapist Donna Malley, a 10-question survey on the definition, assessment, and management of post-stroke fatigue was created (Table 6, Page 68). The proposed survey was taken to a multi-disciplinary survey development group to ensure all questions were appropriate and coherent to a healthcare practitioner population.

The survey development group comprised of Cambridge based community clinical teams including physiotherapists, occupational therapists, and a clinical psychologist. The session aimed to assess the feasibility, understanding, and conciseness of the survey. The survey was then piloted by three physiotherapists and one occupational therapist, as a result of which alterations were made (Appendix 3).

In questions 1, 2 and 7 multiple-choice questions were designed and asked. Questions 1 to 4 were designed to collect demographic information from the participants and so targeted open questions and multiple-choice answer questions enabled quantitative descriptive data to be collected for this purpose. Question 7 was designed following the literature review on post-stroke fatigue measurement which can be found in Chapter 2. To find out more information about specific measures that are commonly used in academic literature, multiple choice answers were given. All other questions within the survey were open questions. As the current literature on post-stroke fatigue clinical practice is sparse, this survey structure was selected to gain the richest descriptive data set.

Question Number	**Question Text**
1	**What profession do you practice?** Physiotherapy Occupational Therapy
2	**What setting do you work in?** Acute care Sub-acute rehabilitation care Community care Primary care
3	**How long have you been working with stroke survivors?**
4	**Briefly, what experience do you have working with stroke survivors experiencing fatigue?**

5	**How would you describe post-stroke fatigue if approached by another healthcare professional?**
6	**Please list the questions which you would ask the stroke survivor in a subjective assessment targeting post-stroke fatigue?**
7	**When assessing a patient you believe may be experiencing post-stroke fatigue, would you use a fatigue specific scale? If yes, which scale(s) would you use?** I would not use a scale Fatigue Severity Scale (FSS) Fatigue Assessment Scale (FAS) Neurological Fatigue Index for Stroke (NFI-Stroke) Faces Rating Scale (NRS-FRS) Other [text box entry to enable clarification]
8	**Why do you assess stroke survivors experiencing post-stroke fatigue in this way?**
9	**What treatment techniques have you employed in helping stroke survivors manage their fatigue and which were the most useful?**
10	**Do you have any further comments to make regarding assessment and management of post-stroke fatigue?**

Table 5. Final survey design transferred onto the online Qualtrics system.

3.5.4 Participants

Study participants were physiotherapists who were members of the Association of Chartered Physiotherapists in Neurology (ACPIN) and occupational therapists who were members of the Royal College of Occupational Therapy (RCOT) Specialist Section- Neurological Practice (RCOT-NSS). All individuals had registered an interest in participating in related research. To be eligible, participants were required to have current registration as a healthcare practitioner, and to have worked with stroke survivors whilst in clinical practice within the United Kingdom.

3.5.5 Questionnaire Distribution

The research lead from each national organisation (ACPIN and RCOT-NSS) distributed an initial invitation email to members who had expressed an interest in participating in stroke-related research. Within the email was a participant invitation including a link to the Qualtrics platform, which provided a participant information sheet and a consent form. Respondents entered their answers directly onto the Qualtrics online platform. After two weeks, a reminder email was sent to all individuals on both mailing lists. The survey remained live for one month following the reminder.

3.5.6 Sample Size

It was hoped that 50 individuals would be recruited from each of the two recruitment organisations (ACPIN and RCOT-NSS). Although this is a high number for qualitative research, the survey also aimed to obtain a variety of responses from therapists with different levels of experience and in different locations across the United Kingdom. As no previous studies have used a survey design to assess post-stroke fatigue clinical practice, the research leads from ACPIN and RCOT-NSS were consulted to find out the response rate for similar surveys. Both individuals said normal responses ranged from 50 to 75 individuals. This number was seen as sufficient to answer the study research questions due to the data being collected which was qualitative and descriptive in nature (Table 6, Page 68).

3.5.7 Data analysis

Responses were collated on the Qualtrics platform. Other survey design platforms were considered, however many of the well-used platforms had lower security and collected identifiable information. All electronic data were stored on a Secure Data Hosting Service (SDHS) protected by a dual authentication (password secured and personal security code secured) located on a firewall-protected network, within an encrypted volume. Data were anonymised and loaded into Microsoft Excel. Responses to all ten questions were analysed by myself and one other investigator (CH). The responses to questions 1 to 4 were used to identify the demographics of study participants. All other questions were analysed thematically, aiming to identify all pertinent themes. Following data familiarisation, both investigators coded 5% of the data initially to ensure a systematic coding strategy, then 40% of posts were randomly selected and coded by investigator 2 (CH) while the remaining 60% were coded independently by myself. After all data had been coded, the allocated codes were discussed and re-coded until agreement was reached. Codes were then grouped into sub-themes that were organised to create a thematic model or table, specific to each question analysed. All responses were checked by both investigators to ensure all data fitted into the themes identified. Descriptive statistics were used to analyse respondent characteristics and report frequencies within the data set.

3.6 Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

3.6.1 Study Research Questions

This study relates to the thesis research questions 1 3 and 4:

(1) Thesis Research Question 1 '**How is post-stroke fatigue perceived?**'

(2) Thesis Research Question 3 '**How do healthcare practitioners assess post-stroke fatigue?**'

(3) Thesis Research Question 4 '**How is post-stroke fatigue managed?**'

3.6.2 Study Design

Two qualitative semi-structured focus groups were conducted using a topic guide focusing on the management of post-stroke fatigue. Focus group discussion was carried out with groups of healthcare practitioners.

3.6.2.1 Design Justification

Focus group discussion was the most appropriate study design to generate new ideas and insights within a social context (Breen, 2006) and it is for this reason that it was chosen for this phase of the research. Other research designs were considered, such as telephone interviews with a random selection of participants from the cross-sectional therapist survey. This design would have allowed further insight to be gained from the descriptive dataset collected, in a cost effective way. However, it became clear over the course of the first 4 studies, that a variety of different healthcare practitioners outside of the therapist role were involved in post-stroke fatigue care. As post-stroke fatigue is evident over the full stroke care pathway, utilising perspectives from healthcare practitioners at all stages from acute to long term community care was appropriate. The study was created to tie together all aspects of the PhD and gain expert opinions on the thesis' fourth research question; how is post-stroke fatigue managed? The thesis working definition was considered when designing the study topic guide and also during analysis when comparing and contrasting to the other studies.

To enable discussion on future directions of post-stroke fatigue management, an overview of initial PhD findings from studies 2, 3 and 4 were presented partway through the focus group. It was ensured that this external insight was given after the participants answered questions on their understanding, assessment, and management of post-stroke fatigue.

The clinician focus group was chosen to gain a greater insight into the findings which emerged from the national therapist survey. The focus group study was the last to be conducted and as such, it had become clear that a wider healthcare practitioner team is often involved in the delivery of post-stroke fatigue education and care. The recruitment strategy was adjusted to account for this, which was hoped to make the findings more generalisable. Bringing together practitioners from different settings and professions was also felt to enable the building of ideas and sharing of perspectives.

3.6.2.2 Topic Guide Justification

Study 5 Topic Guide
How do healthcare professionals understand post-stroke fatigue?
Suggested Questions • How would you explain post-stroke fatigue to another healthcare professional? • How may this vary if you were asked the same question by a stroke survivor or family member? • How often do you explain what post-stroke fatigue is in your role? • Have you received any teaching or training on post-stroke fatigue? If so, at what point and by who?
What do healthcare professionals view their role to be within post-stroke fatigue management?
Suggested Questions • What do you think your role is in managing post-stroke fatigue? Do you feel like you lead management? • What other individuals are part of management programmes where you work? Has this changed? • Do you think you are able to make a difference to these individuals?
What management strategies do healthcare professionals use and what barriers do they face?
Suggested Questions • You have just assessed a stroke survivor and believe they have PSF- what are your next steps? • In your experience, have you included family members or supporters and at what stage?

• What barriers have you faced when carrying out management interventions and programmes? • Do you think there would be barriers to starting a new management programme in your setting?
What could be the future of managing fatigue for a stroke survivor population?
• A short summary of the evidence and research to date will be shown- individuals will then be asked to discuss ‘big ideas’ (if time, within small groups and then all together). The facilitators will guide discussion, focusing mostly on views on feasibility and acceptability.
Interview Close • Is there something else you wish to discuss today? Thank you for your time and sharing your experiences with us today.

Table 6. Topic Guide used for Study 5.

The topic guide was created in consideration of the primary study objective and to align with the findings from the TalkStroke forum analysis study and the cross-sectional therapist survey conceptual studies carried out earlier in the PhD (Table 7, Page 72). A key initial finding from these studies was the role ambiguity of healthcare practitioners in fatigue management. As a result, this was incorporated into the focus group topic guide and study protocol (Appendix 6).

3.6.3 Recruitment

The study followed on from an exploratory survey study conducted with healthcare practitioners. As part of this initial study, respondents (physiotherapists and occupational therapists; members of neurological therapy special interest groups ACPIN and RCOT-NSS) were asked to provide their contact details if they wished to be contacted regarding further focus group research. 124 individuals expressed interest at this stage. The research team sent an invitation email and participant information sheet to interested individuals. Contact was made with these individuals to assess the feasibility of carrying out a focus group in their region, with other respondents based close by. This recruitment method proved challenging due to the limited proximity of interested respondents. Further, previous studies and literature review over the course of the PhD highlighted that several other healthcare practitioners were involved in fatigue management as well as therapists. As a result, snowball recruitment was used following the selection of two regions able to host a focus group. The two recruiters from Cambridgeshire and Royal Cornwall Hospitals Trusts sent an invitation email with information booklet attached to stroke specialist service leads across their trusts. Consent forms were completed by all individuals who attended a focus group before the group began. This recruitment strategy enabled us to gain perspectives from diverse geographical and socio-economic areas of the United Kingdom.

By utilising a snowball recruitment strategy, a wider range of healthcare practitioners were recruited which provided a broader and more generalisable perspective of fatigue management pathways in the two trusts. A negative of this recruitment strategy is the likelihood of volunteers having an interest in post-stroke fatigue already which could reduce the generalisability of the study findings (Browne, 2005). Six different professions were represented at the focus group; physiotherapy, occupational therapy, clinical psychology, discharge planner, district nursing and speech and language therapy. However, notably missing were individuals who practice as GPs, neurologists, or hospital-based nurses. Participant characteristics are detailed in Section 3 of the thesis. Within the interview study, participants reflected on experiences with these professionals and so it could be argued that an important perspective was missed. A nurse and stroke consultant were invited to one of the focus groups however were unable to attend on the day due to busy schedules.

3.6.4 Data Collection

All focus groups were recorded using digital audio recording technology. In both focus groups, refreshments were provided. Following consent and introductions, participants were asked a broad opening question around the topic to ensure comfortability with each other and the setting. This was the same question asked in the therapist cross-sectional survey to assess understanding; “How would you explain post-stroke fatigue to another healthcare professional?”. More targeted questions were then asked to answer secondary research questions 1-3. As the primary facilitator, I presented initial thesis findings encapsulating the underlying theme of shared sense-making and understanding between stroke survivors and healthcare practitioners. Individuals were then encouraged to discuss their thoughts as a group which was followed by a feedback open dialogue session with all focus group participants. It was hoped that this structure would inform discussion around the acceptability and suitability of management interventions. All participants were offered a summary of findings and the opportunity to have a face to face presentation of conclusions.

3.6.5 Myself as the facilitator

Similar to the interview study, due to the subjective nature of qualitative data collection and my role as a researcher and facilitator of discussion, how participants perceived me deserves consideration. I mentioned to participants I was a physiotherapist by profession however clarified I was acting only in the role of facilitator during the session. Most participants assumed I had a subject-specific knowledge and did not attempt to explain technical or clinical terms unless I or the secondary facilitator asked for further clarification. I think that disclosure of my professional role enabled deeper discussion, which may not have been the case if the participants felt they needed to simplify language used or take time to provide explanations. Initially, I needed to ask questions to specific members of the group to ensure all voices were heard however as each focus group progressed, I became more of an observer of discussion between the participants sharing their experiences and views.

3.6.6 Data Analysis

Data were collected through the use of an audio recording device. The recordings were anonymised and transcribed by an external transcription company. Although a deductive approach was taken in the design stages of the study to create the focus group topic guide, an inductive approach was taken to analysis. This meant that although the data that were collected pertained to set research questions, the chosen analytical technique enabled themes to evolve through the coding process. Following transcription, all summaries were checked and recordings were listened back to. NVivo was used for the process of coding, using constant comparative analysis, a technique often used in focus group studies. During analysis, the extensiveness, intensity, and specificity of quotes were considered (Breen et al, 2007). Constant comparative analysis was chosen to enable an emergent-systematic approach to be taken. This was done through the process of axial coding, selective coding, and finally theme creation. This analysis technique enables across-group analysis to determine and refine themes occurring across both focus groups despite the time and location differences (Onwuegbuzie et al, 2009). Discourse analysis was considered, to gain greater insight into the social interactions occurring during the focus groups amongst participants. However, this analytical technique works most effectively when a small set of scenarios are discussed by different individuals. Due to the variety of topics included in the topic guide and the following focus group discussions, it was felt that this form of analysis would constrain the dataset and limit the findings.

3.7 Data Management and Ethical Considerations

3.7.1 Thesis Data security

All electronic study data was stored and accessed through the University of Cambridge Clinical School Secure Data Hosting Service (SDHS), on a password-protected university computer. This storage area is protected by a dual authentication (password secured and personal security code secured), located on a firewall-protected network, and is certified to an ISO29001 security standard. Paper data was stored in key-locked filing cabinets in a locked room within a security card-protected building, with access restricted to the specific study team. Personally identifiable data was stored for one year following the specific study completion on a password protected system or in a locked filing cabinet to allow for the dissemination of study findings. Following this period, all identifiable data is destroyed.

3.7.2 Ethical Considerations

3.7.2.1 Study 2: A thematic analysis of the TalkStroke Forum

The Stroke Association gave the researcher Anna De Simoni access to the forum archives and permission for the data to be used for research purposes. The use of internet data raises important ethical considerations around intrusiveness and whether forum data is private or considered to be within the public domain. The platform hosting the forum was taken down in 2012 and the content is no longer accessible online, apart from through special search engines for archived webpages. Within the thesis and all subsequent publication of findings, effort has been taken to ensure anonymity was maintained for all individuals. De Simoni and colleagues (2016) noted that this specific analysis is classified as low intrusiveness and due to the high number of users, participants were likely to view their posts as public. People signing up to Talkstroke agreed that their data were public upon registering for the forum.

To protect the identity and intellectual property of forum participants, the thesis will report fragments of responses and paraphrase longer discussion points.

3.7.2.2 Study 3: An interview study investigating lived experience of post-stroke fatigue

Recruitment

Stroke survivors often experience multiple problems and so the likelihood that some individuals invited to take part in the study would experience fatigue, as well as aphasia or dysarthria, was high. All study documentation clearly stated that a participant would be expected to take part in an interview. As such, the research team made an implicit assumption that individuals who returned the consent form and wished to participate were unlikely to have significant communication difficulties. The individual's suitability to participate in the study and any additional support needed were discussed when interview time and arrangements were scheduled.

Within the supporter information booklet, individuals were encouraged to join survivors if they felt they had experienced the effects of post-stroke fatigue in a care or support role. The role supporters play in the management of chronic conditions was acknowledged when designing the study. Research has shown their insight can be valuable when developing management interventions (Robinson et al, 2005). They completed a consent form before the interview, similarly to stroke survivor participants.

Consent

No issues regarding informed consent were anticipated due to the study not being high-risk. To ensure the participants understood what they were consenting for, written explanation in the form of a recruitment pack including a letter, participant and supporter information booklets, consent forms, as well as a verbal explanation before the start of the interview, was provided. It was specified what the study aims were, what data would be collected and how it would be used. Participants did not have to answer any questions if they wished not to do so and had the right and ability to end the interview at any point.

Confidentiality

All interview recordings were anonymised before transcription. The NVivo account used for analysis was accessible through one log-in, with only the research team and departmental data manager knowing the details. As a shared account was not used, this helps preserve participant confidentiality. All documentation was approved by the Health Research Association (HRA) NHS Research Ethics Committee (Appendix 5) and was sponsored by the University of Cambridge Research Office (RG99104; Appendix 4).

3.7.2.3 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

Consent

This study recruited specialist therapists in the field of stroke. No issues regarding informed consent were anticipated and it was a low-risk study. Participants were required to sign a consent form to participate in the study. This was within the first section of the Qualtrics online survey and potential participants could not complete the research survey without first fully completing the consent form (Appendix 3). Electronic signatures were obtained for all participants. Following consent, participants were free to withdraw at any time by exiting the browser. Participants did not have to answer any questions if they wish to not do so. Participants were informed of their ability to exit the survey software in the invitation email to which the survey link was attached and in the participant information sheet on the front page of the survey (Appendix 3).

Survey Platform

Qualtrics, a trusted online survey programme was used. Although optional identifier questions were asked in the survey to send findings and details of further research opportunities, no participant details were included in analysis or within this thesis and any subsequent publication of findings. This ensured anonymity is retained. Furthermore, no IP addresses were saved or published.

All documentation was approved by Cambridge University Psychology Ethics Committee (PRE.2017.092), which can be viewed in Appendix 2. NHS ethical approval was not needed for this study, due to the design and population that was targeted.

3.7.2.4 Study 5: A healthcare practitioner focus group investigating post-stroke fatigue management

Participant Confidentiality

To ensure data confidentiality, the research team was not involved in identification of potential participants. Two trusted individuals from each NHS Trust were asked to send an invitation email to potential participants. All information regarding the focus group prior to the data collection session was sent through the two trusted individuals.

Discussion of patient cases

The focus groups followed a semi-structured topic guide and were carried out at a pace which suited the participants. Refreshments were provided prior to and throughout discussion along with an ice-breaker activity to ensure all participants felt at ease. Both small group discussion and whole group sessions were included, to ensure that all participants had the opportunity to express their ideas and experiences. All participants were asked to not use any identifier language when discussing experiences and particular cases to demonstrate their points. It was also requested that discussion did not continue following the group. In the case of sensitive topics, all participants were given the option to contact myself as the chief investigator following the focus group if there were any topics they did not want to discuss within the group setting.

Right to withdraw

Participants did not have to answer any questions that they did not want to and had the right and ability to leave the focus group at any point. Clarification was gained in the case of uncertainty following any responses.

All documentation was approved by the Health Research Association (HRA) NHS Research Ethics Committee (Appendix 5) and was sponsored by the University of Cambridge Research Office (RG99104; Appendix 4).

Section 3: Results

Section 1. Introduction
Section 2. Methods (by study)

Section 3.
Chapter 4 Results (by research question)

-Participant Characteristics

-Thesis Research Question 1: How is Post-Stroke Fatigue perceived by stroke survivors, supporters, and healthcare practitioners?
Study 2: A thematic analysis of the TalkStroke Forum
Study 3: An interview study investigating lived experiences of post-stroke fatigue
Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue
Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

-Thesis Research Question 2: What are the psychometric properties of current measurement scales available for post-stroke fatigue?
Study 1: A Systematic Search and Literature Review of the psychometric properties of fatigue measures used in a stroke survivor population
A stroke survivor and supporter perspective
A healthcare practitioner perspective

-Thesis Research Question 3: How do healthcare practitioners assess post-stroke fatigue in clinical practice?
Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue
A stroke survivor and supporter perspective

-Thesis Research Question 4: How is post-stroke fatigue managed?
Study 2: A thematic analysis of the TalkStroke Forum
Study 3: An interview study investigating lived experiences of post-stroke fatigue
Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue
Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

Section 4. Discussion and conclusions

Chapter 4 - Results

4.1 Participant Characteristics

4.1.1 Study 2: A thematic analysis of the TalkStroke Forum

A preliminary data set was constructed of 104 posts, written by 71 forum users on the Stroke Association hosted TalkStroke Forum. 65 individuals wrote the 89 posts included in the analysis. This included 38 stroke survivors, 23 individuals in a family or carer role and 4 others who were unidentified. All data extracts used in the analysis were from individuals posting about the effect of fatigue, identified by key search terms which are detailed in Table 8, Page 83.

Participant respondents	Number
Identified role	
Stroke Survivor	38
Family or carer	23
Unidentified	4
Total	*65*

Table 7. A table depicting study participant demographic information, collected by ADS.

4.1.2 Study 3: An interview study investigating lived experiences of post-stroke fatigue

Forty-three participants were interviewed; 25 stroke survivors and 18 supporters (Table 9, Page 84). The stroke survivor participants were aged between 47 and 87 (mean age 67), 8 months-37 years post stroke event; 14 were men and 11 were women. 23 of the participants reported more than one other co-morbidity arising from the stroke affecting their physical and cognitive functioning. Two reported feeling like they had recovered or returned to “normal” and discussed their previous experiences of fatigue within their interviews. Fourteen of the supporters participating in the interviews were spouses of the stroke survivors. One sibling, one child and one formal care giver also participated. Participants were interviewed between 33 and 90 minutes.

Name (Pseudonym)	Age (years)	Time since most recent stroke (Closest year)	Supporter role
1 Mr Barnes	62	11 years	Wife
2 Mrs Murray	72	6 years	Husband
3 Mr Anthony	47	7 years	N/A
4 Mr Walker	87	11 years	Wife
5 Mrs Caldicott	59	5 years	Daughter
6 Mr Thomas	74	8 years	N/A
7 Mr Harvey	71	2 years	Sister
8 Mr Emanuel	82	15 years	Wife
9 Mrs Larman	69	Under 1 year	Husband
10 Mrs Smith	79	2 years	N/A
11 Mrs Hansen	49	12 years	N/A
12 Mr Davies	66	19 years	Wife
13 Mr Rutt	70	4 years	N/A
14 Mr Pennick	76	18 years	Wife
15 Mr Halter	58	2 years	Wife
16 Mrs Cockerham	71	2 years	Husband
17 Mrs Zavos	73	3 years	Son
18 Mr Gilchrist	56	37 years	Care Staff
19 Mrs Morton	72	4 years	Husband
20 Mr Simmons	52	4 years	Wife
21 Mrs Langman	67	3 years	Husband
22 Mrs Wilkinson	59	16 years	N/A
23 Mr Bone	68	8 years	Wife
24 Mr Best	64	15 years	Wife
25 Mrs Jenkins	77	9 years	N/A

Table 8. A table depicting study participant demographic information. All names have been changed to pseudonyms to ensure participant anonymity.

4.1.3 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

Seven hundred Occupational Therapists and 800 Physiotherapists were sent a study invitation email to participate in a cross-sectional online survey. One hundred and thirty-seven individuals completed the survey. Occupational Therapists and Physiotherapists responded in similar numbers (66 Occupational Therapists, 71 Physiotherapists). Respondents reported a diverse range of experience working in settings with stroke survivors, identifying as working in acute care (25 respondents); sub-acute rehabilitation care (24 respondents); community care (85 respondents); and primary care (3 respondents). The duration of specialism individuals had worked with stroke survivors ranged from 7 months to 33 years (Table 10, Page 85).

Participant respondents	Number
Profession	
Occupational therapist	66
Physiotherapist	71
Clinical setting	
Acute	25
Sub-Acute	24
Community	85
Primary Care	3
Duration of specialism	
< 1 year	4
1-5 years	29
6-10 years	41
11-15 years	17
16-20 years	19
21 + years	27

Table 9. Respondent characteristics by profession, clinical setting, and duration of specialism.

4.1.4 Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

Two focus groups took place over the period of March to September 2019. Focus Group 1 was carried out with healthcare practitioners from the Royal Cornwall Hospitals NHS Trust and Focus Group 2 was carried out with healthcare practitioners from Cambridgeshire and Peterborough NHS Foundation Trust. Sixteen individuals participated in the study in total (6 participants in Focus Group 1; 10 participants in Focus Group 2). Three further individuals were expected to attend Focus Group 1 however could not attend on the day due to work commitments.

A secondary facilitator was selected for both focus groups however due to participant drop out in focus group 1, I acted as the only facilitator to enable the selected facilitator to participate. In Focus Group 2, the secondary facilitator was an experienced researcher in the stroke field with previous clinical experience in physiotherapy.

4.2 Thesis Research Question 1: How is Post-Stroke Fatigue perceived by stroke survivors, supporters, and healthcare practitioners?

4.2.1 Overview

To answer the first research question, 4 studies were conducted. Firstly, a thematic analysis of the TalkStroke forum was carried out to provide an unbiased insight into perception, use of language and experiences of stroke survivors and their supporters. This was built upon in a semi-structured interview study carried out across the East of England. To gain a healthcare practitioner insight into post-stroke fatigue, a national online survey was sent out to specialist occupational therapists and physiotherapists. Finally, to bring the findings from the 3 studies together, a focus group study was carried out with healthcare practitioners in East of England and Cornwall. Within the next section, the results of each study investigating Research Question 1 will be stated.

4.2.2 Study 2: A thematic analysis of the TalkStroke Forum

Five themes were identified representing a wide variety of perceived understanding and approaches to post-stroke fatigue by stroke survivors and supporters alike. Following data familiarisation, 30 initial codes were created and discussed to enable creation of the final 5 themes that related to how post-stroke fatigue is perceived. The 5 themes and their associated codes are detailed in Table 11 below:

Theme	Code
Medicalisation of Post-Stroke Fatigue: “A classic post-stroke symptom”	1.Silent Disability “It’s the silent disability nobody talks about” 2. Filling mind and attention “Its all-consuming” 3. Comparison to other conditions “Every day in tired but not sleepy, not like M.E.” 4. Suffering “He suffers with fatigue” 5. Effect of stroke “A part of stroke symptoms” 6. Lack of understanding “It’s not understood by them”

Theme	**Code**
Tiredness like no other: “A legacy of stroke”	1. Reassurance “Exhaustion is normal” 2. Comparison and differentiation “The tiredness is most shocking in a way- it’s like nothing else” 3. Caused by stroke “Tiredness is a feature of our affliction” 4. Individual “It depends on damage and recovery” 5. Time frame to legitimise “It is more or less permanent after stroke”
Acceptance and normalisation of Post-Stroke Fatigue: “Part and parcel”	1. Advice giving: patience “Take your time” 2. Time related explanation “Time heals tiredness” 3. Adjustment “Have to get used to it” 4. Advice: Sleep/rest related “Sleep as much as you want to” 5. Submit/give way synonyms “Give in to the tiredness” 6. Comparisons to fighting fatigue “So wonderful to have stopped fighting it” 7. Advice giving: focus on the present “Take every day with care” 8. Recounting information given “I am told it’ll pass”
Fighting Post-Stroke Fatigue: “An unwelcome guest”	1.Term: problem “Tiredness is a big problem” 2. I need/I must [ ] “I need to push to improve” 3.Term: fight[ ] “Fight the tiredness” 4. Examples of fighting “Fight by keeping your mind busy” 5. Advice suggesting ownership- negative connotations “Push yourself to be aware and feel better” 6. Planning “Rigid routine seems to fight it” 7. Sleep and rest- negative connotations “Don’t lie down and sleep”
Survivors biological explanations and beliefs: “Brain healing”	1. Term: neuro[ ] “I was told it’s a neurological tiredness” 2. Legitimacy: Brain “You think you’re resting but your brain is still working” 3. Personification/ownership of the brain “My brain says go to sleep, you’re tired” 4. Legitimacy: Healthcare practitioner information “The doctor said its caused by brain damage and is more or less permanent”

Table 10. Final codes associated with the chosen sub-themes and themes in Study 2, answering Research Question 1.

4.2.3 Themes

4.2.3.1 Medicalisation of Post-Stroke Fatigue: **"A classic post stroke symptom"**

Forum users employed language highly suggestive of medicalisation such as 'suffers with fatigue' (Supporter (SU) 4). Users also directly attributed the fatigue to the stroke event and often referred to a healthcare practitioners' explanation to support this assertation; 'my consultant said it is caused by the stroke' (Stroke Survivor (SS) 21). Yet, there was also much discussion about long-term effects of stroke as 'not understood by the profession' (SS 37) (Table 12, Page 89). One individual reported attending two outpatient appointments following discharge from the stroke ward in which his fatigue was never addressed. This is at odds with the strongly held idea by many stroke survivors on the forum that 'tiredness is very much a part of stroke symptoms… a classic post-stroke symptom'(SS30). Notably, there is ample information about post stroke fatigue available online and in booklet format from various charitable organisations such as The Stroke Association and Chest, Heart & Stroke Scotland, but these resources were not mentioned in forum discussions.

Theme	Selected User Quotes & Paraphrased Discussion Points
Medicalisation of post-stroke fatigue	A man replied that he suffered from tiredness. (SU6) His consultant told him that tiredness is a major after effect of stroke. (SS9) She described tiredness to another user as a classic post stroke symptom. (SS30) Their consultant said the fatigue is caused by the stroke and is a major after effect. (SS21) A stroke survivors' wife shared that her husband had two outpatient appointments but was never made aware of issues regarding tiredness. (SU2)

Table 11. Themes based on exemplar quotes from the Talkstroke Forum archives. SS = Stroke Survivor. SU – Supporter.

4.2.3.2 Tiredness like no other: **“A legacy of stroke”**

A number of forum users discussed the features of post-stroke fatigue itself (Table 13, Page 90). It was described as ‘a fatigue like no other’(SU3), and a ‘neurological tiredness’(SS6). There were multiple references to the idea that ‘stroke can and does cause fatigue’(SS36), that fatigue is ‘a feature of our affliction’(SS9), and some took this further, characterising post-stroke fatigue as a distinct problem; ‘a thing in itself, aside from chronic fatigue syndrome’(SS44). Further, fatigue was repeatedly expressed by forum users as a ‘legacy of stroke’(SS45) or a ‘typical post-stroke legacy’(SS12), encapsulating survivors’ experiences of a long-lasting fatigue linked to the stroke. Forum users felt strongly about their fatigue being unique to stroke, with one responding to a fellow stroke survivor saying, ‘I know stroke can and does cause fatigue’.

Theme	Selected User Quotes & Paraphrased Discussion Points
A fatigue unique to stroke	When reflecting on post-stroke fatigue, a man commented that he felt everybody seemed to suffer from tiredness following a stroke, further describing it as a silent disability that is not often talked about unless it is brought up in discussion. (SS8) When replying to other forum users, one woman described post-stroke fatigue as a stroke legacy. (SU12) One man told other users that he knew his stroke caused the fatigue he experienced after. (SS36) Tiredness was described by one user as a feature of their affliction (SS6) One stroke survivor expressed strongly believing that the stroke can and did cause her post-stroke fatigue. (SS21)

Table 12. Themes based on exemplar quotes from the Talkstroke Forum archives. SS = Stroke Survivor. SU = Supporter.

4.2.3.3 Acceptance and normalisation of Post-Stroke Fatigue: **“Part and parcel”**

Often, stroke survivors asked other forum users ‘is this tiredness normal?’(SS3), obtaining a plethora of affirmative responses (Table 14, Page 91). This can be summarised by the idea proposed by one participant that post-stroke fatigue ‘is a guest you’re stuck with, you’ve just got to learn to live with it’(SS12), and that ‘the feelings are normal and all stroke survivors can relate to the tiredness’(SS29). Along with the reassurance that ‘tiredness (fatigue) is very common post stroke’(SU16), forum posters acknowledged fatigue as an after-effect of stroke. One post from a survivor explained ‘tiredness is common and can last for years post stroke’(SS12). Use of normalisation and reassurance strategies was a recurring response to queries about post-stroke fatigue, demonstrated by the stroke survivor who wrote ‘the exhaustion as other posts have said is normal’(SS5). Another acknowledged the burden of fatigue on mindset and mood, offering ‘your feelings are normal, all of us [stroke survivors] can relate to the tiredness and how you are feeling’. Family members and supporters used the forum to reassure each other, with one responding ‘the tiredness will make him struggle sometimes. It does get better with time’ (SU6).

Theme	Selected User Quotes & Paraphrased Discussion Points
Acceptance and normalisation of post-stroke fatigue	One forum user used metaphor in a response to explain the length of time she believed fatigue may last for after a stroke, telling the user that fatigue is a guest you're stuck with and explaining that acceptance is important to be able to learn to live with it. (SS12) One concerned stroke survivor asked other forum users if the fatigue he was experiencing was normal, seeking affirmation. (SS3) One man responded to a concerned forum user to assure them that their feelings were normal, and all stroke survivors could relate to post stroke tiredness. (SS29) One stroke survivors husband reflected that his wife had learnt what the signs of tiredness were for her personally and understood that they signal a need to rest. (SU5)

Table 13. Themes based on exemplar quotes from the Talkstroke Forum archives. SS = Stroke Survivor. SU = Supporter.

4.2.3.4 Fighting Post-Stroke Fatigue: **“An unwelcome guest”**

In contrast to the theme of normalisation and acceptance some Talkstroke forum users considered post-stroke fatigue to be ‘one of those things we have to try and combat’(SS17). Forum users received advice from some individuals to ‘not give into it’(SU8) – to be ‘continually fighting what’s going on’(SS4) and to ‘find your inner strength, [don’t] let anything beat you’(SU2). Forum posts of a combative nature described the tiredness as ‘annoying’, emphasising that the ‘point is not to give into it, [but] to find ways, little ways, to fight’(SS17). Other users described the feeling of an internal battle; ‘my brain is saying go to sleep you are tired, my mind is saying get lost’. Negative descriptors were often used in this posts, such as ‘annoying’ and ‘a big problem’. Despite this, such posts acknowledged that ‘tiredness after stroke is very common’(SS20), much the same as the forum users accepting and normalising their post-stroke fatigue (Table 15, Page 92).

Theme	Selected User Quotes & Paraphrased Discussion Points
Fighting post-stroke fatigue	One male user highlighted that tiredness was a problem for him and he dealt with it by pushing onwards to fight the tiredness by keeping mentally and physically busy. (SS12) A woman replied that it was important to not give into the tiredness and to find strategies to combat it. (SU15) By related her tiredness to the brain injury, one user responded that it can be overcome, and the brain can outwit the need for sleep. (SS9) One forum user described struggling to decide if she should be resting or fighting the tiredness continually (SS23)

Table 14. Themes based on exemplar quotes from the Talkstroke Forum archives. SS = Stroke Survivor. SU – Supporter.

4.2.3.5 Survivors' biological explanations and beliefs: **"Brain healing"**

Most commonly, forum users attributed post-stroke fatigue to 'the brain healing'(SS17). Several variations of this theme were identified: some stroke survivors and supporters understood it as 'giving the brain the "time off" it needs to start healing itself'(SS21), while others suggested that the 'body is working overtime trying to make sense of what has happened and heal as fast as it can'(SU16). There were also references to information about post-stroke fatigue provided by health care practitioners (Table 16, Page 93). On one occasion, the phrase 'post-stroke fatigue' was employed, where a relative explained he was told by a health care practitioner that his father in law 'may have post-stroke fatigue'(SU17). However, discussions usually centred around the explanation of symptoms given by health care practitioners; that 'stroke causes fatigue'(SS12). Forum users sought to extend such explanations using metaphor for the disease process: 'the clock in your head…is going round at its own pace now' and expressed reverence for the brain; 'a strange thing'(SU9) they could not understand.

Theme	Selected User Quotes & Paraphrased Discussion Points
Survivors' biological explanations and beliefs	One spouse made sense of the tiredness by considering the tiredness as result of the brain damage caused by a stroke event. (SU9) A forum user wrote an affirmative response that the tiredness he often experienced was due to the brain healing. (SS17) A woman drew upon information she had been given by a medical practitioner that post-stroke fatigue occurs because of the brain being tired. (SS18) One woman personified her brain, responding by explaining that if the brain does not get tired, it will not have the rest time necessary to heal. (SS26) One stroke survivor tried to explain how the fatigue felt to other forum users, emphasizing the difference to their pre-stroke fatigue by describing it as a bone weariness as opposed to a sleeping issue. (SS20) A spouse described her husbands' fatigue as strange and confusing, relating it to the brain. (SU5)

Table 15. Themes based on exemplar quotes from the Talkstroke Forum archives. SS = Stroke Survivor. SU = Supporter.

4.2.3 Study 3: An interview study investigating lived experiences of post-stroke fatigue

The following themes were created as a result of transcription coding to answer the secondary research question **"How do stroke survivors and their supporters understand and experience post-stroke fatigue?".**

4.2.3.1 Themes

Overview: Changeability

When asked to describe post-stroke fatigue, the participants often referred to how it felt and their societal roles which had been affected. These included occupational role, the importance of routine and relationships. Four key themes are explained below which are role adjustment, influence of environment, difficulty articulating post-stroke fatigue to others and the comparisons made to their personal expectations.

Role adjustment: ***"it's different for both of us"***

To describe the effect fatigue had on their lifestyle, stroke survivors and their supporters who participated in the study used examples of their roles changing. Often, participants spoke about the impact fatigue had on carrying out activities of daily living which directly translated to their ability to carry out roles. This could mean that the below quotes were referring to physical or cognitive difficulties resulting from the stroke, but the participants attributed the changes to a combination of their fatigue and other post-stroke conditions.

Mr Davies wife gave an example of how their relationship roles had adjusted; “we have just sort of accepted what will be will be. And obviously its affected our relationship with the washing and dressing.. he does what he can, but it is different for both of us y ‘know”. Fatigue also affected participants’ relationships with young and grown-up children. Mrs Cockerham recalled previously supporting her daughter by having the voluntary role as carer for her teenage disabled grandson. She recalled how the sensory triggers associated with post-stroke fatigue had affected her ability to carry this role out and the guilt she felt not being able to support her adult daughter in the way she did before; “My children worry inwardly about me but dont show it- youll be fine um.. I don’t want to burden them. I have proved to her recently that i could help her, to a limited degree but i can help. Her son is disabled and so loud though and I cannot be around him. I used to help every week. I really love him but that’s one thing I can’t do now.” Another participant introduced me to his young family prior to the interview and referred to them when explaining his daily lived experience of fatigue; “It still affects me now- we’ve got four children to look after. It limits where we go- the tiredness stops us. We have a son with autism and I associate with him in many ways.. You overcome a lot of things after a stroke but you have to really think about things the whole time still. When I get tired and I’m trying to think it’ll all go to pot.”

Participants spoke about the effect of post-stroke fatigue on their occupational roles and previous aspirations; “I used to travel.. Now more time is spent at home. Not having a job... My mental is alright but my body and this damn draining tiredness is letting me down”. Mr Halter highlighted his past occupation when explaining the effect of his fatigue. His body language appeared to show exasperation and he depicted feelings of worthlessness which he associated with the lack of an occupational role; “I used to be a headteacher. I cannot do anything being disabled; I am just completely useless". This quote highlighted the broader difficulties participants experienced following the stroke, seemingly as a result of a combination of post stroke conditions which included debilitating fatigue.

Influence of environment: ***"only need to tweak something … and that's it"***

Change of routine was reported as a cause for the onset of post-stroke fatigue, as were changes to environment. Supporters described concern that the stroke survivor they cared for was isolated or not getting social interaction. Conversation and social interaction were often reported as exacerbators of fatigue however; "When theres lots of people in the house it drains me. It's not the noise, it's the bodies- you've altered something." The noise and presence of other individuals was also highlighted by Mr Simmons wife when he was in a social situation outside of the home environment; "We went for a meal just before Christmas and sat in a pub restaurant. There was a wall behind our table and we didnt think about it at all.. I sat facing the wall and he sat opposite me but around and behind us were people so he didnt do much speaking because there was everything going on around and there was noise so it was really difficult to focus. Our friend rang up to check he was okay afterwards." Mr Halter reiterated this perspective, recounting a trip into his local town centre he had recently taken; "If I'm walking in the town and there are loads of people I hate it. My heads pounding because I have to watch everyone." His accounts suggested that the increased cognitive workload associated with changes to environment was a consistent exacerbator of his fatigue.

Another lifestyle change participants frequently mentioned was the uncertainty and inability to plan outside of a set routine, often isolated to the home environment. Mr Pennicks' wife recalled; "we are reluctant to commit to doing things because he will have some days he wakes up and you can see he's tired and I say you are officially given a day off to not do anything then 36 hours later he will be fine for a few days. So it is almost impossible to gage. He will have done nothing the day before to cause the tiredness the next day and it's just come out of the blue". The unpredictability highlighted by this supporter was reiterated by another; "because it comes out of nowhere you can't always see the signs. It's so uncertain now."

Mrs Langman shared that subtler changes to environment and routine had a significant effect and were difficult to predict; "Only have to change anything in the day and I'm done. Or if we go somewhere different. I will be out for two hours and done something different and I'm done in for 24 hours. Tends to be a combination- only need to tweak something little and thats it.". In Mr Bests home we sat opposite his turned off television for the interview. At one point he pointed to the screen and told me about a programme he had been trying to watch; "I can relax in my recliner chair and watch a programme.. there was this squirrel programme and I tried to watch it every day for weeks and just ended up out like a light every time so ive given up. Shame." This is another example of the effect of increased sensory input for some stroke survivors.

Difficult to articulate: *"it's not just tiredness"*

When participants attempted to define or describe the fatigue they often explained how it felt or used analogies. One example of this was Mr Rutts' response when asked to describe his post-stroke fatigue; "It is like when you've done a 12-hour flight and your eyes are achy and whole body is heavy. It happened before but it's worse now and it goes very deep".

Often participants would end their explanation seeking reassurance that they had articulated their experience clearly as is demonstrated in the next two quotes; “It’s not just tiredness and it’s not just tiredness where you could sit down and fall asleep.. I don’t know, it’s a sort of 'eurgh' it is a weird type of tiredness. It is horrible. Does that make sense? I don’t think anyone gets it.” And Mrs Larman who said, “My brains whirring round and I try to pick out the bits that make sense, I know that sounds weird, doesn’t it?”.

One explanation for the participants reassurance seeking behaviours could be the influence of how they perceived their supporters understood and acknowledged post-stroke fatigue. Mrs Cockerham mentioned this; “My son and daughter always tell me to pull myself together and get going but they don’t understand.. they don’t understand how i feel in my brain but they are very like that.” Mrs Zavos also referred to a potential lack of understanding; “People don’t understand how much your brain does in the background that you are unaware of. I realise now because of this tiredness”.

Comparison to expectations: ***“it shouldn’t have happened to me”***

When participants compared their post-stroke experiences to before the stroke event, some reflected negatively or portrayed a longing to recover so they would be able to return to a previous state of ‘normal’. Mrs Caldicott said within her interview; “I must admit the stroke and then this tiredness on top of it has totally changed my life and its.. it has frightened me. Even to now, I am frightened to go away anywhere even if I think I can. It is very hard to cope with. I don’t think I’ll feel back to normal again.” Mrs Smith also referred to the difference between mental determination and the effects of the fatigue, sharing “it just slows everything up.. I want to do things and my mind says do it but the tiredness says no”.

The phrase “this life” or “my life” were used by multiple participants expressing exasperation or a struggle with adjustment after their stroke. Mr Thomas reflected at the end of his interview, “you’re fighting yourself to start with. It’s difficult to start with because that isn’t the life you wanted limited by this, this unpredictable thing.” Mr Walker also recalled his wish to be promoted in his occupational role prior to the stroke and used his previous achievement in higher education to justify his perspective, saying “it just felt like you were wasting your life away because all you wanted to do was sleep. I have always achieved the things I wanted before.” This arguably negative outlook on aspirations past and present was clear to some of the supporter participants, with Mr Simmons wife saying, “He always says I’m no good but he doesnt realise how much he has achieved. He has said I shouldn’t have to achieve it; it shouldn’t have happened to me.”

4.2.3.2 Summary

When stroke survivors were asked to explain or define post-stroke fatigue, they often personified their explanation by articulating their experience in a way that they could make sense of. Key examples of this were comparisons to pre-stroke lifestyle, role, and aspirations. Frustrations were often voiced about the unpredictable changeability in the presentation of post-stroke fatigue which directly affected both the stroke survivor and supporters’ daily routine and outlook. The sensation of fatigue was hard for participants to convey and was often explained through use of analogy or description of how it felt, as opposed to explaining the reason they believed they had the fatigue or specific tangible symptoms.

4.2.4 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

The following themes were created from respondents' answers to the survey question **"How would you describe post-stroke fatigue to another healthcare professional?"**. Responses varied in length from 2 to 148 words, with a median of 49 words. All individuals who consented to take part in the survey submitted a response.

4.2.4.1 Themes

Overview: An Important Medical Condition

The survey question generated a diverse range of responses, which can be broadly represented by the following themes (Figure 11, Page 101). Firstly, respondents highlighted that post-stroke fatigue is a serious and common condition, experienced differently by individual patients. Secondly, the responses emphasised that post-stroke fatigue is a medical condition that should be recognised as a legitimate symptom of stroke. Finally, therapists acknowledged there were differences approaches to how healthcare practitioners define and conceptualise post-stroke fatigue and also exhibited varying personal levels of understanding through their answers to the survey question.

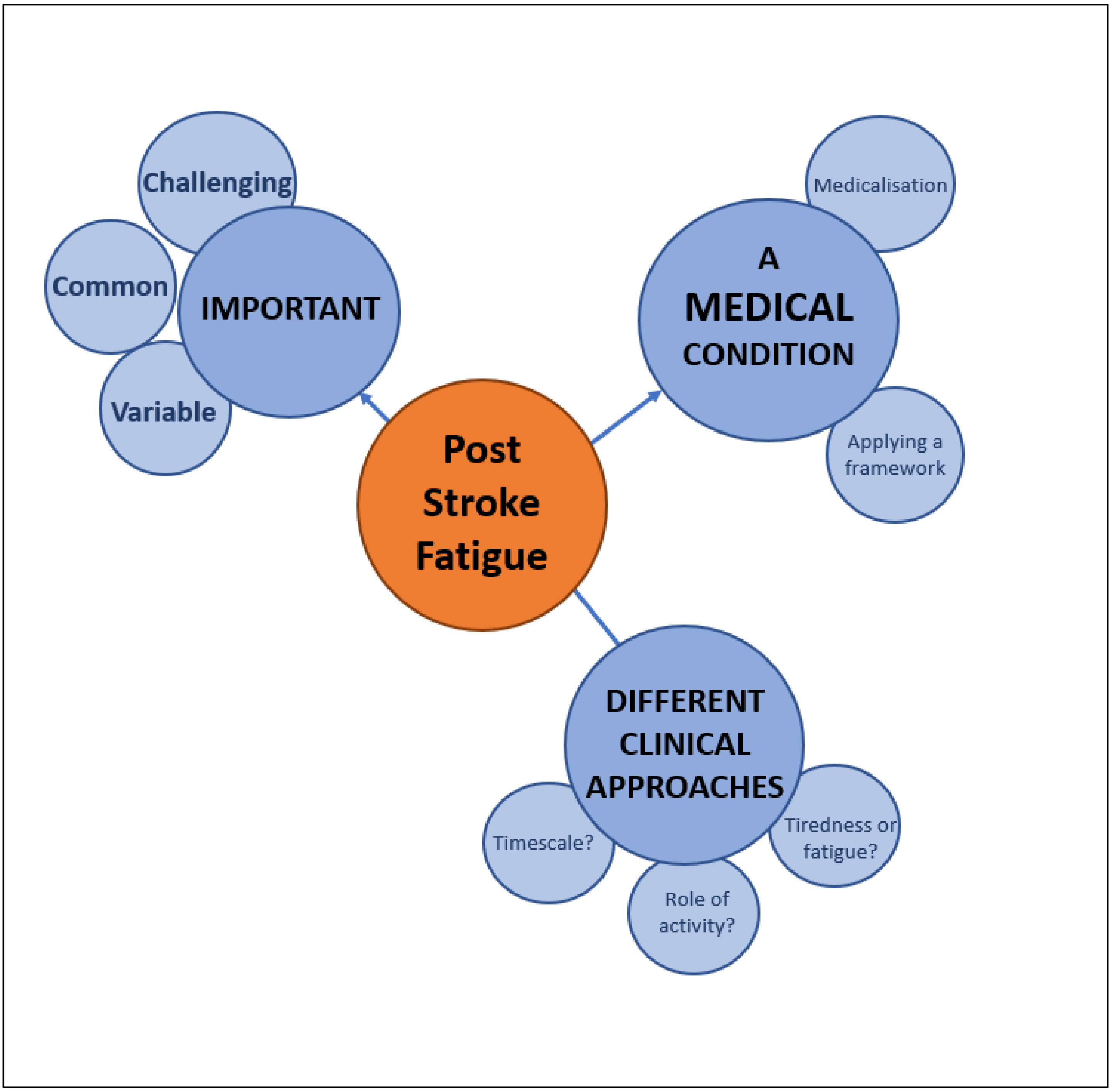


Figure 11. A visual representation of key themes arising in answer to the question ‘How would you describe post-stroke fatigue to another healthcare professional?’

Important: ***Challenging, Common and Variable nature***

There was consensus among responses that post-stroke fatigue was debilitating and deeply pervasive among stroke survivors. Respondents described post-stroke fatigue by using the descriptor ‘overwhelming’, and various other words to that effect. The term ‘debilitating’, and descriptors such as ‘all-consuming’, ‘extreme’, and ‘tiredness like no other’ were typical.

Challenging

Descriptive language was a marked feature of the responses, as therapists responded creatively to the challenge of explaining the difficulties of post-stroke fatigue to colleagues. Further, respondents highlighted the challenging nature of post-stroke fatigue and the effects this had on their patients. Answers stated, ‘patient’s often feel like they are ‘thinking through mud’ Occupational Therapist 9 (OT9) and ‘pulling heavy boots on’ (OT32). Others emphasised the traumatic nature of post-stroke fatigue, describing it as ‘hitting a brick wall’ (OT62), and ‘like your brain had been in a washing machine on a spin cycle’ (OT47).

Extended analogies were employed to convey the experience of living with post-stroke fatigue. One response suggested, ‘I sometimes describe it as a bruise on the brain, and if you imagine a bruise on your ankle, you can see it’s sore and stiff and you can’t walk much before needing to rest’ (OT27). One respondent directly referred to using ‘the spoons analogy’(OT58). Coined by Christine Miserandino in 2003 to describe her experience of lupus, ‘Spoon Theory’ explains fatigue associated with chronic medical conditions by referring to having only limited number of ‘spoons’ of energy that the patient can ‘spend’ during the day (https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/). In a similar manner, another reported, ‘I describe the brain/body has having a 'battery' just like a car…Post stroke the battery can be less full to start with, can be used up more quickly than usual and can take longer to recharge and not always fully’ Physiotherapist 8 (PT8).

Common

Pervasiveness was highlighted as a key issue; respondents typically used the terms 'common', 'very common' and 'extremely common' to describe post-stroke fatigue, often to start their response. Efforts to quantify this frequency were mixed; one answer asserted that post-stroke fatigue 'affects nearly all stroke survivors' (OT55), and another that '[post-stroke fatigue] affects a large number of patients, approx. 25% are experiencing severe fatigue with a further 25% experiencing moderate fatigue' (PT47). Another felt that, 'Following stroke approx. 75% of patients' experience fatigue as a symptom' (OT25).

Variable

Respondents emphasised the complex and variable nature of post-stroke fatigue as a condition, describing it as having several components or affecting multiple aspects of a patients' life. Respondents attributed post-stroke fatigue to 'a mix of physical and emotional factors' (OT3), or provided more detailed causative processes, such as 'hormones, neurotransmitters and cognitive load…exacerbated by secondary factors such as diet, sleep, medication' (OT28). The impact of post-stroke fatigue was also described as 'holistic', with multiple categories ('physical and cognitive') or specific aspects of impact ('adversely effects patients sleep, appetite, motivation' (PT25)).

Furthermore, respondents described the manifestation of post-stroke fatigue as particularly insidious. Several reported that the fatigue experienced by stroke survivors was disproportionate to the cerebrovascular accident that had occurred, saying, '[post-stroke fatigue] has the highest impact in the least neurologically/physically impaired stroke patients' (PT16). One respondent described patients as only experiencing post-stroke fatigue when 'they start trying to get back to everyday activities' (OT56), and several indicated that fatigue affected patients' ability to communicate with their family.

A Medical Condition: Legitimisation

Medicalisation of Symptoms

Responses emphasised the medical nature, and thus legitimacy, of post-stroke fatigue as a condition. Post-stroke fatigue was described as a ‘condition’ or ‘symptom’ of stroke, from which patients were ‘suffering’. Some respondents explicitly differentiated post-stroke fatigue from tiredness, writing that post-stroke fatigue was ‘completely different to “normal” tiredness’ (OT11) or ‘not the same as being tired’ (OT32, PT18). Similarly, medicalising were efforts to quantify the fatigue, with respondents employing phrases such as ‘it can be measured, monitored, and energy conservation strategies applied’ (OT22).

Scientific language was used to support these assertions; participants attributed post-stroke fatigue to processes of damage and healing in the brain. Neurological explanations given for post-stroke fatigue included, ‘the brain reorganising connections’ (OT24), ‘[post-stroke fatigue happens] as neuroplasticity occurs’ (PT26), and post-stroke fatigue being ‘caused by the effect of stroke on hormones, neurotransmitters and cognitive load’ (OT28). One respondent attributed fatigue ‘in-part to impairment of the regulatory systems in the brain - disruption to the network connections’ (OT54).

Applying a framework

In the absence of an existing formal classification framework, respondents offered a variety of systematic approaches to organise post-stroke fatigue into a number of constituent causes or effects. These included classifying fatigue into ‘peripheral’ vs. ‘central’, and ‘primary’ vs. ‘secondary’. This is typified by the following response: ‘there is usually a primary (i.e. central, or disease-specific) mechanism and a secondary (loss of fitness/function, mood/sleep related etc) mechanism at work’ (OT64).

4.2.4.2 Different Clinical Approaches

There was variation in understanding between therapists, which was both explicitly identified by respondents acknowledging differences and implicitly conveyed by variation between responses highlighting different levels of understanding.

Several respondents highlighted the different approaches within their multi-disciplinary teams (MDT). One therapist wrote, ‘the doctors sometimes prescribe the patients modafinil … patients are often reviewed by the psychologist and the fatigue can be identified but I think there is a universal lack of knowing the best way to treat these patients’ [PT24]. A community physiotherapist highlighted this difficulty more explicitly, writing, ‘I do sometimes feel that OT and PT can give slightly conflicting messages. I appreciate that pacing is important, but sometimes [phrasing] can be very vague and misinterpreted...I often explain this …the OTs tend to be much more likely to encourage patients not to overdo things… it can be a very tricky balancing act’ (PT33). Another community-based physiotherapist asserted that, ‘There are different approaches in each discipline. OT[s] have most knowledge on fatigue management. Nursing and psychiatrists have the least knowledge and skill set to manage fatigue’ (PT48).

In addition to the acknowledgement of divergent opinions between health practitioners, there were substantial differences in the terminology used to define post-stroke fatigue. Respondents presented definitions that directly contradicted their peers. Key points of difference were whether post-stroke fatigue was ‘fatigue’ or ‘tiredness’, whether fatigue was related to activity undertaken, and to prognosticate.

Tiredness or fatigue?

The majority of respondents distinguished between the concept of ‘tiredness’ and fatigue’, or defined fatigue as a particularly intense variant of tiredness (‘tiredness like no other’), as previously discussed. That these comments typically occurred at the start of the response suggests that this distinction was considered important. Other responses used the terms ‘tiredness’ and ‘fatigue’ interchangeably, for example, ‘A tiredness that is not replenished by sleep and…can be physical, mental and emotional fatigue’ (OT63). In other responses, it was unclear whether the terms were used synonymously (‘feelings of mild to extreme tiredness’) (PT32). Some respondents appeared to define fatigue by its speed of onset, defining fatigue as, ‘feeling very easily tired’ (OT9) and ‘[to] get tired very quickly’ (PT54).

Role of activity?

Though there was consensus that fatigue had a serious effect on patients’ abilities to carry out activities of daily living (ADLs), there were similar inconsistencies between therapists in relating fatigue to activity. Some respondents wrote that post-stroke fatigue could ‘not be attributed to activity’ (OT3) and was ‘not related to the level of activity a person undertakes’ (OT20). One felt post-stroke fatigue was ‘characterised by not being associated with recent levels of activity’ (OT31). Conversely, others felt that the key to managing fatigue was to ‘understand...how activity affects these [energy] levels’ (OT22), and use ‘pacing’ as a strategy. Some responses were more equivocal, writing ‘impact is not necessarily related to activity levels’ (PT16) or ‘not always linked to activity completed’ (OT32). Others indicated that fatigue was disproportionate to activity.

Although response variation existed in how to incorporate rest most effectively into a management programme, respondents consistently referred to rest when defining post-stroke fatigue. It was clear that therapists felt rest or a lack thereof affected patients' experience of post-stroke fatigue and should be considered when assessing for clinically significant fatigue. One stated 'the best thing is to encourage the person to take complete rest...before doing anything else' (OT12), whilst others agreed; the fatigue 'reduces over time if adequate rest [is] taken (PT63)' and that it 'requires frequent rest periods' (OT23). Others mentioned rest but conversely were of the opinion that the condition 'does not necessarily resolve following rest' (OT06) and is 'not eased by rest' (OT31). Others framed it as more of a diagnostic symptom, stating that post-stroke fatigue is 'an absolute need to sleep and rest' (PT55).

Timeframe?

Finally, there was a marked discrepancy between responses offering a timescale for post-stroke fatigue. Respondents suggested that post-stroke fatigue, 'lasts…from weeks, to months to years or permanent' (PT6), 'usually improves 1 year to 2 years post stroke' (PT53), and 'may [last] for several months or even years' (OT56). Similar in style were the responses, 'inability to participate in physio sessions longer than 15-20 mins' (PT55) and 'usually improves 1 year to 2 years post stroke' (PT53). Other responses addressed progression more vaguely, describing post-stroke fatigue as 'ongoing', or lessening 'with time'. Again, these discrepancies suggest a degree of unconscious inconsistency in understanding and clinical practice.

4.2.4.3 Differences by professional background

No differences were found between occupational therapists' and physiotherapists' perceived understanding of post-stroke fatigue, though physiotherapists used medicalised terminology such as "symptom" and "condition" more frequently than their occupational therapist counterparts. Length of clinical experience also appeared to have little impact on responses from therapists with between 5 and 20 years' specialisation in stroke. Therapists with over 20 years' experience alluded more frequently to the effect of post-stroke fatigue on ADLs and patient energy levels, often providing shorter and less holistic responses. Individuals with up to five years' experience in the specialism demonstrated a notably medicalised approach.

Respondents in the acute setting typically used 'medicalised' terminology compared to those working in the community, among whom metaphor and patient expression were more common. Among the 25 respondents who identified themselves as working in acute care, answers were overwhelmingly characterised by the medicalisation of post-stroke fatigue, and by the conceptualisation of fatigue as a symptom of vascular injury. There was an emphasis on the frequency of occurrence of post-stroke fatigue. Respondents were more likely to use statistics for emphasis. Respondents who identified themselves as working in acute care tended to use terminology more similar to a 'dictionary definition' of the condition. Conversely, those working in subacute (25) or primary care (3) tended to define stroke in terms of its lived impact, particularly with regard to rehabilitation and the effect of post-stroke fatigue on specific tasks, effort, and rest. Subacute and primary care-based respondents were more likely to describe post-stroke fatigue in terms of impact on daily life and patient engagement with rehabilitation sessions, or in a holistic manner.

The majority of respondents identified themselves as working in a community setting (81). These responses were characterised by a focus on the clinical management, lived experience of post-stroke fatigue, and the use of metaphor. Though metaphor was a common feature of responses, it was particularly characteristic among community-based therapists. Several community-based respondents relayed patient descriptors of fatigue as part of their definition, such as 'trying to "think through treacle"' [OT18]. Almost all respondents who commented on variation in definitions and limitations to a common understanding of post-stroke fatigue, identified themselves as a community therapist. Though responses from this group displayed the most variation in definition of the key features of post-stroke fatigue, this was likely affected by the disproportionately large sample size.

4.5 Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

The following themes were created as a result of transcription coding to answer the secondary research question **"How do healthcare practitioners understand post-stroke fatigue?"**

4.5.1 Overview: A common post-stroke challenge

Three sub-themes were decided upon following coding of the focus group transcriptions. They were chosen to encompass the overall theme of healthcare practitioners perceived post-stroke fatigue as a common clinical challenge. The three themes were: the importance of patient reassurance, the challenge in examining fatigue due to varying patient presentations and the integration of post-stroke conditions as an exacerbator of fatigue symptoms.

Reassurance: *"trying to take that burden off"*

Participants identified the debilitating effect fatigue has on activities of daily living and rehabilitation, reiterating within the focus group the importance of reassuring patients and their family that it is normal and to work within their limits. An example of this was "I often try and take that guilt off patients when they return and tell them you're not going to be able to do everything and all your exercises. Focus on the necessities. So, trying to take that burden off". When asked how participants would explain fatigue to their colleagues and patients, one clinical psychologist reacted with laughter, saying “Well it’s almost a given that patients with stroke have fatigue [laughs] it’s just so common. And I make sure they know that too”. As well as providing reassurance about the nature and commonness of post-stroke fatigue, the healthcare practitioners identified other factors which affect the severity of fatigue and suggested a reassurance strategy is breaking this down; “It’s important to explain there are a lot of different reasons they may be fatigued and so there are lots of ways we can work to cross off those potential factors and by doing that, reducing their fatigue”. One participant mentioned consideration of the term used to describe fatigue, to normalise it; “In this team it's not a term at all, the word fatigue.”

Individual approaches: ***“whose motivation is it?”***

Healthcare practitioners felt it was difficult to accurately define post-stroke fatigue because of how differently each individual experiences it. This directly transferred to discussion around ensuring patient-centred assessment. One participant said, “Every patient obviously is a very different presentation so instead of giving I guess a standard explanation you tend to talk with them about what they’re experiencing”.

Participants described different coping styles and approaches to understanding post-stroke fatigue, which affected how to give information most effectively to patients. One OT explained; “There are some patients that are aware of fatigue and some that aren’t and need a lot of education and structuring then there are others who have a level of denial and sort of things will be the same so highlighting for different groups of patients that the rehab and approach needs to be tailored to that individual”.

Another aspect of individualised care which the focus group participants touched upon when considering the importance of patient perception was the role of the family and spouse. The importance of the family support network to pass on information was never questioned; however, it was considered that the presence of loved ones could affect patients’ motivations to engage. One participant said “Yeah, what's going to drive you to get up and walk. Is it because your wife says you have got to go for a walk or is it because you really want to go for a walk? Its sometimes... It is difficult to untangle when you're there with the family. Whose motivation is it to get up and walk?”

Part of a post-stroke package of symptoms*: “contributing factors”*

The fatigue itself was often viewed by the healthcare practitioners participating as only one factor that needed to be considered when aiming to understand the full patient picture. It was suggested that the healthcare practitioner must have an awareness of other contributing and aggravating factors. A physiotherapist participant in focus group 1 explained her experience; “You must help them understand that many of their other difficulties they are concerned about are contributing factors to their fatigue.”. This point was made in focus group 2 with a community based occupational therapist discussing the value of working with the patient as opposed to simply providing information; “As you’re working with them you can help them acknowledge that other areas may be contributing factors. It may be if somebodies’ vision has changed or just trying to negotiate their environment and consciously process whats going on. That can be such an arduous process and really contribute to their fatigue.”

Another focus group 2 participant related this to the training they received initially and how the training may have encouraged a narrow outlook to be taken; “The training is often about fatigue as its own symptom and doesn’t really tell you about how it might affect everything else. I think rehab does need to be more global and focused for that specific patient and the fine detail and strategy needs to be thought out”.

4.2.6 Summary

Participants across professions and settings offered their clinical experiences demonstrating the complexity of approaching and unpicking the components of post-stroke fatigue. Several factors were reported to affect how the stroke survivor may present and how these factors needed to be considered during information giving. These included the stroke survivor and supporters approaches and coping styles in addition to contributing and aggravating factors. This expanse of factors makes understanding and explaining post-stroke fatigue difficult.

4.3 Research Question 2: What are the psychometric properties of current measurement scales available for post-stroke fatigue?

4.3.1 Overview

To answer the second research question, a systematic review of the psychometric properties of post-stroke fatigue measures was conducted. This was first carried out in February 2017 and revisited in November 2019, to ensure it included more recent studies. Although not explicitly designed to answer this research question, findings from the therapist national survey and the healthcare practitioner focus group study can also be considered when assessing acceptability and face validity of the measures included in the systematic review. The range of stroke survivor perspectives recounted in the interview study also gave a patient insight into barriers that may be faced when using subjective measures.

4.3.2 Study 1: A Systematic Search and Literature Review of the psychometric properties of fatigue measures used in a stroke survivor population

4.3.2.1 Study Selection

760 papers were retrieved; 35 met the inclusion criteria (Figure 12, Page 114). Data selection occurred in 2 stages. Following Stage 1, 9 of the included papers investigated a post-stroke population. Following Stage 2, 8 further papers were included. The 8 papers all carried out psychometric evaluation on a scale identified within Stage 1 of data extraction, using a neurological population other than stroke. All other studies initially included were excluded at this point. Full texts were retrieved for further inspection. The included literature varied in quality and design. The number of studies which evaluated fatigue measurement scales thoroughly on several validity and reliability measures was an improvement when considered Meads' 2007 review, especially for internal consistency, test-retest reliability, and divergent reliability. There was considerable disparity between study designs and sample sizes.

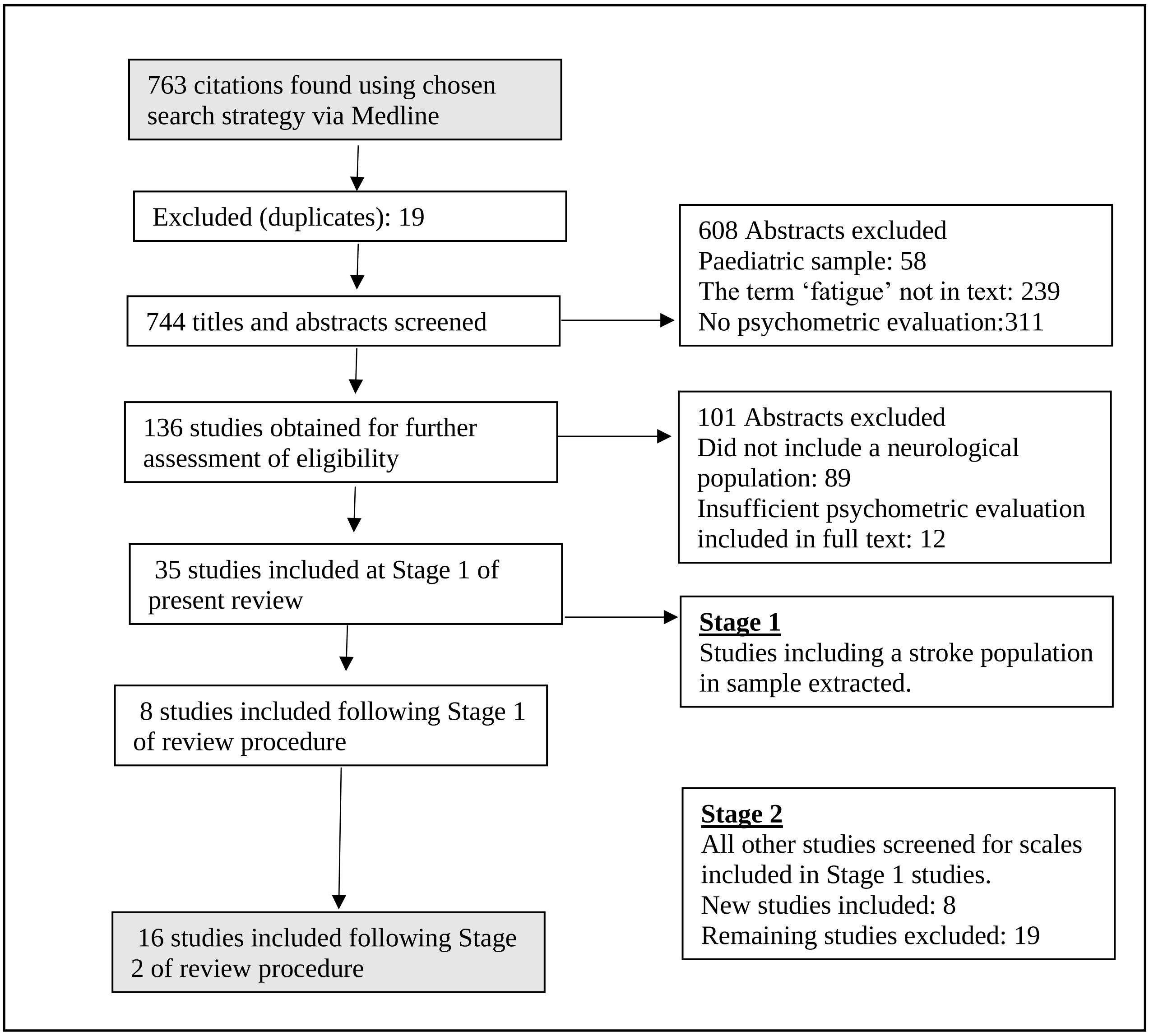


Figure 12. Flow chart depicting review search strategy.

4.3.2.2 Study Characteristics

First Author	Year Published	Study title	Study design
Nadarajah	2017	Test-retest Reliability, Internal Consistency and Concurrent Validity of Fatigue Severity Scale in Measuring Post-Stroke Fatigue	Cross-sectional study design
Ozyemisci-Taskiran	2019	Validity and Reliability of Fatigue Severity Scale in Stroke	Cross-sectional survey design
Lerdal	2011	Psychometric Properties of the Fatigue Severity Scale-Rasch Analyses of Individual Responses in a Norwegian Stroke Cohort	Longitudinal study of post-stroke fatigue using standardised questionnaires at 4 time points
Valko	2008	Validation of the Fatigue Severity Scale in a Swiss Cohort	Cross-sectional postal survey design
Chuang	2015	Reliability and validity of a vertical numerical rating scale supplemented with a faces rating scale in measuring fatigue after stroke	Scale administration at two time points in an outpatient medical centre setting
Butt	2013	Measurement of fatigue in cancer, stroke, and HIV using the Functional Assessment of Chronic Illness Therapy — Fatigue (FACIT-F) scale	Cross-sectional e-survey design in a controlled research setting
Mills	2012	Validation of the Neurological Fatigue Index for stroke (NFI-Stroke)	Mailed questionnaire survey design with 6 qualitative interviews
Mead	2007	Evaluation of fatigue scales in stroke	Scale administration with interviews
Meca-Lallana	2019	Assessing fatigue in multiple sclerosis: Psychometric properties of the five-item Modified Fatigue Impact Scale	Cross-sectional survey design
Learmonth	2013	Psychometric Properties of the Fatigue Severity Scale and the Modified Fatigue Impact Scale	Scale administration at two time points in a rehabilitation setting
Valderramas	2012	Reliability and validity study of a Brazilian-Portuguese version of the fatigue severity scale in Parkinson’s disease patients	Cross-sectional survey design
Hagell	2006	Measuring fatigue in Parkinson’s disease: a psychometric study of two brief generic fatigue questionnaires	Cross-sectional survey design
Grace	2006	Measuring fatigue in Parkinson’s disease: a psychometric study of two brief generic fatigue questionnaires	Cross-sectional survey design
Amtmann	2012	Comparison of the psychometric properties of two fatigue scales in multiple sclerosis	Self-report survey design
Tellez	2005	Does the Modified Fatigue Impact Scale offer a more comprehensive assessment of fatigue in MS?	Scale administration at two time points in a rehabilitation setting
Vickrey	1995	A health-related quality of life measure for multiple sclerosis.	Self-report survey design

Table 16. Individual study characteristics of each study included in the systematic review.

4.3.2.3 Risk of bias within studies - *Stage 1. Stroke population studies*

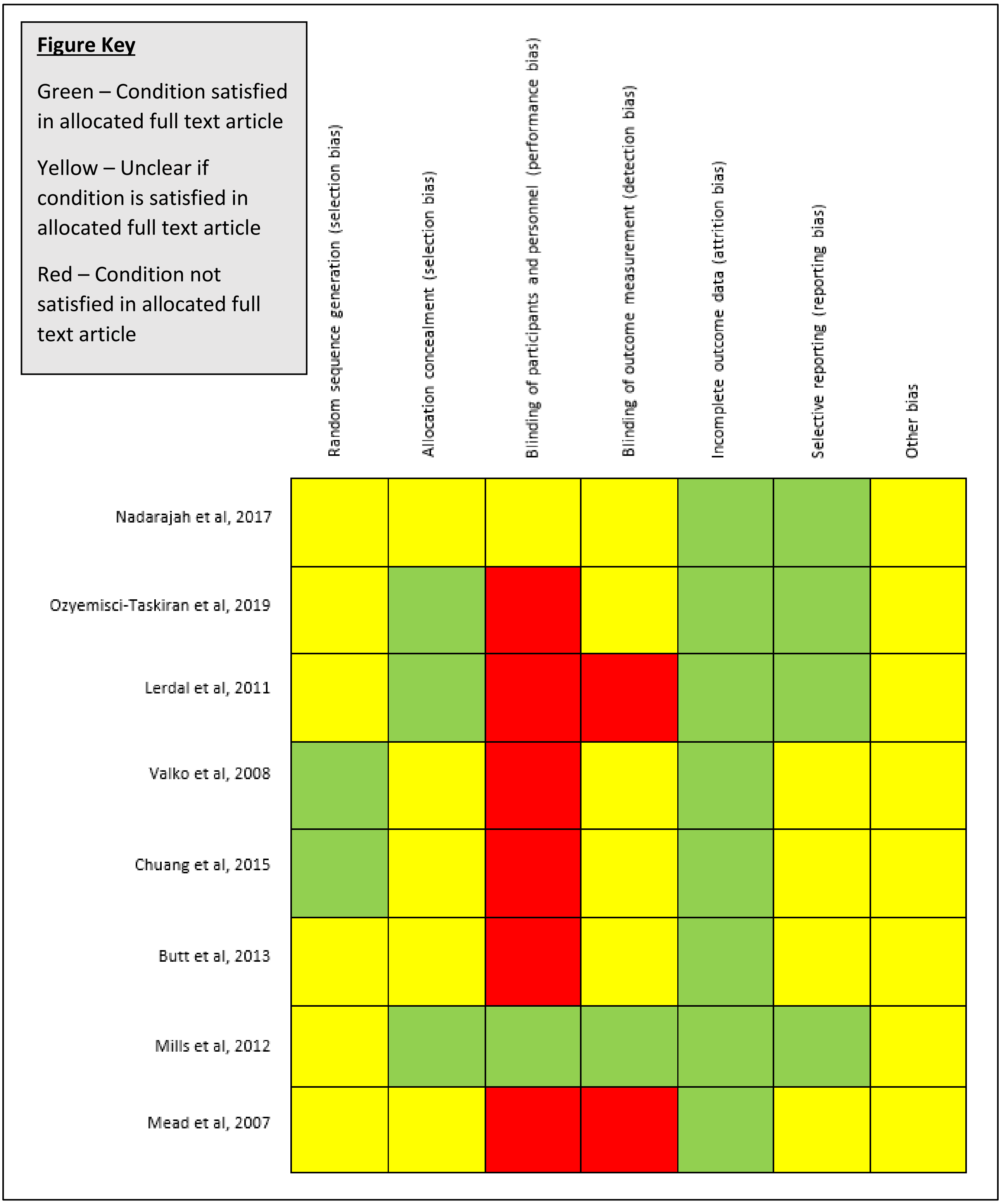


Figure Key

Green – Condition satisfied in allocated full text article

Yellow – Unclear if condition is satisfied in allocated full text article

Red – Condition not satisfied in allocated full text article

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome measurement (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Nadarajah et al, 2017	🟨	🟨	🟨	🟨	🟩	🟩	🟨
Ozyemisci-Taskiran et al, 2019	🟨	🟩	🟥	🟨	🟩	🟩	🟨
Lerdal et al, 2011	🟨	🟩	🟥	🟥	🟩	🟩	🟨
Valko et al, 2008	🟩	🟨	🟥	🟨	🟩	🟨	🟨
Chuang et al, 2015	🟩	🟨	🟥	🟨	🟩	🟨	🟨
Butt et al, 2013	🟨	🟨	🟥	🟨	🟩	🟨	🟨
Mills et al, 2012	🟨	🟩	🟩	🟩	🟩	🟩	🟨
Mead et al, 2007	🟨	🟨	🟥	🟥	🟩	🟨	🟨

Figure 13. Risk of bias matrix for individual studies in Stage 1 of Study 1 literature review.

Risk of bias within studies- *Stage 2. Neurological population studies*

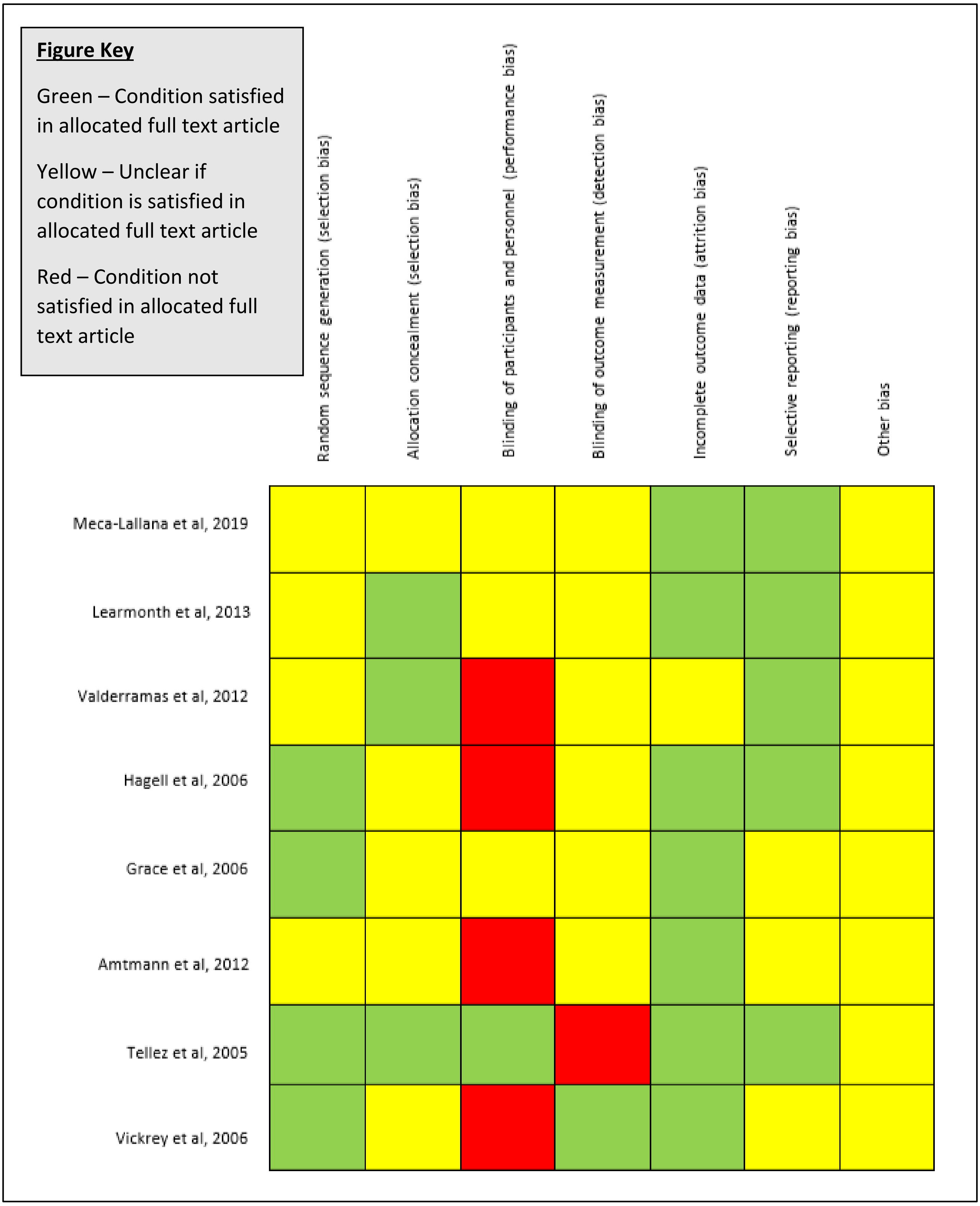


Figure Key

Green – Condition satisfied in allocated full text article

Yellow – Unclear if condition is satisfied in allocated full text article

Red – Condition not satisfied in allocated full text article

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome measurement (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Meca-Lallana et al, 2019	🟨	🟨	🟨	🟨	🟩	🟩	🟨
Learmonth et al, 2013	🟨	🟩	🟨	🟨	🟩	🟩	🟨
Valderramas et al, 2012	🟨	🟩	🟥	🟨	🟨	🟩	🟨
Hagell et al, 2006	🟩	🟨	🟥	🟨	🟩	🟩	🟨
Grace et al, 2006	🟩	🟨	🟨	🟨	🟩	🟨	🟨
Amtmann et al, 2012	🟨	🟨	🟥	🟨	🟩	🟨	🟨
Tellez et al, 2005	🟩	🟩	🟩	🟥	🟩	🟩	🟨
Vickrey et al, 2006	🟩	🟨	🟥	🟩	🟩	🟨	🟨

Figure 14. Risk of bias matrix for individual studies in Stage 2 of Study 1 literature review.

4.3.2.4 Results of individual studies

Scales tested in a stroke population

8 studies were found which assessed the psychometric properties of fatigue scales, using a stroke survivor population (Table 18, Page 118-19). The number of participants in the included studies ranged from 6 in a qualitative interview study which formed part of one studies evaluation process to 235 who participated in a postal survey investigation. Studies were conducted internationally within the UK, Sweden, Switzerland, America, Malaysia, Taiwan, and Norway. Each scale will be described in more detail below.

Scale Type and Author	Sample Size	Construct measured	Reliability	Validity
Fatigue Severity Scale-9 (Nadarajah et al, 2017)	Group 1) 50 stroke survivors Group 2) 50 controls2	Functional impact of fatigue; physical and mental. Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Concurrent validity with VAS-F and SF-36v2. Discriminative validity between groups against healthy controls.
Fatigue Severity Sale-9 (Ozyemisci-Taskiran et al, 2019)	Group 1) 46 stroke survivors, Group 2) 52 control subjects admitted for musculoskeletal complaints	Functional impact of fatigue; physical and mental. Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Concurrent validity with SF-36v2. Concurrent validity between groups, considering matched age and gender.
Fatigue Severity Scale-9 (Lerdal et al, 2011)	119 stroke survivors	Functional impact of fatigue; physical and mental. Feeling of fatigue	Internal consistency, considering scale items.	Face validity, considering scale items.
Fatigue Severity Scale-7 (Lerdal et al, 2011)	119 stroke survivors	Functional impact of fatigue; physical and mental. Feeling of fatigue	Internal consistency (Cronbach a at baseline and 18-month follow-up).	Concurrent validity with VAS-F at baseline and 18 month follow up. Sensitivity to change.

Fatigue Severity Scale-9 (Valko et al, 2008)	235 stroke survivors	Functional impact of fatigue; physical and mental. Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Concurrent validity with VAS and between groups against healthy controls.
Neurological Rating Scale- Faces Rating Scale (Chuang et al, 2015)	106 stroke survivors, across 3 different sites	Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (systematic bias).	Concurrent validity with vertical-NRS. Sensitivity to change.
Functional Assessment of Chronic Illness Therapy- Fatigue Scale (Butt et al, 2013)	51 stroke survivors aged 18 or over	Feeling and impact of fatigue	Internal consistency (Cronbach a).	Face validity.
Neurological Fatigue Index-Stroke (Mills et al, 2012)	6 stroke survivors	Physical and cognitive symptoms. Response to sleep and rest/sleep.	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Concurrent validity with FSS and VAS.
SF-36v2 – Vitality Subscale (Mead et al, 2007)	55 stroke survivors	To assess vitality, defined as energy level and fatigue, feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Face validity. Concurrent validity with MFSI.
Profile of Mood States- Fatigue Subscale (Mead et al, 2007)	55 stroke survivors	Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (Mean Difference).	Face validity. Concurrent validity with MFSI.
Fatigue Assessment Scale (Mead et al, 2007)	55 stroke survivors	Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Face validity. Concurrent validity with MFSI.
Multidimensional Fatigue Symptom Inventory (Mead et al, 2007)	55 stroke survivors	Feeling of fatigue	Internal consistency (Cronbach a). Test-retest reliability (Mean Difference).	Face validity. Concurrent validity with FAS and POMS-F.

Table 17. Fatigue scales validated in stroke populations, found in the literature review.

Scales further validated in neurological conditions other than stroke

Scale Type and Author	Sample Size	Sample Population	Reliability	Validity
Fatigue Severity Scale-9 (Learmonth et al, 2013)	82	Multiple Sclerosis	Test-retest reliability (ICC).	Not stated.
Fatigue Severity Scale-9 (Valderramas et al, 2012)	30	Parkinsons	Internal consistency (Cronbach's a). Test-retest reliability (ICC).	Concurrent validity with Parkinsons Disease Questionnaire.
Fatigue Severity Scale-9 (Hagell et al, 2006)	250	Parkinsons	Internal consistency (Cronbach's a).	Concurrent validity with FACIT-F.
Fatigue Severity Scale-9 (Grace et al, 2006)	231	Multiple Sclerosis	Not stated.	Concurrent validity with MFIS.
Fatigue Severity Scale-9 (Amtmann et al, 2012)	1271	Multiple Sclerosis	Internal consistency (Cronbach's a).	Concurrent validity with MFIS-Physical and MFIS-Cognitive.
Fatigue Severity Scale-9 (Tellez et al, 2005)	60	Multiple Sclerosis	Not tested.	Concurrent validity with MFIS.
FACIT-Fatigue Scale (Hagell et al, 2006)	118	Parkinsons	Internal consistency (Cronbach a). Test-retest reliability (ICC).	Concurrent validity between fatigued and non-fatigued participants (P Score).
SF-36v2-Vitality Subscale (Vickrey et al, 1995).	231	Multiple Sclerosis	Internal consistency (Cronbach a). Test-retest reliability (R score).	Not stated.
Multidimensional Fatigue Symptom Inventory (Meca-Lallana et al, 2018).	302	Multiple Sclerosis	Internal consistency (Cronbach a).	Not stated.

Table 18. Fatigue scales validated in neurological populations, found in the literature review.

8 studies carried out with neurological populations were found which assessed the psychometric properties of the fatigue scales using a stroke survivor population (Table 19, Page 120). The number of participants in the included studies ranged from 16 to 250 who participated in a multiple condition postal survey investigation. Three studies utilised a mixed

methods design incorporating a qualitative and quantitative design and 5 studies reported using a quantitative cross-sectional survey design.

4.3.2.5 Included Psychometric properties of scales that have been assessed in stroke populations

In the following section, the characteristics and psychometric properties of each scale listed in Table 18 (Page 118-19) for stroke survivors are presented. Where a study with a different neurological population evaluated a scale included in Table 19, the findings are presented.

Fatigue Severity Scale- 9 point

The Fatigue Severity Scale (FSS) aims to measure fatigue severity in a way that facilitates research in the experience of fatigue in a variety of medical and neurological disorders.

Content

The FSS is made up of nine statements which concern the respondents' fatigue and measure its effect on motivation, exercise, physical function, ability to carry out duties, interference with work, family, or socialisation.

Items/Subscales

The scale has nine items which are combined to form an overall measure of a persons' severity of fatigue symptoms. Each item is made up of a 7-point Likert scale where 1= Strongly Disagree and 7= Strongly Agree. The total score signifies the severity of the respondents' fatigue. It has good evidence of internal consistency, test-retest reliability, and score validity (Krupp et al, 1989). Study-by-study psychometric properties are stated below.

First Author	Sample Population	Reliability	Validity
Nadarajah et al	Stroke	Good internal consistency (Cronbach a=0.94), good test-retest reliability (ICC=0.93)	Concurrent validity: good correlation w (r>0.60), weak with SF-32v2 (r= -0.32), good sensitivity between groups against healthy controls (P<0.01).
Ozyemisci-Taskiran et al	Stroke	Excellent internal consistency (Cronbach a=0.928), good test-retest reliability (ICC=0.74).	Good concurrent validity between FSS and SF-36v2 (r=-0.498, p<0.0001) in stroke survivor group. Poor concurrent validity between groups despite matched age and gender.
Lerdal et al	Stroke	Scale item 1 and 2 found to lack unidimensionality, reducing internal consistency (Cronbach's a= 0.78).	Scale item 1 and 2 found to lack validity due to construct differentiation
Valko et al	Stroke	Good internal consistency overall (Cronbach a=0.96), items 1 and 2 significantly lower (Cronbach's a 0.70 and 0.77 respectively). High test-retest reliability.	Concurrent validity: good correlation with VAS-F (r=0.70). Good sensitivity between groups against healthy controls (P<0.01).
Learmonth et al	Multiple Sclerosis	Moderate test-retest reliability (ICC=0.751).	Concurrent validity: strong correlation between FSS and MFIS-Physical (r>0.5).
Amtmann et al	Multiple Sclerosis	Excellent internal consistency (Cronbach's a=0.93).	Good concurrent validity with MFIS-Physical (r=0.77). Poor concurrent validity with MFIS-Cognitive (r=0.55). Good concurrent validity with MFIS-Total (r=0.74).
Tellez et al	Multiple Sclerosis	Excellent internal consistency (Cronbach a=0.91)	Good concurrent validity with MFIS (r=0.68).
Valderramas et al	Parkinson's	Excellent internal consistency (Cronbach a=0.95). Excellent test-retest reliability (ICC=0.91).	Good concurrent validity with Parkinsons disease questionnaire (r=0.93).
Hagell et al	Parkinson's	Excellent internal consistency (Cronbach a=0.94).	Excellent concurrent validity with FACIT-F (r=0.77).
Grace et al	Parkinson's	Not stated.	Good concurrent validity with MFIS-Physical (r=0.75). Poor concurrent validity with MFIS-Cognitive (r=0.44). Good concurrent validity with MFIS-Total (r=0.68 p<0.0001).

Table 19. Psychometric properties of the Fatigue Severity Scale-9 studies included in the systematic review. All scores and interpretations stated as they appear in the study text.

Psychometric properties of the Fatigue Severity Scale were most often reported in the literature. Internal consistency was reported within all studies except 1 (Table 20, Page 122).

Reported reliability scores differed between studies, both within studies evaluating the scale with a stroke population and across neurological populations. Internal consistency scoring (Cronbach's alpha) across studies was consistent in Multiple Sclerosis patients (range from 0.90 to 0.94) and stroke survivors (range from 0.90 to 0.96). Two studies reported poor within scale item internal consistency, suggesting the overall scale internal consistency scores reported may not reflect each item. This was the case for two conditions: stroke and Parkinsons. Test-retest reliability was not as frequently reported (ICC score) and ranged across studies from 0.74 to 0.93. Two of the three studies reporting in test-retest reliability reported scores between 0.74 and 0.76, suggesting Nadarajah and colleagues score of 0.93 may be an outlier. Similar study sample sizes were used in Nadarajah and Ozyemisci-Taskirans' studies which could suggest other external biases affected Nadarajah's scoring. Individual study risk of bias scores are stated in Figure 13 and 14, Pages 116 and 117).

Two studies reported on individual items lacking criterion validity reducing sensitivity to change. Scores were validated with other multi-dimensional fatigue scales, namely the VAS-Fatigue scale and SF-36v2. Scores were also compared to control groups in 3 out of 4 stroke survivor studies.

Fatigue Severity Scale- 7 point

Items/Subscales

There is one subscale which is made up of 7 items. Each item is made up of a 7-point Likert scale where 1= Strongly Disagree and 7= Strongly Agree. The total score signifies the severity of the respondents' fatigue.

Psychometric Properties

Lerdal and colleagues carried out a two-stage evaluation of the Fatigue Severity Scale, following initial evaluation of the 9-point scale which highlighted reduced internal consistency and high mean-square validity of 2 items. An adjusted 7-point scale was tested in a longitudinal study and evaluated at 6-month time points up until 18 months had passed. In Lerdals' study, the 7-point scale received higher psychometric property scores across all reliability and validity measures. In the 7-point scale, reliability was measured by scoring internal consistency and was rated as good, improving over time after an 18 month follow up (Cronbach's a=0.86 at baseline; Cronbach's a= 0.92 at 18 months follow-up). Overall the FSS-7 scored 0.71 for internal consistency. However, concurrent validity with the VAS-Fatigue Scale was low, scoring between 0.40 and 0.53 at the two time points.

Neurological Rating Scale- Faces Rating Scale

The Neurological Rating Scale- Faces Rating Scale (NRS-FRS) aims to measure fatigue intensity in stroke, with each number on the scale representing the individuals perceived severity of fatigue.

Content

The NRS-FRS is a single-item fatigue measure, combining two commonly used scales. The Neurological Rating Scale (NRS) has been used to measure fatigue in stroke, MS, spinal cord injury and cancer. The Faces Rating Scale (FRS) has been used successfully to measure pain in individuals who are cognitively impaired or illiterate. For these reasons, Chuang and colleagues believed the NRS-FRS would be appropriate to measure post-stroke fatigue and more generalisable across different strokes diagnoses.

Items/Subscales

Test subjects are asked “How fatigued do you currently feel?”. The 10-centimetre scale is made up of a combination of the vertical NRS on a scale of 0 to 10 and the FRS made up of 6 facial expressions. “No fatigue” is indicated by a number 0 and a smiling face, while number 10 and a crying face indicated “worst possible fatigue”.

Psychometric Properties

Chuang and colleagues developed and evaluated the Neurological Rating Scale-Faces Rating Scale as a measure to be used with stroke survivors. Psychometric testing was carried out on the scale, with reliability demonstrated by a high internal consistency score (Cronbach’s a= 0.95), interpreted by the authors as “good”. This score was comparable to the more commonly used scales within the review such as the Fatigue Severity Scale and Fatigue Assessment Scale. Good test-retest reliability was also shown, with a small -0.16 difference between tests shown (95% CI, 0.92-0.96), despite the high number of participants in the study, which has been shown to lead to higher ICC scores (106 across 3 sites). This demonstrated no significant systematic bias was present. Concurrent validity was only assessed with a measure similar to the newly developed scale, which has not been validated with stroke survivors. The authors stated there was a high concurrent validity at test and retest (test-p=0.85; retest-p=0.84).

Functional Assessment of Chronic Illness Therapy- Fatigue Scale

The Functional Assessment of Chronic Illness Therapy- Fatigue Scale (FACIT-Fatigue) aims to measure fatigue in chronic illnesses during an individual's daily activities over the past week.

Content

The FACIT-Fatigue Scale is made up of thirteen statements which concern the respondents' fatigue and measure its effect on activities of daily living.

Items/Subscales

The level of fatigue is measured for each statement on a five-point Likert Scale where 0= Not fatigued and 0= Very fatigued. Statements 7 and 8 are positive statements and so are reverse scored. The individuals total score is multiplied by eighteen and divided by the number of items scored.

Psychometric Properties

First Author	Sample Population	Reliability	Validity
Butt et al	Stroke	High internal consistency (Cronbach a=0.91)	Fatigue highly correlated with quality of life (r=0.80)
Hagell et al	Parkinsons	Excellent internal consistency (Cronbach a= 0.90). Good test-retest reliability (ICC= 0.85).	Good concurrent validity between fatigued and non-fatigued participants (P<0.0001).

Table 20. Psychometric properties of the Functional Assessment of Chronic Illness Therapy-Fatigue Scale studies included in the systematic review. All scores and interpretations stated as they appear in the study text.

Butt and colleagues were the first research team to evaluate the Functional Assessment of Chronic Illness Therapy- Fatigue Scale using a stroke survivor population. The relatively small sample size compared to other evaluation studies included in the review should be considered when interpreting the findings. Internal consistency was assessed using Cronbach’s Alpha in both studies, allowing cross condition comparison. Both studies produced a good or excellent score when referring to reporting guidance, in line with the other scales assessed in the review. Despite the two studies giving similar internal consistency numerical scores, the words used to interpret the scores varied with one interpreted as “good” and the other “excellent”. Face validity and scale acceptability were assessed by Butt and colleagues in the stroke survivor evaluation study, however were not quantified within the study reducing replicability of assessment (Table 21, Page 126).

Neurological Fatigue Index- Stroke

The Neurological Fatigue Index- Stroke Scale (NFI-Stroke) aims to measure the physical and cognitive symptoms of fatigue. It also assesses individuals’ response to sleep and rest.

Content

The NFI-Stroke is made up of twelve items which concern the respondents’ fatigue and can be split into a cognitive score, physical score, and summary score. Each item starts with a single instruction asking the individual to consider their experiences over the past four weeks.

Items/Subscales

There are two subscales which are made up of 12 items, utilising interval scaling. Each item is made up of a 4-point Likert scale where 0= Strongly Disagree and 3= Strongly Agree. The total score signifies the impact of the respondents’ fatigue.

Psychometric Properties

Mills and colleagues developed the Neurological Fatigue Index-Stroke scale to address whether the commonly used NFI scale could be made condition specific. Content analysis was carried out using face-to-face interviews, followed by a postal survey study to psychometrically evaluate the scale. The scale was designed to have a physical and cognitive sub-scale, which the authors perceived to capture post-stroke fatigue more fully. However, following framework analysis of the interviews, no items were changed from the MS condition specific version of the scale. Good test-retest reliability was shown (0.90). Although slightly lower, the studies internal consistency score for the scale was still interpreted as a good overall score (Cronbach's a= 0.82). The study authors interpreted the reported concurrent validity scores with the Fatigue Severity Scale and VAS Scale as 'good', considering the accepted rating scale it scored average to poorly when tested against the two scales (FSS= 0.622; VAS= 0.534).

SF-36v2- Vitality Subscale

The Short-Form Health Survey is a generic patient report measure that aims to assess health-related quality of life in general and chronic condition populations. The vitality subscale assesses energy level and respondents feeling of fatigue.

Content

The SF-36v2 is split into three components: physical, mental, and other. The vitality subscale is within the mental component. Respondents are asked to consider the last four weeks when answering.

Items/Subscales

There are four items within the subscale, which are each measured using a weighted Likert scale. Each item is totalled to provide a summed score from 0= negative health to 100= positive health. It is recommended that each subscale is considered seperately as opposed to taking a total score or comparing the physical and mental component. This is due to the measures' two dimensionality.

Psychometric Properties

First Author	Sample Population	Reliability	Validity
Mead et al	Stroke	Good internal consistency (Cronbach a=0.76 at time point 1, 0.78 at time point 2), average test-retest reliability across items (ICC=0.51).	Adequate face validity. Moderate concurrent validity with MFSI (-0.47), POMS-F (-0.58), FAS (-0.41)
Vickrey et al	Multiple Sclerosis	Good internal consistency (Cronbach's a=0.84). Good test-retest reliability (ICC=0.85).	Not stated.

Table 21. Psychometric properties of the SF36v2- Vitality Subscale studies included in the systematic review. All scores and interpretations stated as they appear in the study text.

Despite the SF36v2 questionnaire being a commonly used global measure following stroke, the vitality subscale has only been evaluated once with a stroke population. Meads' findings suggested that the vitality subscale performed fairly weakly when assessed for psychometric reliability and validity measures. The reported internal consistency scores did however stay consistent across time points. As compared to Meads' study, Vickrey's evaluation study using Multiple Sclerosis patients found the scale performed better when assessed for reliability and validity with a Multiple Sclerosis sample. However, the sample size was small, which could reduce the generalisability of the findings. It was also not compared to any other clinical population or fatigue measurement scale, raising questions around the validity of the methods used in the study and also reducing comparability across conditions (Table 22, Page 129).

Profile of Mood States- Fatigue Subscale

The Profile of Mood States-Fatigue (POMS-Fatigue) scale is a subscale within the short form POMS self-reporting questionnaire which aims to quantify the feeling of fatigue, in particular measuring the effects of variables which affect trait-levels of fatigue.

Content

The POMS-Fatigue subscale is made up of seven adjectives which concern the respondents' fatigue within the last week and at the present moment.

Items/Subscales

The subscale is made up of 7 items, with a score range between 0 and 28. Each item is made up of a 5-point Likert scale where 0= not at all and 4= extremely. The total score signifies the severity of the respondents feeling of fatigue.

Psychometric Properties

Mead and colleagues also assessed the psychometric properties of the POMS-Fatigue Scale in their review of fatigue scales evaluated with stroke survivors. All four validity and reliability measures extracted for this literature review were assessed and the scale performed well in all categories except test-retest reliability, where a significant mean difference between time points was reported. Testing was carried out three days apart by the same investigator so no inter-rater reliability bias should have been introduced. Internal consistency scores were retained over 2 timepoints (timepoint 1: Cronbach's a= 0.76; timepoint 2: Cronbach's a= 0.78). Face validity was assessed and agreed to be adequate. Concurrent validity with the MFSI rated similarly to other validity measurements carried out within Meads' study (0.75). No studies have tested the psychometric properties of the fatigue subscale with other neurological populations.

Fatigue Assessment Scale

The Fatigue Assessment Scale (FAS) is a general measure which aims to assess the presence of fatigue in a variety of populations.

Content

The FAS is made up of ten questions which concern the respondents' fatigue. It is split into mental and physical subscales and respondents must provide a score for each question, even if they are not indicating a presence of fatigue.

Items/Subscales

There are two subscales which are each made up of 5 items. Each item is made up of a 5-point Likert scale where 1= No fatigue and 5= Substantial fatigue. Questions 4 and 10 are reverse scored. A total score of below 22 indicates no fatigue and a score from 22 to 50 indicates the presence of fatigue. Scores from the physical and mental subscales can be used independently. The Minimal Important Difference is at least 4 points or 10 percent change in the respondents' baseline value.

Psychometric Properties

Despite the Fatigue Assessment Scale being reported as a commonly used measure following stroke, and being recommended in clinical guidelines for this reason, its psychometric properties have only been tested by Mead and colleagues in 2007. Meads' findings suggested that the scale performed best out of the four scales measured for test-retest reliability (ICC= 0.94) and performed averagely for all other properties, scoring 0.58 for internal consistency at timepoint 1 and 0.62 at timepoint 2. Face validity and ease of use was determined following patient interviews, with participants able to answer and understand all questions asked. Concurrent validity was exhibited with the MFSI (0.71). The scale also was recommended by the authors at the end of the review as the best choice for stroke.

Multidimensional Fatigue Symptom Inventory

The Multidimensional Fatigue Symptom Inventory (MFSI) aims to assess the principle manifestations of fatigue, namely the severity, frequency, and daily pattern of fatigue as well as interference with quality of life (Stein et al).

Content

The MFSI consists of statements which are either rationally derived (global, somatic, affective, cognitive, and behavioural manifestations of fatigue) or empirically derived (general, physical, emotional, mental and energy level specific manifestations of fatigue). Respondents are asked to consider the truth of each statement during the last week.

Items/Subscales

The Inventory consists of 83 items which are each rated on a 5-point Likert scale where 0= not at all and 4= extremely. The scoring can be split into rationally derived and empirically derived scales or combined for a total sum.

Psychometric Properties

First Author	Sample Population	Reliability	Validity
Mead et al	Stroke	Good internal consistency (Cronbach a=0.91 at time point 1, 0.93 at time point 2), poor test-retest reliability (significant mean difference shown)	Average face validity (one descriptor changed from “pooped” to “exhausted”), good concurrent validity with FAS (0.81) and POMS-F (0.85)
Meca-Lalanna et al	Multiple Sclerosis	Good internal consistency (Cronbach’s a= 0.90). Good test-rest reliability (r= 0.86).	Not stated.

Table 22. Psychometric properties of the Multidimensional Fatigue Symptom Inventory studies included in the systematic review. All scores and interpretations stated as they appear in the study text.

The fourth measure assessed by Mead and colleagues was the Multidimensional Fatigue Symptom Inventory (Table 23, Page 133). Meads findings suggested that the scale performed poorly when assessed for test-retest reliability, with a significant mean difference found between scores at the two testing timepoints. The scale performed well for concurrent validity with FAS (0.81) and POMS-F (0.85) and also was scored highly for internal consistency. However, during interviews with stroke survivors, participants struggled with the wording of questions asked within the items, suggesting its face validity is lower for stroke survivors. Face validity was not assessed in Multiple Sclerosis so cannot be compared between conditions. Meca-Lalanna and colleagues rated internal consistency similar to Mead (Cronbach’s a= 0.90).

4.3.2.6 Risk of bias across studies

Risk of bias across studies was assessed in the following categories (Yavchitz et al, 2016):

Reporting Bias

Reporting bias was assessed by individual study in Figure 13 and 14 (Pages 113 and 114). In 8 out of the 16 studies included in Stage 1 and Stage 2 of data extraction, evidence was shown that all data had been stated and no selective reporting occurred. In the other 8 studies, there was no evidence to suggest reporting bias had or had not been considered. For this reason, reporting bias may have occurred and affected the findings and conclusions within this review.

Misleading interpretation

Several studies within the review interpreted the quantitative data presented differently to the reporting guidelines for reliability and validity (Bjorna et al, 2015; Beslow et al, 2012). The guidelines suggest that scores should be interpreted in 10 percent increments with 0.90 being excellent, 0.80 being good, 0.70 being average and 0.60 being poor). Some studies reported 0.70 scores or lower as good and no reference was made to reporting guidelines.

Inappropriate extrapolation

No issues with inappropriate extrapolation were clear on the independent study level. Within the review findings, the first and second stages of data extraction were made clear and presented in separate tables. This ensured the studies using a stroke population were reported seperately to studies evaluating scales with a different neurological population. As all secondary neurological populations were reported together, this could lead to inappropriate comparison however it was not intentional.

4.3.3 Summary

Many outcome measures have been developed for fatigue, however there are still limited condition specific scales. The Fatigue Severity Scale remains the most used outcome measure by researchers studying post-stroke fatigue. It is also now the most evaluated scale, when tested on neurological populations including stroke. Four evaluation studies have been carried out on the scale since the last measurement review was published in 2007 (Mead et al, 2007). The FSS-7 has shown greater reliability and validity in a stroke survivor population than the commonly used 9-point scale and scored comparatively well with the Fatigue Assessment Scale when assessing reliability.

However, concurrent validity with other fatigue measurement scales remains inconsistent which may reduce the ability to compare between studies and outcome measures. There is no single scale which performed consistently highly across all 4 reliability and validity measures assessed within the review. Although the results are similar to those found by Mead and colleagues over a decade ago, there has been a large amount of growth in the field and several other promising measures have been developed and begun to be evaluated.

4.4 Research Question 3: How do healthcare practitioners assess post-stroke fatigue in clinical practice?

4.4.1 Overview

To answer the third research question, two studies were conducted with healthcare practitioners. The stroke survivor and supporter perspective was also considered by reviewing the transcripts from the interview study. Firstly, a national online survey was sent out to specialist occupational therapists and physiotherapists to gain a first insight into recent clinical practice. To build upon these findings two focus groups were carried out with healthcare practitioners in East of England and Cornwall. Within the next section, the results of each study pertaining to research question 3 will be presented.

4.4.2 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

The following themes were created from respondents' answers to the survey question **"Please list the questions which you would ask the stroke survivor in a subjective assessment targeting post-stroke fatigue?"**. 127 therapists responded to the question, with 8 choosing to abstain (6 physiotherapists, 2 occupational therapists). All non-respondents answered all other questions within the survey. Response length ranged from 5 to 237 words (average post length of 119 words). The majority of responses addressed multiple of the identified themes.

4.4.2.1 Themes

Responses were categorised into answers which indicated the therapist would use subjective assessment in their clinical practice and those who stated that they would not. Within each category, posts were coded to enable theme creation (Figure 15, page 137).

The findings within each category are stated below, starting with the responses that indicated the therapist did utilise subjective assessment in clinical practice. Four themes were created to summarise the data (Figure 15, Page 134). These were (1) The individuals perception of fatigue (2) Current lifestyle (3) Activities of daily living (4) Cognitive impact.

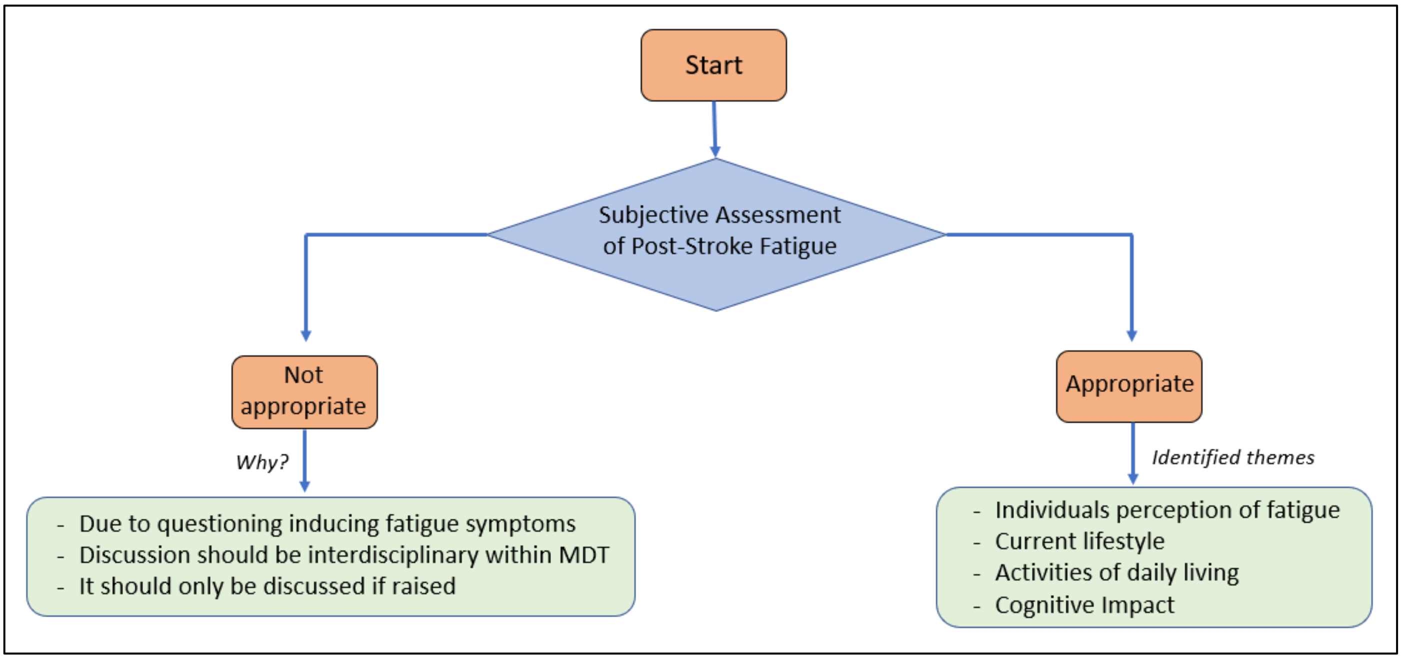


Figure 15. A visual representation of key themes depicting therapists' subjective assessment of post-stroke fatigue arising in answer to the question "Please list the questions which you would ask the stroke survivor in a subjective assessment targeting post-stroke fatigue?"

Answer Given: Would subjectively assess

Individuals perception of fatigue

Responses which aimed to inform the therapists' understanding of how the stroke survivor perceived their fatigue could be fitted into one of four sub themes; how post-stroke fatigue felt to the individual, the stroke survivors awareness of fatigue, questions that would open up an information giving conversation and lastly what the stroke survivors priorities were. All responses within this theme were patient-centred and aimed to build the patient picture.

Feeling of Post-Stroke Fatigue

Respondents frequently used open questions to understand how the fatigue is perceived by the individual. This sub-theme had a variety of different types of questions within it, some asking about “feelings/sensations you get when you feel extremely tired”, while others asked how the fatigue affected the stroke survivors other post stroke symptoms “i.e. pain, tone, cognition”. The variable nature of post-stroke fatigue was investigated by therapists asking about the changeable nature and patterns of the fatigue. Therapists from the acute setting often attempted to objectify their questions, relating the patients experience to the 24-hour picture; “how does it feel today and what problems is it causing you?”.

Awareness

Finding out how aware the individual was of their fatigue was the next most commonly stated set of questions. Some respondents broadly asked the individual about this area, whereas others asked specifically if “they are aware fatigue is a symptom of their stroke?” or “are you able to recognise signs you are fatigued?”. Throughout responses eliciting how aware the individual was, medicalised terminology was used, with all respondents using the term “fatigue” as opposed to other variations such as tiredness or exhaustion, and several calling it a “symptom” of the stroke. One individual asked, “do you consider fatigue to be a problem?” to judge their awareness.

Information Giving

Some of the subjective questions aimed to gain more insight into how aware the stroke survivor was of the presence of their fatigue. In comparison, far fewer respondents asked questions aiming to assess the individuals perceived understanding. One respondent built a simple explanation into his question; “do you think you have fatigue, this is more than tiredness, it is when you feel weary and that you have less energy than normal for you?”. One occupational therapist coupled information giving and a suitable management strategy into the same question, suggesting a link between the two areas.

Priorities

A few respondents considered patient specific facilitators, asking the stroke survivor about their “fatigue related goals”, priorities and if they felt they needed support to manage their fatigue. Other therapists aimed to gain insight into the stroke survivors’ concerns, asking about “sources of stress or worry”, often coupled with questions trying to establish overall level of wellbeing.

Overview: Lifestyle

Within the subjective assessment, therapists aimed to gain a broader insight into the stroke survivors’ role in their home and community amongst any external factors which may inform the management strategy taken. Responses within this theme were asked by more therapists working in the community setting as compared to those working in acute or sub-acute teams. The three sub-themes within this theme are; the stroke survivors’ role in the home and community settings, what their lifestyle was before having the stroke and finally to assess the impact of any supporters or care-givers.

Role in the home and community

Therapist responses probed into what the individuals ‘normal’ lifestyle was like currently and before the stroke event occurred. Some asked questions explicitly such as “is it stopping you trying to take part in any specific occupations?", whilst other questions asked more implicitly "is fatigue limiting what they need to achieve and how?". Questions extended beyond typical occupational activities to their role in the home and leisure activities they may like to do. One respondent asked a much broader question; "can they manage to go out?", which could lead to more specific questions guided by the stroke survivor.

Pre-Stroke Lifestyle

Therapists asked questions surrounding the stroke survivors' lifestyle prior to their stroke within their responses. Most specified differences in sleep patterns and quality, for example "how have you been sleeping since your stroke?". One explicitly compared it to before the stroke event, calling this period of their life the individuals "normal". All questions related to a behaviour such as sleeping or a specific activity, suggesting this question was used as a method of comparison.

Involvement of significant others

Questions involving relationships with family and friends were a common occurrence in the responses. The specific nature of the questions however was variable. Some therapists asked about family and friends' observations and "whether others notice" the fatigue. Others asked about how they "respond and support" the individual with their fatigue. One response queried if "people around you understand it?". These responses suggest the many ways relationships can affect stroke survivors in both a positive and negative way, whilst also showing therapists understand the importance friends and families have in a stroke survivors recovery.

Overview: Daily Routine

Another recurring theme within therapists' subjective history taking was daily routine. This could be expected, considering the professional background of the two groups responding to the survey. The areas of routine asked about varied, with some therapists focusing on the individuals rest and sleep pattern and others aiming to gain an insight into specific tasks and activities which triggered an onset of fatigue for the individual. The four sub-themes were; insight into how the stroke survivor planned their routine prior to intervention, how their fatigue limited their activities of daily living and self-care, how well the stroke survivor sleeps and how often and lastly what triggers and alleviators the stroke survivor was aware of considered over a 24 hour period.

Routine Planning

Questions were asked explicitly and implicitly around planning of routine and individuals "typical day". Some therapists asked about certain factors which they considered to be part of a routine, for example "do you rest in the afternoon or can you stay awake all day?" and "how much downtime do you have?". Others asked what about the stroke survivors current planning; "do you plan your days and week?". The most common activity highlighted in the questions around routine planning was rest and sleep during the day. One individual attempted to stratify this somewhat, asking "what is the length of your daytime sleep/naps?".

Limitation to activity

One of the most common groups of questions asked were related to specific activities of daily living. Many respondents attempted to specify which activities were affected, for example "what specific tasks are causing you the most difficulty because of fatigue?". Some therapists followed their questions with a VAS scale, to gain quantitative values; “Can you rate from 0-10?”, “please rate 1-10 where 1 you feel exhausted and 10 you feel fine”. One individual also aimed to collect a more detailed response, however used descriptive language to guide the individuals answer, asking “…changes in energy levels? Feelings of lethargy? Is this specific to certain tasks or throughout the day?”. Another response asked a question which could be considered a ‘textbook’ approach to the survey question; “How does your presentation after stroke affect your ability to participate in purposeful and meaningful activities of daily living?”.

Sleep hygiene and pattern

Respondents queried stroke survivors sleep behaviour, in particular focusing on sleep hygiene and pattern. Several responses asked how the individual sleeps at night; “do you sleep well at night?”, “do you need to wake frequently?”. Frequency of disturbances was queried both within a single night and also over a longer time period, such as “daily, a few times a week, weekly”. Others asked more specifically how their sleep hygiene affected their fatigue and energy levels during the day using descriptors such as “do you feel refreshed?” and “do you feel sleepy even when you have slept well?”. A community physiotherapist asked specifically about the environment and location the individual sleeps, querying “bed, sofa, specialist chair?”.

Triggers and alleviators

Therapists often asked stroke survivors what particular activities triggered or accentuated the fatigue and what they currently were doing to alleviate the fatigue or better cope with its effects. Some of these questions asked specifically about coping strategies they had thought of, for example "is it relieved by rest or sleep in the day? and "how much can you do for yourself before a rest?". Others asked more open questions, leaving it up to the individual to respond with their own ideas and strategies; "what makes it worse?". One respondent posed a consideration instead of a subjective question, saying they would "establish if there were any signs of a boom-bust cycle".

Overview: Mood disturbances

Finally, many of the respondents who indicated they would carry out a subjective assessment as part of their clinical assessment of post-stroke fatigue asked the stroke survivor about how their fatigue affected their mood. Considering the evidence and history of post-stroke fatigue as a condition, this was an unsurprising finding. The two sub-themes were; questions regarding how the stroke survivors mood changed in different scenarios and more detail about the psychosocial impact of fatigue on the stroke survivor and those close to them.

Alterations in mood

Some respondents included questions in their subjective history taking about the impact on their mood and mental health. One individual responded to the question very simply, asking "do you feel anxious/depressed?". Another posed an open question; "how do you generally feel now?". One respondent asked a similar question, however then linked it to the individuals "emotional wellbeing", clarifying the response they were hoping to receive. Some individuals asked about symptoms associated with low mood and mental health difficulties, asking "do you find yourself bored?" and "are they motivated to do routine pre stroke activities?".

Psychosocial impact

Most questions asking about management of social situations focused on the effect of post-stroke fatigue on communication. Some therapists asked about how conversations and social interaction affected the fatigue; “are you tired after long conversations demanding your attention?”. In contrast, others asked how the fatigue affected social interaction; “do you struggle to follow conversations or lose interest?”, “what is the impact on engagement in home and family life?”. One respondent approached this area of questioning from a management perspective, asking “how do they find concentrating and managing distractions?”.

Answer Given: Would not subjectively assess

Although an option was not given for respondents to indicate not carrying out a subjective assessment, 10 respondents indicated in their answer that they did not subjectively assess for post-stroke fatigue in their clinical practice. The reasons given are stated below.

Discussion within multi-disciplinary team

One individual working in acute care reported that in her team, the topic of post-stroke fatigue would not be raised with the patient. Instead, other strategies were reported to be used; “we discuss fatigue within the team and use observation”.

Cognitive workload for stroke survivor

One respondent reasoned that “questions are the quickest way to induce fatigue!”. They then went on to explain how they would carry out an assessment, listing strategies such as observation of movement patterns, speech, language, posture, and cognition. Another respondent noted that getting a full detailed assessment of an individuals’ fatigue is “sometimes not obvious to them or their family and takes 5-6 sessions to get a handle on”. They offered the Fatigue Severity Scale as an alternative assessment method.

Stroke survivor led discussion

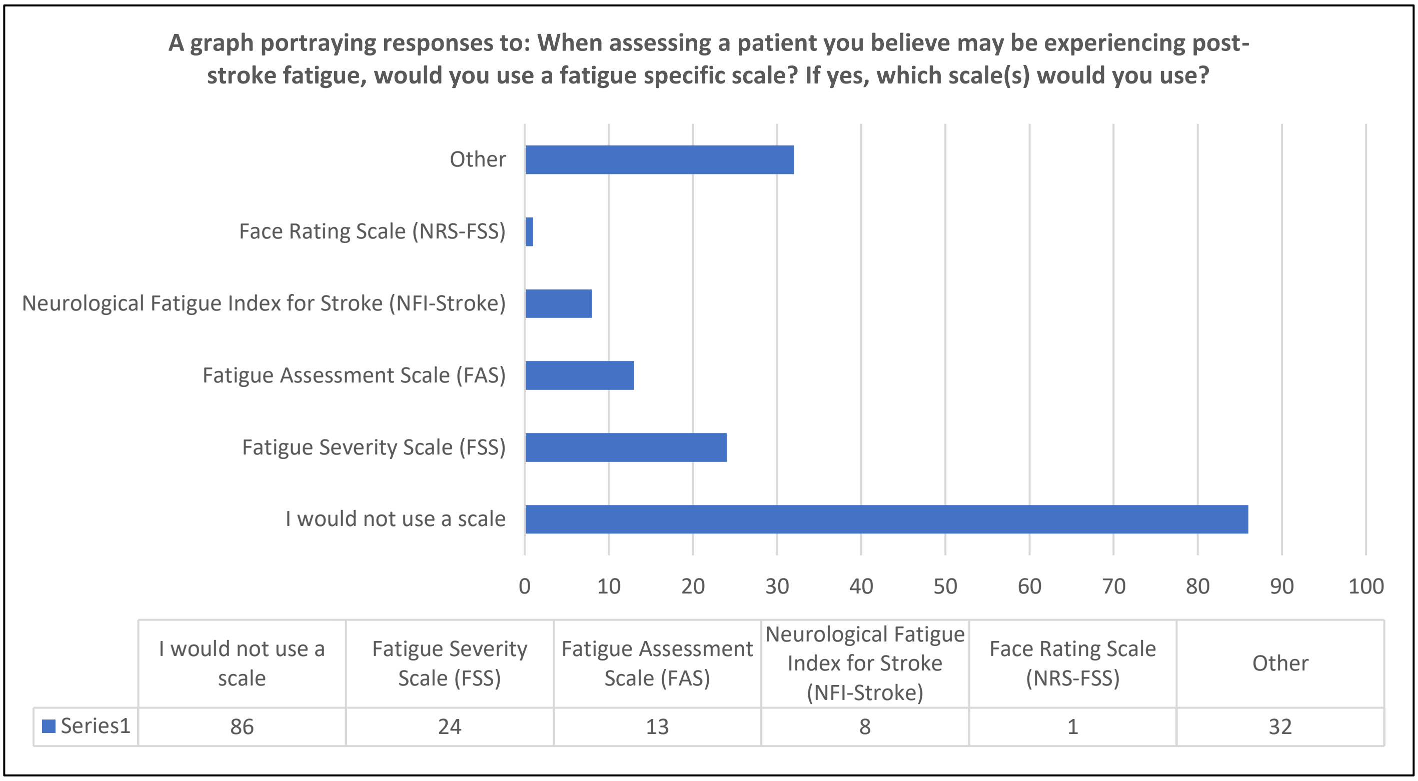
One individual reported that they would not assess post-stroke fatigue unless the patient had identified it as a problem first. This was similar to another response who gave the answer “nothing specific, dependent on the patient”. Another justified their answer by identifying that fatigue is often within a set of post-stroke changes and as such they would not target it directly.

Use of Patient Reported Outcome Measures in Clinical Practice

Within the cross-sectional therapist survey, respondents were asked about the use of measurement scales when assessing post-stroke fatigue. Figure 16 (Page 146) depicts the respondents answers to the survey question **“When assessing a patient you believe may be experiencing post-stroke fatigue, would you use a fatigue specific scale?”.**

All therapists responded, with 27 choosing to select both ‘I would not use a scale’ and ‘Other’ (11 physiotherapists, 16 occupational therapists). Response length for individuals who selected ‘Other’ ranged from 1 to 33 words. 13 of these responses included a patient reported outcome measure which was not on the pre-defined list. These can be seen in Figure

17, Page 147. All other therapists responded stating they used a fatigue diary, were unaware of the scales on the multiple-choice list or referred to another member of their team for post-stroke fatigue assessment.



	I would not use a scale	Fatigue Severity Scale (FSS)	Fatigue Assessment Scale (FAS)	Neurological Fatigue Index for Stroke (NFI-Stroke)	Face Rating Scale (NRS-FSS)	Other
■ Series1	86	24	13	8	1	32

Figure 16. A graph depicting the number of respondents selecting each multiple-choice answer to Question 7 of the online survey ‘When assessing a patient you believe may be experiencing post-stroke fatigue, would you use a fatigue specific scale?’

Use of Patient Reported Outcome Measures

Question 8 on the survey gathered more detailed information on therapist choice of assessment tool, as shown above (Appendix 3). The below section analyses responses to the question **“Why do you assess stroke survivors experiencing post-stroke fatigue in this way?”**. 126 therapists responded, with 11 choosing to not answer (9 physiotherapists, 2 occupational therapists). Of the participants who responded to question 7, but did not respond to question 8, 11 were physiotherapists by background and 2 were occupational therapists. Response length ranged from 2 to 137 words.

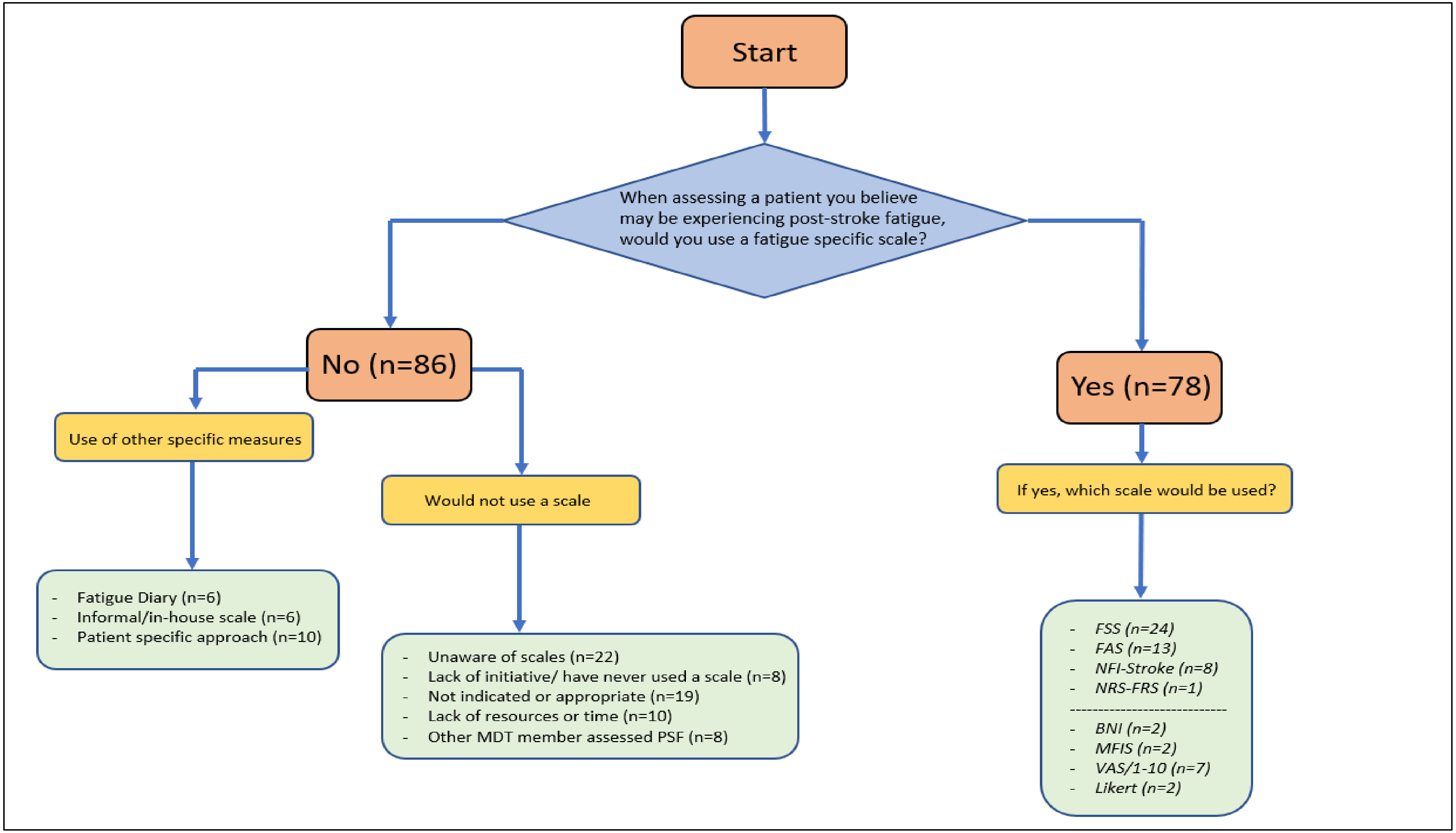


Figure 17: A flowchart depicting survey respondents answers to Question 7 and 8 of the online survey: 7) When assessing a patient you believe may be experiencing post-stroke fatigue, would you use a fatigue specific scale? 8) Why do you assess stroke survivors experiencing fatigue in this way?

Answer given: Would use a scale (multiple choice answer selected)

In the below section, responses have been categorised into those which suggested they used an outcome measure in clinical practice and those that did not. Answers in the 'Other' textbox which indicated use of a measure not on the pre-defined list were included in the category "used an outcome measure".

Fatigue Severity Scale (FSS)

Most respondents described the FSS as providing a useful baseline from which to monitor the effects of treatment. Several mentioned that the ability to record a baseline measure was important due to post-stroke fatigue being a "very subjective experience". Some emphasised its "nice brief" nature and benefits of being "freely available, no cost and accessible". When reasoning their choice of answer, a variety of responses were given. Some therapists referred to the evidence base, while others mentioned that it had been a team decision; "it is the accepted scale used within our team recommended in a conference talk". Two respondents mentioned that they had changed to FSS from using MFIS, however did not justify why they made the change.

Fatigue Assessment Scale (FAS)

Though not as common an answer as FSS, most respondents gave a similar reasoning for using the FAS; a baseline to make comparisons. Some mentioned using it as a starting point for a discussion about fatigue with the patient about different elements of their fatigue, noting "it helps to identify triggers to fatigue" and "patterns of behaviour like boom and bust". Respondents described its multiple purposes in clinical practice as a tool to start conversation but also as a useful "standardised" numerical baseline measure for their patients to use.

Neurological Fatigue Index-Stroke (NFI-Stroke)

A common theme throughout responses that eluded to using a scale, several therapists mentioned using the NFI-Stroke "to give a base line for treatment". One therapist stated the scale had purpose across multiple conditions; "I have just recently discovered the NFI. I use the same for MS and find it good for differentiation". Most therapists who selected the NFI-Stroke as their chosen assessment method used the scale in conjunction with the FSS.

Answer Given: Would use a scale ('Other' option suggested)

Barrow Neurological Institute Grading Scale (BNI)

Despite citing the BNI as their chosen assessment method, respondents gave mixed reports on how effective they felt the scale had been within their clinical practice. The scale was often used as a result of the therapist searching external sources and referring to relevant literature. When assessing face validity, one respondent reported their team felt "the BNI covered what we wanted it to cover", however went on to say that after using it in practice they were unsure if they would continue to use it.

Modified Fatigue Impact Scale (MFIS)

The MFIS scale was selected by respondents owing to its applicability as a baseline tool at the beginning of an intervention period. It also was "used as a discussion tool with the patient, so that any other issues can be identified". Several respondents described the MFIS scale as detailed, thorough and an effective objective measure for the patient. However, respondents reported that it was either not their standard method of assessment or that they had moved towards using the FSS instead.

Visual Analogue Scale (VAS)

Use of a Visual Analogue Scale (VAS) or another 1-10 score was mentioned often, among therapists who advocated positively and negatively to the use of a scale. The VAS was frequently described as being used in conjunction with a fatigue diary. Respondents justified their choice of a VAS scale using a variety of reasons including “to obtain an indicator of energy levels throughout a working day”, “to measure the impact of their rehabilitation” and “to measure fatigue perception” when setting functional tasks as goals.

Likert Scale

Two respondents mentioned using a Likert scale to “rate and monitor specific functional goals”. Similar to respondents who identified using a VAS scale, therapist answers stated that there were further benefits such as “it allows the patient to be able to self-manage as we are a short-term service”. Another respondent noted that they devised their own Likert scale, justifying their choice; “this allows the patient to self-reflect and as such provide insight to their fatigue levels”.

Answer Given: Would not use a scale

The below answers are from respondents who reported alternative assessment strategies.

Fatigue Diary

Fatigue diaries were cited as a commonly used assessment tool to give patients insight into their own fatigue, establish patterns, and to begin introducing self-management. The justification for using a diary varied substantially between therapists, with some using the data collected as an assessment tool “to assess how severe their fatigue is” or “to help guide intervention”. Other responses were more targeted to the patient; “to help improve the persons’ awareness” or “help them to take some control … and establish activities that have greater impact”.

Hybrid/in-house scale

Several respondents described specific in-house scales or established practices that were used within their multi-disciplinary team instead of a formal scale. Several were similar in format to a 1-10 or VAS scale. The purpose of using the scale varied dependent on the respondent, highlighting the flexible nature of this option. Many of the scales described by respondents had the option to provide further detail following the initial self-rating scale to “set realistic goal”, “provide advice” and assess “value of activities”. Several respondents alluded to the chosen scale being “in house” or there being “no history within the team using formal assessment tools”.

Patient-specific approach

A proportion of respondents described tailoring their approach to each patient and using scales only where they felt it was indicated or if the patient agreed it would be useful. Two mentioned modifying the FSS to their patient, “to get a sense of how they experience their fatigue” and “look at improvement”. Several described using patient-specific functional goals instead of objective measures, especially if the fatigue affected their patients cognitive or language function. Throughout, the subjective nature of post-stroke fatigue was highlighted as justification of their choice.

Answer Given: Would not use a scale

The below answers are from respondents who reported not using objective measurement as part of their assessment.

Unaware of scales

Many did not realise scales were available, and several commented that they would use a scale now they had been made aware by the survey. Most responses that indicated a lack of knowledge about scales also justified this with another key factor, for example having limited time or getting enough information from in-service training. Several cited their inexperience as a reason for not using a scale and mentioned that there was no leadership on using scales in their workplace.

Lack of consideration/never previously used a scale

Several respondents mentioned that they had not received training on using a formal scale, and that there was no historical use of a scale in their team. There was an implication that the issue had not been addressed appropriately by their team in many of the responses. Some alluded to this being a weakness in their responses that could be improved upon; “it is maybe something we should formalise in our service”. Others felt use of a scale or formalised assessment method were not necessary, stating “I find subjective questioning effective in our setting” and considering the patients’ perspective, responding “patients don’t always want to focus on their fatigue”.

Not indicated/appropriate

The most represented answer among respondents who did not use a scale was that it was not indicated or appropriate for their patients. Some respondents, particularly those working in acute care, felt that patients were too disabled or did not have enough awareness of their fatigue to use a scale. One mentioned that patients often did not want to focus on their fatigue. Several reported that they had previously used scales but that they felt these were less useful than subjective questioning. One respondent mentioned that they felt scales were more appropriate for junior staff, with the implication that they should not be needed by senior staff. One respondent suggested that scales were 'inherently problematic' and unethical.

Lack of resources/time

A lack of time to complete assessments was frequently cited among reasons not to use a scale. Respondents mentioned their high workload and the demands on their time, the number of deficits patients often presented with, and the significant number of existing scales they were expected to use. Several reported that a conversation was often more useful than a scale, with the implication that scales for fatigue represented another administrative burden that impeded optimal patient care.

Not viewed as part of professional role

Another reason frequently cited by respondents that did not use a scale was that fatigue was addressed elsewhere in their MDT. Several physiotherapists reported that OTs or specialist nurses were involved in managing fatigue in their team. Similarly, several respondents working in acute care felt that fatigue was better addressed in a community setting.

Other Reason Given

Several respondents who answered that they did not use a scale to assess fatigue answered the second part of the question with reasons that a scale would be indicated. These were similar to the responses given by those who used scales, and answers were represented in more or less the same proportions. For example, responses included, ‘An objective measure to reassess’, ‘understand relevance to daily functioning’, ‘affects their progression rate’, ‘indicates their perception and measurement of fatigue’, and other similar responses.

4.4.3 Summary

A multitude of different clinical approaches are taken to assessment of post-stroke fatigue by Occupational Therapists and Physiotherapists including use of both subjective and objective strategies. Use of subjective history taking was more prevalent amongst respondents however a common reason for not using patient reported outcome measures in practice was a lack of knowledge, which indicates outcome measures are rarely a consistent component of post-stroke fatigue assessment across clinical settings.

4.4.3 Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

4.4.3.1 Overview

The healthcare practitioner focus groups provided an opportunity to discuss the post-stroke fatigue and stroke care pathways in more detail. Role ambiguity became clear in Study 4 when therapists were asked about assessment and so a question was included in the focus group topic guide to examine why this may be. The following themes were created as a result of transcription coding to answer the secondary research question **“What do healthcare practitioners view their role to be within post-stroke fatigue care?”**.

4.4.3.2 Theme Overview: *Ambiguity*

The importance of assessing and managing fatigue as a multi-disciplinary team was highlighted, however often this was felt to not be the case due to differing levels of knowledge, experience and approaches taken in different settings worked in. Overall, this meant the role of the healthcare practitioner was not felt to be clear cut. The theme is made up of three sub-themes; post-stroke fatigue care being team led, priority level varying dependent on the setting practiced in and the presence of discipline specific approaches.

Team Led

When initially asked about the role healthcare practitioners play in fatigue management, both focus groups agreed that there was not a clear lead in each setting. The importance of working as a multi-disciplinary team and communication within this team was stated on numerous occasions. “In ESD it is across the board, I think. Also depends on if its speech, language, mobility. It doesn’t sit anywhere in particular.” This participant touched upon the multi-faceted nature of post-stroke fatigue which could be why its assessment and management is often not led by one specific practitioner. However, as discussions progressed it became clear that sometimes certain factors did affect how fatigue management was led. Due to fatigue’s debilitating effects on activities of daily living, it was felt that often therapists carried out more management or were more knowledgeable. However, the importance of working as a team to provide high quality care was discussed also. One occupational therapist offered, “it’s often the therapists who bring up fatigue in MDTs and then the doctors will look at meds and things as a result of us saying something first”. This was the case across both focus groups with a participant in focus group 2 saying “the doctors and nurses take on board what we are saying but we lead it. So we do joint assessments and work with them together. Its more therapy led than medical led." This model where therapists guide management and other medical practitioners input where needed was reiterated by an Early Service Discharge team practitioner. "Certain OTs are more educated but SALT and dietetics... they liaise with us more but I don't think they really discuss it with patients. I am not sure if they have discussions. I think itll be an assumption more you know? People always seem to talk to their physios; they just want to walk again or their loved one to walk".

In some community settings, participants highlighted that limited resources meant one individual may be carrying out all fatigue management. One physiotherapist based in Devon said, "it depends where you work and depends on your team. So in my team it is just me so it would be the physio. It also depends on who has been involved before when they get to community". One individual carrying out management may not just be related to limited resources however and in some teams, practitioners with a specialist interest in an area may choose to lead. An example of this within the Cambridgeshire focus group was; "I don't think there is a main person as such . On wards you always get people with an enthusiasm. So I am doing it but that is because I am interested in it. And then I take the lead."

Priority level dependent on setting

Within focus group 2, there were clear differences between how healthcare practitioners in the same profession approached post-stroke fatigue in different settings. One acute therapist cited the complex presentation of the patients she assessed and worked with when she recalled "I am not actually sure the last time I asked a patient about fatigue. We give so much information and have so many different things to consider on the ward it tends to be more discussed in handover or multidisciplinary team meetings”. An acute care therapist in the other focus group explained a very similar experience, suggesting it is not a hospital specific scenario; “I think theres a lot more done around managing fatigue to enable rehab but not much is really said about why it happens and it isn’t often assessed seperately. You are not getting that subjective... And it is a very subjective thing. You can't necessarily get that from patients, or in a very very adapted way with speech and language therapists.”

Several of the participants agreed and sympathised with this however one community therapist raised her view that fatigue should be a high priority earlier on to maximise potential; “We all know that fatigue tends to be worse in more impaired patients and know that’s part of the presentation and so it really should be monitored and considered by clinicians from the early stages right the way through with education, in my opinion.”

In contrast, in both focus groups the individuals who spoke for the longest amount of time when discussing management strategies identified as community occupational therapists. They took a proactive approach to management and prioritised follow-up. The discussion highlighted the different priorities of healthcare practitioners depending on the patient type and setting.

4.4.4 Summary

There was a lack of clarity in what the focus group participants felt their role was in fatigue management and the conversation mostly centred around the different practitioners involved with care. Assessment and management was often led by an individual in the multidisciplinary team with an interest in fatigue and participants believed active care was mostly carried out by occupational therapists and supported by medical and other allied health professions as needed, depending on the other aspects of the stroke survivors' recovery which it was affecting.

4.5 Thesis Research Question 4: How is post-stroke fatigue managed?

4.5.1 Overview

To answer the fourth research question, four studies were conducted. Firstly, a thematic analysis of the TalkStroke forum was carried out to provide an unbiased insight into experiences of stroke survivors and their supporters when living with fatigue. This was built upon in a semi-structured interview study carried out across the East of England. Within the national online survey which was sent out to specialist occupational therapists and physiotherapists, a question was asked about current management strategies the participants were using in their clinical practice. Finally, to bring the findings together two focus group studies were carried out with healthcare practitioners working in Cambridgeshire and Cornwall. Within the next section, the results of each study relevant to research question 4 will be stated.

4.5.2 Study 2: A thematic analysis of the TalkStroke Forum

The following themes were created as a result of transcription coding to answer the secondary research question **"What suggestions do forum users make to cope with post-stroke fatigue?"**. The themes were; involvement of healthcare practitioners, changes to the stroke survivor and supporters lifestyle and the consideration of mental and physical elements of post-stroke fatigue when considering coping strategies.

The initial codes following transcription and data familiarisation are shown in Table 24, Page 159-60. Often, these extracts were within posts where the forum user was reassuring another user or trying to explain their own experience. The term management was rarely used and so it could be suggested several of the strategies below were being done intuitively by stroke survivors and their supporters to enable them to cope with post-stroke fatigue.

Theme	Code
Involvement of Healthcare Practitioners	1. Perception of primary care practitioners *“GP seems to have no opinion on fatigue”* 2. Refence to information provision *“I use Stroke Association website and booklet”* 3. Practitioner signposting: Stroke groups and clubs *“There are support groups and clubs like Headway”* 4. Advice: Seek support from medical professions *“I think you should get advice from professionals”* 5. Practitioner advice on management strategies *“My consultant advised against napping in the day”* 6. Belief in medical management *“Need to keep up with the physiotherapy”* 7. Medication/pharmaceutical advice *“I was told to check my medication. Some make the tiredness worse.”* 8. Occupational advice *“Both GP and consultant stressed to build up work hours again gradually”*
Lifestyle changes	1. Term: sleep *“Need more time to sleep than previously”* 2. Daytime rest periods *“Rest 15 to 30 minutes daily”* 3. Activity pacing *“Pacing yourself is important”* 4. Reference to lifestyle ‘before’ *“Life is different and you must learn to recognise fatigue and work around it”* 5. Acceptance of change *“Accept when you need to take rest breaks”* 6. Goal setting related to lifestyle *“Small realistic goals to build independence”* 7. Practical suggestions: occupation/role *“Reduce hours returning to work and gradually increase”* 10. Planning and preparation *“Plan days in advance”* 11. Activity justification *“The physical activity improves muscle activity”*

Mental vs physical recovery	1. Term: patience *“Patience is key”* 2. Reference to mental strength *“Recovery depends on strength of mind”* 3. You need to be strong, determined and have grit to progress 4. Advice supporting other users *“Don’t be hard on yourself”* 5. Reference to the sudden nature of stroke *“You need time to settle after a shock to the system”* 6.Advice: relaxation *“Relaxation CDs work for me”* 7. Mood changes when fatigued *“Need to remember your emotions when you are tired”* 8. Expert patient approach *“Listen to your body”*

Table 23. Final codes associated with the chosen sub-themes and themes in Study 2, answering Thesis Research Question 4.

It was striking that stroke survivors posting on the TalkStroke forum appeared to often seek support with the practicalities of employment after stroke from healthcare practitioners, yet simultaneously reported that their fatigue was not well understood. For example, one stroke survivor reported that ‘my GP doesn’t really have any opinion on the tiredness (but is happy to keep signing me off from work)’ (SS21).

Forum users were more likely to recommend simple practical solutions such as ‘pacing yourself’ (SS4), than approaching healthcare practitioners for support in managing their fatigue. Indeed, one survivor was supported by forum users posting that ‘just because your doctor cannot help [with the tiredness] it does not mean the be all and end all’ (SS13). Suggestions of short trips outside and gentle exercise were made, and the individual was encouraged to ‘give a few things a try to see how you feel’ (SU6), rather than pushing for medical help with the fatigue.

Returning to work was a recurrent topic of conversation on the stroke forum, with many posters voicing their concern over how they might cope with the transition back to a work routine whilst still experiencing complexities associated with post-stroke fatigue (Table 25, Page 161). Voluntary work was encouraged, since ‘if you did voluntary work, you'd be able to work when able and rest other times’ (SU9). Often, advice on returning to work was sought from healthcare practitioners, with forum users reporting for instance ‘both my GP and consultant have stressed I should go back [to work] on reduced hours’ (SS21), and another explained ‘my consultant has signed me off as unfit for the foreseeable future…I could not manage work for lots of reasons - tiredness, concentration, memory’ (SS8).

Involving healthcare practitioners	“Counselling is a positive move. The tiredness is a problem, I occasionally need a half hour cat nap” (SS16) “both my GP and consultant have stressed I should go back [to work] on reduced hours” (SS21) “just because your doctor cannot help [with the tiredness] it does not mean the be all and end all. Give a few things a try to see how you feel” (SU4) "my consultant has signed me off as unfit for the foreseeable future…I could not manage work for lots of reasons - tiredness, concentration, memory" (SS12) “my consultant advised me not to nap in the daytime” (SS1) “I was told by my GP that tiredness is one thing I would have to get used to and in time will get better. For now I have to accept it is now a part of me.” (SS6) "GP doesn’t really have any opinion on the tiredness (but is happy to keep signing me off from work)" (SS21) “Four years on I’m exhausted daily. My GP says its neuropathic” (SS4)

Table 24. Themes based on exemplar quotes from Study 4 interview transcripts. SS = Stroke Survivor.

Theme 2. Lifestyle changes

When advising other forum users, a plethora of lifestyle suggestions were made by survivors and carers (Table 26, Page 162), chiefly in respect to learning to ‘pace yourself’ after stroke (SS12). One stroke survivor summarised their experience as being ‘about learning to live within your new limitations and taking it easy when needed’ (SS31). Others suggested gentle exercise as something that ‘really does shrug the tiredness off’ (SU5), and many survivors advocated learning to ‘listen to your body’ in order to gauge the appropriate amount of activity and rest.

Lifestyle Changes	"One thing I have found useful and really does shrug the tiredness off is exercise" (SS26) "I know how to pace myself now" (SS2) “it's about learning to live within your new limitations and taking it easy when needed” (SS6) “it's about pacing yourself, in time you learn to know how much you're able to do without being too tired. Learn to listen to your body and rest when need be” (SS24) "try to set yourself small but realistic goals as a way of building up your confidence like a visit to a supermarket, making a bus journey alone - small steps are the way forward, accept when you need to rest" (SU6) "if you did voluntary work, you'd be able to work when able and rest other times. The tiredness will go in a matter of time" (SS4) “it's a matter of learning to take regular rest breaks, listening to what my body is telling me and doing what I can get away with” (SS21) “it is no good overdoing it and making yourself ill, if I feel tired the first thing I do is go and have a lay down” (SS12)

Table 25. Themes based on exemplar quotes from Study 4 interview transcripts. SS = Stroke Survivor.

Theme 3. Mental vs. physical recovery

For some stroke survivors, post stroke fatigue is an emotional, rather than physical, problem (Table 27, Page 163). One described being pleased with their progress yet being ‘annoyed at myself for concentrating on my physical recovery without really taking my mental recovery into account - I still get bouts of fatigue that knock me for six’. Yet for others, overcoming the fatigue was considered part of the physical recovery from stroke. One survivor reported that ‘apart from tiredness and intermittent vertigo the physical effects of a stroke I experienced in April have thankfully passed".

Mental vs Physical Recovery	“I am a little worried about how I will cope due to the tiredness” (SS7) "Mum has recovered fairly well physically and has now learned to accept signs of overwhelming tiredness that she needs to rest!!” (SU14) “physically Mum does okay, tiredness is still a big problem for her but she's learnt what she can and can't manage now.” (SU1) "Apart from tiredness and intermittent vertigo the physical effects of a stroke I experienced in April have thankfully passed" (SS20) "I’m pleased with what I have achieved but annoyed at myself for concentrating on my physical recovery without taking my mental recovery into account. I still get bouts of fatigue that knocks me for six" (SS5)

Table 26. Themes based on exemplar quotes from Study 4 interview transcripts. SS = Stroke Survivor.

4.5.3 Study 3: An interview study investigating lived experiences of post-stroke fatigue

The following themes were created as a result of transcription coding to answer the secondary research question **"What multidisciplinary team input do stroke survivors and supporters receive in the community setting?"**. Following a theme surrounding the perception and purpose of healthcare practitioners emerging in the TalkStroke forum analysis, this question was included in the stroke survivor and supporter interview study to gain a more in-depth insight.

Overview: An accessible source of expertise

Discussion around the role of the healthcare practitioner was largely met with apprehension and recollections of accounts where the individual or supporter had a negative experience with a member of the multi-disciplinary team. However, throughout the interviews it was clear that stroke survivors and their supporters regarded the advice and support they received from trusted healthcare practitioners highly and their expertise was valued. Three main sub-themes emerged regarding management of fatigue which will be discussed in greater detail below; the important of the patient-clinician relationship, the stroke survivor and supporters perception of the healthcare practitioner understanding what they were experiencing and the awareness of healthcare system complexities which made engagement more challenging.

Patient-Clinician Relationship: *"it's fun but I trust him"*

The importance of a good patient-practitioner professional relationship was discussed and reiterated throughout several of the interviews. Stroke survivors and their supporters had greater trust in the information they were given and described an overall better experience if they had developed a positive relationship with their healthcare practitioner, regardless of setting or role. Mr Barnes' wife recounted a negative experience where several different members of a multi-disciplinary team discussed discharge with her after Mr Barnes' ward doctor had told the family he was not yet medically fit. "In hospital, I had to ask the sister about a test result as we hadn't heard anything from the doctor after he told us he wasn't happy. On the Thursday or Friday I had a call from the physio or OT about him coming home and I mentioned the test... She said oh well it is not in his notes. On the Monday, the other of the two rang me and said the same thing. It was frustrating because I didn't know what had happened and didn't want something to be missed."

Communication was often mentioned when considering the input from healthcare practitioners. Some participants preferred their healthcare practitioner to take a realistic fact-based approach whilst others found clear timescales and recovery markers unsettling. Mr Thomas recalled a positive experience whilst he was sat with his physiotherapist watching other patients walk past in the hospital corridor; "I said to my physio hopefully thatll be me once I get my new leg- you've had a stroke, that won't be you mate. The difference between you and him is you had a stroke. And do you know what... I liked that and we have a laugh y 'know, it's fun but I trust him like". In contrast, Mr Emanuel's wife found that the language their GP used had a lasting impact and affected their on-going engagement with the service. "He doesnt need to be judged and for someone to make him feel like less of a person... when I said about the tiredness the doctor said to me 'oh come off it, you know he doesnt have much to live for'. At the time we just laughed then two or three days later something happened and he said I dont have much to live for. It was meant in jest but because it came from the doctor it had an impact. There's not really much point going."

Clinician Understanding: *“they showed me. That was good.”*

Participants reported not having confidence in healthcare practitioners understanding of their fatigue. Often, queries were answered as a result of family members asking specific questions. Others reported not asking for support or education as they felt fatigue was not as important as their other post-stroke conditions. Mrs Jansen said she did not ask “because there are so many people with so many things you… you just feel like a fraud.”

The use of visual aids to accompany verbal information giving was reported to be helpful. Participants perceived this as a sign the practitioner wanted to help and that they understood their medical history and background. Mr Thomas recalled; “They bought me in a plastic brain and showed me. They looked at my records so they could I reckon and I could physically see it and see what was wiped out. That was good. They understood.”

Healthcare System Complexities: *“getting back in touch isn’t as easy as you think”*

Although not explicitly stated, an underlying theme that emerged was stroke survivor and supporter perceptions of gaps and challenges within the clinical pathway. Participants recalled long wait times to be seen by a clinical specialist, who they viewed as a general practitioner or consultant. Mrs Zavos proved an exception to the rule, suggesting a perceived bias: “I’m very lucky because I think if you have stroke/cancer on your records they see you quickly. I normally get an appointment that afternoon when I call.” Citing widely publicised time pressures on primary care clinicians, some stroke survivors and their families felt like their fatigue-related concerns not severe enough to add to their GPs caseload. Mrs Jenkins mentioned, “it is very difficult deciding whether to call for help. You dont want to be a pain in the bottom but I am always told I made the right call when I have gone in.” and Mr Bone recalled, “we havent really spoken to the GP. I just feel, perhaps it is naïve... I was bought up that if you didn’t do what is expected you’re skiving. It might seem we aren’t trying maybe.”

Continuity of care was considered an important aspect of an effective fatigue management pathway. Positive experiences were described by interviewees who had maintained contact with hospital-based healthcare practitioners once in the community. Mr Harvey explained “every 6 months I go in for a check-up. Its ongoing care with the consultant. And they gave me a phone number before I left. Didn’t think I would need it then you know but it’s just nice to have the option and not be abandoned”. This however was not the experience for all and several stroke survivors mentioned feeling alone or abandoned by the healthcare service. “Youve had a stroke and thats it- thats how it felt. There was nobody to phone up once you left the hospital. Getting back in touch isn’t always as easy as you think.”

Mr Anthony suggested that his care could have been improved if there was a central point of contact to improve communication between practitioners. “It could do with a bit more people talking to each other. They should really make one person responsible for a patients care and I think that should be the GP. Or maybe the occupational therapist. But there should be one person overseeing whats going on with the patient.”

Theme Summary

When discussing healthcare practitioner input and support, the three main themes that arose were patient-practitioner relationship, variability in clinician understanding of the stroke survivors lived experience and perceived healthcare system complexities which made perceived continuity of care challenging for stroke survivors and their supporters. Positive experiences which were recalled consistently used vocabulary which was suggestive of sense-making and respect of the stroke survivors difficulties, even if they fell outside of the practitioners clinical remit.

The second main area of interest within the stroke survivor and supporter interview study was current management of fatigue.

Overview: Supported self-management

Considering the demands on primary care clinicians, gaining an insight into successful coping mechanisms carried out in the community could help healthcare practitioners design acceptable and feasible management packages. The following sub-themes were created as a result of interview transcription coding to answer the secondary research question **"What management strategies do stroke survivors and supporters use to cope with Post-Stroke Fatigue?".** They were; the value of outside support, use of individualised goal setting to guide routine and prioritisation throughout the day, the importance of effective information giving and creating an achievable daily routine.

Outside support: *“I don’t know what I’d have done without him”*

Over three quarters of stroke survivor participants chose to have a family member or care-giver present in their interview, who we collectively term as supporter within this section. The positive language used by supporters was notable when discussing the stroke survivors’ post-stroke journey, such as “he always says I’m no good but he doesnt realise how much he has achieved. I see every step”. Stroke survivors often used pronouns such as “us” and “we” suggesting they viewed their recovery as a team. Stroke survivor participants credited their supporters as helping them overcome significant mental and physical challenges following the stroke and when dealing with on-going chronic fatigue. Mrs Larman said “I don’t know what I’d have done without him. Just have laid in bed all day so I do not do anything to make the tiredness come on. I would give up... I would”. Some of the supporter participants had previous occupational experience within the care sector and highlighted the benefit of this during the interview. Mr Barnes wife described how it had helped them adjust quickly, saying “I guess it just happened and you just adjust so yeh. Probably because ive seen people similar it is not too much of a shock and when I’m calm, he is too. He trusts me”

For individuals living alone who were not in close contact with family members, community and neighbourhood support was mentioned as helpful for “little tips... my neighbour told his friend three blocks down who had a mother who had a stroke... they told me what it would be like. It is much worse for her but like it is still someone who went through it y ‘know?” Another spoke about his friend in the community who he phoned each week even if he was too tired to get out the house; “Its useful to talk to my friend because you dont know what to expect and he sees the progress too when he does see me. He walks on just a walking stick now. I hope I’m like him one day”.

Charities were viewed by many participants as a separate source of support to healthcare practitioners and organisations. Charity involvement was consistently viewed as helpful and discussed as a positive addition to the care pathway. Charity input was mostly from organisations such as the Stroke Association and Headway. Participants recalled that first contact was made by telephone soon after their discharge and they were then offered a face to face visit. When discussing useful input, Mrs Jenkins replied "The stroke society lady was more helpful than anyone. She visited me regularly- I told her about it and she said it is all part of it and can take literally years to go back to normal. It reassured me as I did not know what was going on. She was really reassuring and helped so much."

Individualised Goal Setting: *"you've got to go for it … nobody is going to help ya"*

Each participant described a different lived experience, describing their post-stroke fatigue and how they were either knowingly or subconsciously managing their fatigue day to day. Every participant demonstrated an awareness of personal triggers and associated factors. Mrs Langman compared the fatigue to pre-stroke; "It happened before but it's worse now and it goes very deep. I cannot do anything and feel... I'm completely useless". Mr Simmons also noted the effect the fatigue had on his mood but then highlighted the importance of having a positive attitude when considering his coping strategies. He said "It does wind you up and you do feel low so you've got to kick yourself up the backside, come on... lets get going. I have to be positive and think forwards y 'know."

Other participants, including Mr Pennick, mentioned how choosing a personal project or goal to aim for kept him motivated and reminded him what he could do as opposed to what he could not as a result of his post-stroke fatigue. His goal was to be able to keep a puppy; “You’ve got to go for it because if you don’t then nobody is going to help ya so I do try and push myself. I give myself projects like when I learnt to walk up the stairs again- I go up and down the stairs like I’m normal now. Youve got to push yourself all the time. You have got to have an ulterior motive. Mine is I’m getting a new puppy and need to walk and train it and if I can do it I can have one. So you’ve got something to aim for.” Mr Gilchrists’ wife recalled how incorporating activities her husband had enjoyed before the stroke helped, recalling what she termed a ‘miracle’. “He always used to run marathons.. for years and years he did. We have the best neighbours; we have lived here for nearly fifty years. One day he was sat in the garden about to nod off and the neighbour jetted him with a water gun and started running. Suddenly he ran.. and then stopped but he did it and he was so alert. I think it was his body remembering”.

Effective Information Giving: *“they were really helpful”*

When considering strategies that had helped them manage and cope with the fatigue, several participants mentioned how the information gathered through independent searching or during clinical consultations was valuable in helping both the stroke survivor and supporter to adjust their expectations regarding capabilities of the stroke survivor and expected length of time for recovery or improvement in fatigue symptoms. A standard question asked during the interviews was ‘Has post-stroke fatigue/your tiredness been explained to you?’ Mr Rutt responded, “they didn’t ever explain what it was no but they told me it could go on for months or years and told me how it may affect things I like doing like my gardening and walks. I don’t really mind if I don’t know why if I know what it would make hard I think”. Several participants recalled being provided with written information at the point of acute care discharge or within a resource pack by the early service discharge team. Many reported finding this a useful resource to refer to, but rarely used it immediately. Mrs Morton said “Early discharge team gave a folder of resources to help manage after the stroke. I did look through it initially but it’s been more useful the last six months or so once we have settled a bit”. Mr Harvey said having a combination of resources was useful; “Got loads of papers explaining all about it and a number to ring her any time- they were really helpful.” For others, information giving and receiving took a different form. Mr Halters’ wife added, “we have started going to a stroke group once a fortnight. We havent been before and we havent done anything else socially… he hasn’t been ready because of the battle of tiredness and concentration.”

Routine: ***“you can’t put your life on hold”***

When discussing managing their fatigue, many participants referenced their daily routine and the adjustments needed to accommodate for the changeability of post-stroke fatigue. Participants felt that their ability to manage and adjust depended on how their close support network accepted the fatigue. Mr Halters wife spoke about the need for a flexible daily routine; “We just sort of adjusted our lives to those breaks. I'll be doing something and come in and hes nodded off. It happens quite a lot during the day yeh”. In contrast, Mr Simmons recounted the barriers fatigue had on his routine. “We couldn’t plan anything or go out anywhere or do anything because I just felt so tired all the while”. Those who managed by adjusting their lifestyle to incorporate a flexible routine often mentioned specific tasks or goals they incorporated into their day.

Two examples volunteered by Mr Davies and Mrs Smith were:

"We try and walk into town but when we do, I must sit and relax. I walk slower than before and I have to watch all the people around me. I must take more breaks."

"You can't put your life on hold you have got to try. I will do a few things and then I'll sit down then start again. I've got friends I try and go and see for tea. So I have something to aim for and I can practice my talking."

Mrs Murrays husband summed up how they manage their routine day to day; "Its accommodating for it and preparing."

Theme Summary

Participants responded to questions regarding secondary research question three 'What management strategies do stroke survivors and supporters use to cope with post-stroke fatigue?' with a variety of management techniques. Throughout the interviews, the importance stroke survivors placed on a supportive family and community network became clear. Management strategies varied, however all interviewees who reported being at a point where they were coping with the fatigue described the importance of learning to understand the body. Adjusting daily routine to account for the stroke survivors personal exasperating and alleviating factors led to perceived better coping ability. Stroke survivors and their family members also described needing to educate themselves and understand the fatigue to be able to fully accept its presence and move forwards to a "new normal". Self-management strategies were reported as the most common coping strategy and participants felt they most effective alongside informed education and external encouragement.

The final area of interest within the stroke survivor and supporter interview study was future management of fatigue.

Overview: The informed patient

A series of open and guided questions were asked to answer the final secondary research question **"What would stroke survivors and supporters want an intervention aiming to help them cope with post-stroke fatigue to consist of?".**

Three sub-themes were created from the data which were the perceived need for a clear pathway, healthcare practitioners having an enhanced understanding of the patient and the need for management strategies to be adaptable. These are explained in more detail below.

Enhanced Understanding of the Patient: *"they haven't been through it"*

Participants recounted negative experiences with healthcare practitioners who they perceived dealt with the stroke survivor as a condition and not understanding the difficulties the individual felt. When asked what she felt may have made managing her fatigue easier, Mrs Cockerham told the interviewer; "I felt there was nothing I could do to change it. I think if you speak to other people who have been through it, it would help. Even like the stroke societies they haven't been through it. I think they should employ someone who has been through it. So you are speaking to someone who's literally been through it". Another participant referred to the limited applicability of standardised resources when dealing with the variable nature of post-stroke fatigue; "Throw all the books out the window and just do what you can. Believe in yourself, let people help you."

Participants described the power of utilising family members who spend the most time with the stroke survivor to fully understand the individual and how their fatigue presents. Mr Barnes said “I needed to keep reminding myself of things. I would have forgotten straight away. Family members are so important so they do remember things I do and how I act and stuff. My head is like a vacuum and all the stuff I remember is floating around. The first six months you need to look at the person doing the caring and involving them in the recovery and listening to them with what is happening.” Mrs Hansen agreed that when taking a patient-centred approach to fatigue management, family are an important part of the puzzle; “I think it should be a family thing when this happens. I have learnt that it doesn’t only change your life, it changes theirs as well.” Mr Best also highlighted that he felt the healthcare practitioner role in fatigue management was to educate and advise as opposed to administering care which could be assisted by a significant other or family member “I’d rather a face to face chat and then have tools to deal with it myself with [wife]”.

Supporters gave examples of events at home which only they had witnessed, when explaining the stroke survivors’ presentation. This further highlighted the useful insight which supporters have when healthcare practitioners are creating and carrying out a fatigue management programme. Mr Pennicks’ wife gave an example; “If everything was put out in front of him he could do it. But after getting washed and dressed he would need to sit down on the sofa and sleep for two hours. I just thought if I could get him to do more things it would help him progress.”

Adaptable Management Strategies: *"everyone is different and an individual"*

Throughout the interviews, participants did not highlight one management strategy with certainty that they believed had reduced the severity of their fatigue or its impact on their life. It became clear that this was due to the variable and unpredictable nature of the fatigue which meant having adaptable management strategies was more appropriate. During many interviews, the stroke survivors' fluctuating mood alongside the variability of their post-stroke fatigue was mentioned. When asked what they would advise another stroke survivor dealing with post-stroke fatigue, this became clear. Mr Halter replied to the question saying; "It is very easy to let the dark side take over but you shouldn't and especially with tiredness. It will get better and it's about time. Everyone is different and an individual. And what worked for me may not work as quickly for you. It's something that you need to be aware of but you must work around it".

Common language used included 'working around it' and 'accommodating', highlighting the importance stroke survivors and their supporters placed on accepting the fatigue but not letting it interrupt day to day life where possible. Mr Bones wife summed this up with an analogy; "In the end you have to play the cards you are dealt, and we need to accommodate these factors."

The interview participants described certain areas which they thought needed to be addressed to be able to offer adaptable management strategies. Transport to attend healthcare practitioner consultations was emphasised as a challenge for many of the families, especially in the initial period after discharge. Mrs Larman said "I would rather over the phone input.

We go down to the GP but sometimes it's a bit of a nightmare to get there." As mentioned previously, participants reported that stroke survivors and their supporters are often given large quantities of information prior to discharge from the acute ward setting. From the participants' experience, they felt this often is not retained into the sub-acute phase of their recovery. Participants suggested that it would be useful if provision of information leaflets could become standardised practice at the point of discharge or at initial contact with a primary care practitioner. This standardised advice could then be adapted to the individual in question. Mr Thomas said; "I'd like to talk to other people but also have a booklet to take home. I get the book I was given out if anything I'm not sure about happens." Participants who had been given copies of the Stroke Association leaflet mentioned it would be improved with inclusion of stroke survivor accounts. Mr Gilchrist said; "It would have been useful to have a booklet so you could go back and its written in there clearly and you can understand it. I think having peoples' experiences in would be a brilliant idea too. Everyone experiences different things… I think?"

The potential role of pharmacological intervention was considered in several of the interviews, with varying opinions. This lack of consensus shows that even if an effective pharmacological treatment were offered, not all individuals would want this management strategy. Below are two answers to the same question asked in the interview:

Interviewer: "If a new medication was developed for fatigue would you want it?"

Mrs Murray: "I would, 100 percent. I feel like I've wasted the last few years of my life due to tiredness."

Mr Bone: "I take ten in all and so I don't really want to take anything else y 'know? If it were something that would enhance my life maybe we would consider it."

A Clear Pathway: *"sometimes you have questions"*

Interview participants mentioned reduced clarity when trying to understand the services healthcare practitioners could provide to support them with fatigue. When asked what they thought good fatigue management should look like, it was expressed that ensuring continuity of care would increase stroke survivor and family members' confidence in medical services. Prior to discharge, it was suggested that recognition of fatigue in the ward setting and informed advice tailored to the patient would be valuable. There was no consensus on what aspects of fatigue education were most important however two participants highlighted negative experiences they had around language used by healthcare practitioners in the acute setting.

Mr Emanuel's wife appeared exasperated when she recalled; "The issue I have is the 2-year thing. It's the worst thing of all. Youve got 2 years mate and thats your lot. And telling us he only had 2% chance and they were preparing us for the worst.. I just think perhaps they shouldn't say that. They should say nobody knows and we will have to see". In contrast, Mrs Hansen expressed wanting more clarity and clearer information; "Nobody states that it could take years to get rid of the tiredness. And sometimes it never goes away but they dont explain that to you- or maybe I forgot"

Mr Bests' wife explained that in the first month following the stroke, her husband wasn't able to fully process all the information he was given and so knowing who to contact once discharged would have been helpful. "There was nobody to phone up once you left the hospital. Getting back in touch isn't always as easy as you think". Mr Walkers' wife recounted a conversation that her husband had at discharge which helped maintain communication and continuity of care, if needed. “When they rang he said he was fine but they gave a number in case we wanted to talk to them again. Sometimes you have questions which you dont need answers to straight away.” When forms of communication were discussed, several participants suggested a phone consultation or follow-up with a healthcare practitioner the stroke survivor knew. Mrs Larman offered that it gave a more person-centred experience; “A telephone or.. that sort of communication. I think you can hear in a persons’ voice whats going on. It’s more of a true response.”

Following discharge, participants often said they believed the optimal time for contact from a healthcare practitioner would be within the first two to six weeks. This links to the previous theme, where stroke survivors and supporters reported feeling most supported when there was continuity of care or no large unanticipated breaks between contacts. Mr Anthony offered; “I’d rather not straight after as your minds a bit jumbled but probably the first 2 weeks or definitely first month. Then you have time to settle back down at home and get things sorted before thinking of other things.” Mrs Wilkinson referred to the six-week marker as a good time for further input as it was a point where she was coming to terms with the longer-term changes following stroke; “I would have liked information about a month after I’d say. Within 6 weeks. I had it in my head I would be normal again at 6 weeks and it never worked out like that”.

This information would preferably come from a trusted healthcare practitioner who in most cases was thought of as the family GP. Stroke survivors reported a preference to see the same clinician and supporters often reasoned this by feeling it improved the patient-practitioner relationship; “I like to see the same doctor because they all have different ideas and don’t have the time to look at my history. I’d rather see the doctor for advice face to face”.

Participants contemplated their own experiences and often reiterated the variability of family members and supporters being included in consultations and ward-based sessions. It was felt strongly that advice and education should be given to the stroke survivor and family member or significant other. Stroke survivors were unsure of how healthcare practitioners perceive family and supporters and often reminded me in the interview that these are the experts in the stroke survivors condition as they spend most time with them following discharge. The below extract from Mrs Morton's interview explains captures this.

Interviewer: Would it have helped to have more information at the start?

Participant: Yes. if I had known more… My daughter said the same because they dont give support to the family. They give support to the stroke victim but the stroke victim doesnt always understand that support and nine times out of ten you'll forget what they have said. So I think if they involved families more and then they can relay it to you time and time again. They are always there, see? They do need to change that outlook definitely."

Stroke Association and Age UK resources were considered useful and sometimes considered aspects of community care healthcare practitioners do not advice on such as how to reduce the financial burden of not being able to return to work. Participants reported being able to connect on a more personal level with individuals from these organisations however also often mentioned an awareness that the support charities offer may not be accessible for all. Mrs Zavos suggested that there should be clearer links between primary care clinicians and charity services. She said "I think the Stroke Association do a really good job but there should be a person in each region. I think they need to be everywhere".

I think they should be more involved with your GPs and when you leave the hospital let them come and have a word with you. It was just after I came home I got a phone call then they came to see me”.

Group sessions were described as useful by some participants however many of the stroke survivors involved in the study felt their stroke was not severe enough to be worthy of a space. Supporter participants were more open to the idea of meeting others and discussing the issues faced from post-stroke fatigue. Mr Rutts’ sisters responded to one question; “He got referred to a stroke group in hale ran by the hospital which we went to for 6 sessions. We found it was useful didn’t we?”. Mr Pennick suggested a group intervention would not be helpful immediately after discharge; “I think a group would be helpful a little bit later because youre not absorbing everything at the time.” Another consideration for healthcare practitioners signposting management in a group setting which was mentioned by supporters was an awareness of the age group of individuals accessing it, highlighting the importance of social interaction when engaging with this type of management; “For groups he struggles being in his 50s as he doesnt fit into the young or old category. I think your social requirements are different to the others. So yeh, we tried it but didn’t keep going”

Finally, participants mentioned the varied understanding levels of community based care staff, with one stroke survivor recounting an experience which made her doubt the individuals’ knowledge of the after effects of stroke; “I think it should be explained to the carers that visit you after the stroke- thats what ive found anyway. If they had something to read after it, they may understand and be a bit more caring. Some people look at you like you have lost the plot when you just switch off or I start slurring because I need a break.”

Theme Summary

The interviews offered insight into stroke survivors lived experience of post-stroke fatigue and areas participants felt were important to be considered when developing future management strategies. Throughout discussions during the interviews it was clear that continuity of care was important to stroke survivors and their supporters. Participants were of the opinion that the variable presentation of post-stroke fatigue may mean that one standardised management intervention would not be generalisable to all stroke survivors. To be able to adapt education resources and management interventions, interviewees felt it was important for the care provider to understand how the individual they are supporting experiences post-stroke fatigue.

4.5.4 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

4.5.4.1 Overview

The following themes were created from respondents answers to the survey question **"What treatment techniques have you employed in helping stroke survivors manage their fatigue and which were the most useful?"**. 138 individuals responded to the survey question (66 occupational therapists, 72 physiotherapists). Within these responses, 43 different techniques were suggested. The most common answer given was education (67 respondents) whereas anxiety management, use of a bedside fatigue chart, cognitive behavioural therapy and an ensured follow-up were all suggested by only 1 therapist. Provision of education and pacing were suggested significantly more than any other technique. Responses varied in length, ranging from 1 word to 170 words. Most therapist respondents chose to list the treatment modalities they would implement as opposed to elaborating on select techniques. Similar to the above two questions, several of the physiotherapists reported referring patients who had been identified as experiencing post-stroke fatigue onwards to an OT. Utilising a framework analysis, the management strategies presented by respondents are summarised below.

Theme Overview: Individuals' perception of fatigue

Within this theme, management strategies which targeted the individuals' understanding and awareness of post-stroke fatigue through information provision were included. Education was suggested broadly and more specifically, with therapists referring to Stroke Association advice and information booklets. To increase stroke survivors' awareness of their fatigue, strategies such as trigger identification and use of fatigue diaries were offered. One therapist referred specifically to the "Boom & Bust" cycle, to help stroke survivors apply their new knowledge to their own lifestyle and trigger identification.

Lifestyle

No therapists directly referred to management strategies targeting change of role in the home and community. However, some therapists did assess and use strategies which were effective for the individual before their stroke occurred. Influencing factors and co-morbidities were considered, with therapists reviewing diet, medication, and exercise. Some community therapists reported adjusting the home environment to alleviate the individuals fatigue levels. Similar to Question 7, incorporating the family picture into chosen management was highlighted, but only by a small number of therapists.

Daily Routine

Another reoccurring theme within therapists' responses was routine planning. Some responses were tangible and immediate, such as positioning management and incorporating a seating regime into the patients' day. Other strategies were more focused around helping the individual to manage their own routine more effectively. These ranged from modifying and varying activities within their day, encouraging pacing and planning, to putting strategies in place to conserve energy. Many respondents focused on management of daytime rest and night sleep hygiene. Some therapists focused their management strategy on the individuals' activity levels however also targeted their awareness and perception of the fatigue by suggesting keeping an activity diary. Another common suggestion targeting future self-management was pacing of day to day activities and engagements.

Cognitive Impact

Highlighting therapists understanding of the multi-factorial nature of fatigue, the next theme which aligns with the initial assessment categories of questioning, was management strategies targeting the cognitive effect of post-stroke fatigue. The strategies targeted a variety of cognitive changes which could occur as a result of or be accentuated by fatigue; these included attention, concentration, mood changes and tedium. The link between fatigue and depression after stroke was touched upon, with some respondents incorporating awareness and management interventions into their sessions. One individual alluded to using the CBT model when necessary and several others indicated relaxation formed part of their management interventions.

System-related management

Another theme arising from responses was management strategies reliant on changes within a wider department or hospital system. These included ensuring stroke survivors received follow up at set time intervals to track the course of their fatigue and working within the multi-disciplinary team to administer best treatment. This was more commonly reported by therapists working in an acute setting, in close contact with other healthcare practitioners and clinical staff.

4.5.5 Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

The focus group study provided the opportunity to gain greater insight into management of post-stroke fatigue in different professions and settings. The cross-sectional therapist survey highlighted the huge variety of management strategies utilised across the UK by therapists but could not collect data which would explain why. The following themes were created as a result of transcription coding to answer the Focus Group secondary research question **“What management strategies do healthcare practitioners use and what barriers do they face?”**

Overview: Symptom management approach

Participants across all settings described in-depth assessment and education tools used however felt there was not effective hand over between clinicians across the management pathway. Three clear themes were identified as important factors in current management which were carrying out a detailed subjective assessment, educating the stroke survivor and family on post-stroke fatigue and supporting them to self-manage in the community setting. The three themes are covered in greater detail below.

Multi-factorial subjective assessment: *“clinical expertise is needed”*

Despite clearly starting the final section of both focus groups with a presentation and open question regarding post-stroke fatigue management, healthcare practitioners in both focus groups reiterated the importance of an effective assessment to guide the clinical decision making needed to develop and carry out a patient-specific management programme. There was a consensus that one treatment or strategy would not work for all patients and individualising care was vital. One occupational therapist considered her current practice and said to the group; “Really you need to create a formulation with that person and then that’s a visual representation and gives a whole picture of that particulars persons’ fatigue and all the elements contributing to it. Although the leaflet gives information, thats all it does really. Clinical expertise is needed to break it down.”

Information Giving: *“I explain so they understand why”*

One of the key strategies utilised by healthcare practitioners present at the focus groups was information giving, to educate the stroke survivor and their supporter where appropriate. One participant gave an example of this; “I tend to use analogies, like if you’ve been poorly with the flu and you just can’t get out of bed… your body is fighting something and trying to repair. It is just like that.” Following this, another individual present in the group offered her own suggestion which she had found worked for her patients and their family members; “You repair when you sleep. Although you can’t see what is going on, you still are. I explain that so they understand why their relative is so tired.” Throughout the focus group discussions, language describing significant others and family members was used, much like in the above quote, however support and inclusion of these individuals in care was rarely mentioned alone.

Ways of providing information to stroke survivors and their family members were discussed. Use of the Stroke Association fatigue leaflet was highlighted in both focus groups, showing two different trusts in quite different geographical locations use this resource. One participant at the Devon based focus group explained the benefits using this resource gave; “When we give the leaflet they tend to say thank you for giving me that fatigue leaflet because at least I know I’m normal now. I have found in my experience it really helps to normalise and destigmatise the fatigue.”

As was the case at many points during the groups, discussion around patient and family education prompted the healthcare practitioners present to reflect on post-stroke fatigue management more broadly; “Definitely, having more information other than the basic management would be very beneficial. for us and for the patient”.

Self-management: *“looking to build their own awareness”*

Strategies to enable the stroke survivor to better understand and manage their fatigue were put forward within the groups. These strategies were suggested by community and early service discharge team healthcare practitioners. The complex and changeable nature of stroke survivors’ conditions when on the acute ward were seen as barriers to this form of management. One physiotherapist working within a Cambridgeshire acute stroke ward said; “The patients we deal with have complex fatigue issues, so are those who perhaps can't recognise it themselves. I think it is quite a different management strategy and quite difficult to manage because you're not getting that subjective”. She went on to suggest monitoring of day and night routine was most effective for this subset of patients, “I suppose, in that way, then it's the 24-hour management which is really, really important, and how we adapt our therapies to short sessions or twice daily but short sessions, or physiotherapy taking a real back seat because the swallow is most important. Team communication is most important to get it right.”

Often, self-management strategies incorporated improving the stroke survivors understanding of how fatigue affected them specifically, routine adjustment and objectively rating their fatigue levels. One participant emphasised the importance of incorporating a self-rating scale or fatigue diary into their management; “I think one of the key factors is getting them to self-rate their fatigue. And trying to get them to do it so you know there can be things like diaries or there may just be straight forward sheets that we offer where they are literally just saying what they did and their fatigue levels at that particular time so it's a very quick and dirty way of helping them to understand, you know, sort of work out across the week if they have hot spots for fatigue if they have fatigue that accumulates as the week goes on.”

These key principles were echoed by Early Supported Discharge practitioners, who emphasised the value of guiding the patient but letting them decipher patterns of their fatigue independently; “In ESD we are looking for people to build their own awareness because you can give them the education about fatigue, which is really helpful as a starting point, but as soon as they start to recognise those patterns themselves they will come back to you and say ah, this is starting to make a bit more sense now and this particular activity is making me tired or... That's really helpful. And before getting into all the management strategy, it’s about helping people with pacing and prioritising which is why we often visit routinely.”

Rest breaks were identified as a common coping strategy before and after intervention from a healthcare practitioner. This was considered by one focus group participant in more detail, citing the ambiguity of a patient "rest break". He said; "So the other side of it is getting people to become more responsible for their activity levels and actually thinking about maybe not sleeping but just having short rest periods and changing some of their behaviours. So you do have to go into details. You need to know. If someone is saying I'll have a rest in the afternoon, that could be a ten-minute rest or it could be a three-hour deep sleep so you really need to know the absolute details."

One occupational therapist spoke about how fatigue management often fits into one or several of the stroke survivors' other goals and so sometimes incorporating fatigue management strategies into other active rehabilitation or goal setting activities is more common than creating a unique management programme. They said; "It might not be someone returning to work. It may just be somebody who is just getting active again, and has a goal to go... To get to the shop or you know, whatever their goal is. So you know, it's all about building the goal up with them, so it's all manageable, but they are the ones that are taking responsibility for moving it forward."

Summary

Therapists were actively managing fatigue in their clinical settings however there was clear and significant variation between teams, settings, and practitioners. The subjective element of fatigue management was touched upon and the importance of fully understanding the stroke survivors lived experience of the fatigue and main goals. Barriers to one standardised management method were thought to be the stroke survivors' ability to communicate and engage with the practitioner and varying clinical knowledge and experience.

In the final section of each focus group, participants were asked to consider the evidence presented to them and their own clinical experience. As a group, they suggested ideas which they felt would improve the current post-stroke fatigue management pathway.

Overview: Education focused

The following themes were created as a result of transcription coding to answer the secondary research question **"What could be the future of fatigue management for a stroke survivor population?".** The topic guide questions focused on this study research question followed a presentation of the initial PhD findings. Participants felt fatigue management pathways would be improved with standardised education and training across settings and NHS bands, incorporating terminology stroke survivors understand and engage with. They suggested that this could be adjusted dependent on the patient presentation however a standardised starting point would improve overall care. Three main areas were suggested: standardised resources with the purpose to educate, a fatigue handover between settings across the management pathway and improved training and clinical education opportunities.

Creating an educated baseline: *"patients will feel able to talk"*

The need for all individuals within teams and across the stroke pathway more broadly was seen as a clear priority for future work. One participant who identified as a team lead said; "It definitely is flagged by staff as they come through the team as an area they would like more support with. We identify it as an area rotational and new staff need to know about but don't have many resources to direct them to… we normally direct them to the stroke association leaflet."

Suggestions of resources which could be utilised across the pathway were given by focus group participants. Drawing on previous discussions within focus group 1, one participant said: “Fatigue screening... I think that would be quite a good idea. If only... Because it opens up a conversation doesn't it”. Screening for fatigue would be justifiable because of its common nature and as this individual recalled after this, previous stroke survivor studies in the PhD highlighted that it is an under recognised d topic which patients and their families do not want to bring up in a consultation. This challenge was also mentioned by a participant in focus group 2, considering techniques to increase its visibility; “If we can make it more of an organic thing, a measurable thing consistently measured and seen like a symptom just like weakness hopefully over time itll start getting recognised more and patients will feel able to talk about it because it’s more recognised.”

The Stroke Association leaflet was discussed, considering its benefits and drawbacks. One clinician highlighted that patients who received the leaflet found it useful and so ensuring all patients received this information was a high priority; “We need to check the stroke packs. Yes, I havent looked at them for a while actually. So I guess it’s just everyone knowing about those resources and using them consistently”. However others came forward with a more critical viewpoint, saying: “The thing I’ve always found with the leaflet is it gives a lot of information and that can be hard for some people. We often go in as community and find even family members are so overwhelmed and havent even looked and processed that sort of information”. This expanse of information was also mentioned by a family liaison advisor; “At discharge they do get an awful lot of information.. it won’t just be fatigue. It will be medication and driving and language and that I think applying that knowledge you’ve just been given is quite tricky. The value of this generic advice isn’t that great until you can apply it.”

Following presentation of the TalkStroke survey findings, some participants considered the increase in internet and smartphone technology over the last decade and how this could be utilised for patient education. One individual suggested; “It would be interesting to have a… I don’t know if it exists already but an online package that people could access. Like MS have a package called What is and then the MS symptom. So the basics. We appreciate it needs to be tailored but about how common it is, what stroke survivors typically say, typical advice… the standard ideas around management. It would be quite helpful if people could access this package as a starting point.” Another practitioner in the room added to this idea, recommending including information less readily available but highlighted as important to the patient; “Maybe highlighting things which stroke survivors don’t always think about like the memory and mood. Because not everyone gets early service discharge, we can’t rely on that and most people can access a resource on their home computer.”

Finally, activity diaries were seen as a valuable resource to be used across settings and although currently used by some, an acute care therapist suggested “Starting a patient diary from day dot because we think it’s really acute they are always going to be tired you know?”. The value of sharing resources and adjusting following courses and education was also apparent. Below is one exchange between an acute care and community care therapist.

Participant A *“Do you have an activity diary?”*

Participant B *“I do but since I went on the last course ive adjusted it a bit.”*

Participant A *“I was just wondering if we could share resources and put these things on the shared drive.” Could you share it with me so we have a consistent one? Because if we start fresh, we will have different resources again.”*

Healthcare practitioner support: “*we all need to be on the same page*”

An acute care physiotherapist said “You need to see a range of patients presenting all very differently and maybe describing the symptom very differently. And some its very obvious when you get to the bedside and others you have to be skilful in your questioning and getting their trust and rapport”. This perspective highlighted how experience in a stroke setting and training on history taking could play an important role in achieving a high level of care for stroke survivors experiencing post-stroke fatigue. An occupational therapist also participating in the focus group followed the physiotherapists comment up by considering how clinical staff could become more skilful at person-centred history taking. She said; “I’m thinking cbt or motivational interviewing. Maybe it would help that relationship and help with readiness to self-manage.”

Within the trusts which the focus groups took place in, training was available in a variety of ways. In focus group 1, the band 6 therapist present had received training as part of their competencies; “We do have competencies and lots of area we have to cover but I suppose they differ for different bands and rotational staff and static staff”. However, others in the group also identified the role of healthcare practitioners with a specialist interest, saying; “More training is needed definitely. We are okay because we have some experts in our team but the other disciplines and healthcare professions... we all need to be on the same page.”

In focus group 2, access to training was identified as happening within in service training opportunities and conference attendance which highlights two less standardised education mediums; “We have had access to training in a variety of ways, so we have had in service training and last year at the UK Stroke Forum had a nice lecture”. Community therapists within the team also signposted useful organisations and groups for ongoing training. These do have an important place in providing up to date knowledge, which participants felt is not always the case with competency training. “Through stroke and heart we had a whole load of assessments and training with one of those being post-stroke fatigue. The specialist interest group also does too. So we do get updated. There is a lot of crossover with other neurological patients too so we work very closely with MS patients for example who also suffer from debilitating fatigue so we have quite well-structured assessments and triages for fatigue.”

There was no clear consensus on when training for clinicians would be most useful or pertinent for patient care, with one individual highlighting the different options and potential gaps with each; “It would be good for new staff to come to us with some knowledge so maybe it should be in student curriculums but also you only really learn how it presents when you are on the job. Having the theory is great but I think you need to see the patient in front of you and their very individual symptoms. There is nothing quite like that”.

Handover across pathways: *“well why wasn’t I told that at the last place”*

Being in a focus group setting, the benefit of discussing a clinical problem with healthcare practitioners at different stages of the fatigue management pathway was clear. Differences between teams and settings were highlighted and quick solutions were found as a result of being together in one room. This made participants consider what they felt was a gap in the care pathway and an area that could be improved upon. One therapist considered; “I do think that’s something that’s missing. That continuity between care services. They go one place and get told something then go somewhere else and think well why wasn’t I told that at the last place- nobody has told me that.”

As well as standardising education across clinical settings, the value of resources across all stages of the fatigue management pathway was also discussed within focus group 2; “I was thinking, in acute we see fatigue so much but don’t really document it like in community… so I think a fatigue diary would be great for us too. How much are they sleeping at night. Then they could carry that over in their notes when they go to ESD or community setting. And it is looking back at how you felt two weeks ago and thinking about the differences. It would help you in ESD to target therapy times because you would see from our notes.”

This was affirmed by another participant who suggested use of handover and multidisciplinary team paperwork; “I would say it should be added to the MDT sheet so it’s a recognised problem and then you’ve got your goals to manage it. This could be passed along”

The clarity of note taking was also seen as an area that could be improved, for greater clarity when handover happens either within a team or between settings; “I guess we don’t really write if we cease therapy sessions because of overwhelming fatigue and actually that would be really useful wouldn’t it so actually maybe addressing care more from a fatigue point?”

Patient empowerment: *“there is almost an invisible barrier”*

Participants from multiple disciplines voiced the importance of putting stroke survivor lived experience at the centre of management efforts moving forward. The suggestions mainly revolved around improving engagement with the stroke survivor and their supporters. One participant spoke about normalising fatigue by sharing others experiences and further, the value of resources where the patient and family members could utilise these in their own time. He said; “I think YouTube videos have helped a lot of my patients. Watching the video then reading the comments. It gives them quite a big boost. Nowadays with social media you can access people with different skills and knowledge”. A clinical psychologist present for the first focus group also mentioned using face to face communication to ensure the individuals own values and concerns were considered “More face to face, more talking. And then we can link that with learning whats important to them”.

In focus group 2, a physiotherapist described the dynamics of the acute setting which potentially put an early barrier up for engagement between stroke survivors and sharing of lived experience; “I’m hoping we could have a bit more space for group working. Because in the acute setting you go onto an ortho ward and theres so much banter with six men on a bay saying look I can do this, I can do that. On a stroke ward it’s almost like although they are in beds separated by nothing there is almost an invisible barrier and nobody talks to each other. Maybe in a more secure environment they feel more able to open up.”

A final consideration for future practice was developing already available resources, such as information booklets. Participants suggested adding stroke survivor experiences, ways they understand fatigue and language they use. She also touched upon the benefit of these resources being available for all healthcare practitioners at different stages of the management pathway; “It would be nice if we could have a united leaflet handout about how we should describe fatigue which the gps, doctors, we all used. So everyone uses the same language and patients and families are getting consistent feedback”.

4.5.6 Summary

Four themes were generated, guided by the study research questions:

1. A Common Post-Stroke Problem: Participants felt understanding and approaching post-stroke fatigue in the clinical setting was difficult and depended on various factors including the stroke survivors coping style and contributing variables and co-morbidities.

2. Collaborative Care: The importance of assessing and managing fatigue as an MDT was highlighted, however often this is not the case due to differing levels of knowledge, experience and settings worked in.

3. An advisory role: Participants across all settings described in-depth assessment and education tools used however felt there was not effective hand over between clinicians across the management pathway.

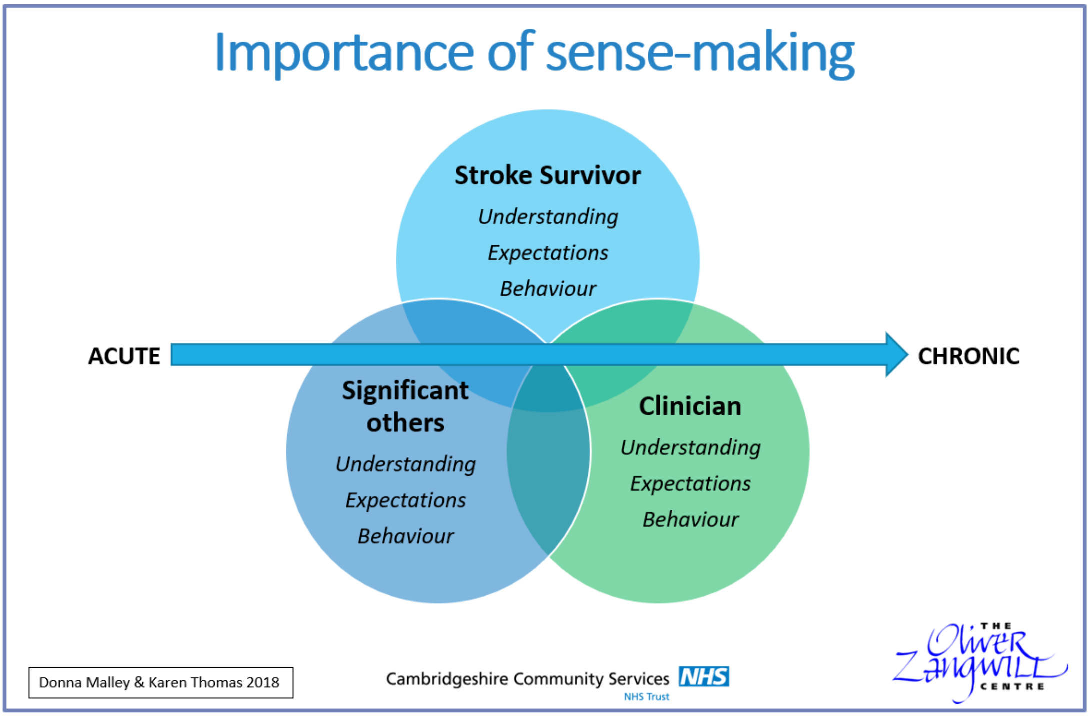
4. Standardised Care: Participants felt fatigue management pathways would be improved with standardised education and training across settings and NHS bands, incorporating terminology stroke survivors understand and engage with. They acknowledged that this could be adjusted dependent on the patient presentation however a standardised starting point would improve overall care.

Section 4: Discussion and conclusions

Lay Summary

In the first three sections of this thesis, the research questions have been introduced and justified, five studies have been explained, and the results have been presented to inform the thesis aim.

In this final section, the findings will be interpreted, compared to research within the field and used together to inform future research directions. Recommendations will also be made which could guide post-stroke fatigue care pathways. As a reminder, three perspectives were sought to understand how fatigue is experienced and made sense of. The three perspectives were the stroke survivor, supporter, and healthcare practitioner. By using the model of sense-making introduced at the beginning of the thesis, it was hoped that the full lived experience could be explored and used to build upon current care pathways.



Section 1. Introduction
Section 2. Methods (by study)
Section 3. Results (by research question)

Section 4. Discussion and conclusions

-Summary of the thesis
-Key findings
-Study limitations

-Thesis Research Question 1: How is Post-Stroke Fatigue perceived by stroke survivors, supporters, and healthcare practitioners?
Overview
Comparison to literature
Comparison between perspectives
Interpretation
Summary

-Thesis Research Question 2: What are the psychometric properties of current measurement scales available for post-stroke fatigue?
Overview
Comparison to literature
Comparison between perspectives
Interpretation
Summary

-Thesis Research Question 3: How do healthcare practitioners assess post-stroke fatigue in clinical practice?
Overview
Comparison to literature
Comparison between perspectives
Interpretation
Summary

-Thesis Research Question 4: How is post-stroke fatigue managed?
Overview
Comparison to literature
Comparison between perspectives
Interpretation
Summary

Conclusions

Chapter 5 - Discussion

5.1 Summary of the thesis

Each of the five studies carried out within this PhD project aimed to improve insight into one or more of the thesis research questions, to answer the thesis aim.

Thesis Aim

To contribute evidence to support improved assessment and management of post-stroke fatigue.

As a reminder, the four constituent research questions were:

Research Question 1: How is Post-Stroke Fatigue perceived by stroke survivors, supporters, and healthcare practitioners?

Research Question 2: What are the psychometric properties of current measurement scales available for post-stroke fatigue?

Research Question 3: How do healthcare practitioners assess post-stroke fatigue in clinical practice?

Research Question 4: How is post-stroke fatigue managed by stroke survivors, supporters, and healthcare practitioners?

The following table summarises each of the thesis studies and their key findings. These will be discussed in greater detail within the research question framework. The chapter will conclude with recommendations and considerations for future practice. I will begin working on these within a clinician and stroke survivor workshop, held in Cambridge during 2020.

5.2 Key findings

Chapter	Key findings
Study 1 – Systematic Search and Literature Review of post-stroke fatigue outcome measures	-Many outcome measures have been developed for fatigue in chronic conditions, however there is still no gold standard outcome measure for post-stroke fatigue when considering psychometric analysis. -Fatigue Severity Scale remains the most used outcome measure by academic journals and researchers studying post-stroke fatigue. The FSS-7 has shown greater reliability and validity in a stroke survivor population than the commonly used 9-point scale.
Study 2 – Thematic analysis of stroke survivor and supporters on TalkStroke online forum	-Novel naturalistic insight provided into stroke survivor and supporter post-stroke fatigue perception and management strategies. -Informal explanations and metaphorical terminology were used by forum users to explain post-stroke fatigue to others. This could guide healthcare information provision. -Stroke survivors and supporters use informal online communities to gain reassurance and support from others in a similar position.
Study 3 – Semi structured interview study of stroke survivors and supporters	-Informal support from family members and community play a key role in stroke survivors' ability to cope with post-stroke fatigue. -The perceived under recognition of post-stroke fatigue may reduce the likelihood of stroke survivors actively seeking help. -The unpredictable and variable nature of fatigue is distressing and acts as a barrier to routine, roles, and personal aspirations.
Study 4 – Online survey of therapist clinical practice with stroke survivors	-Therapists view post-stroke fatigue as a highly debilitating condition, deserving greater attention in training and clinical practice. -Notable variation was found between respondents' definitions and characterisations of post-stroke fatigue, which could suggest discrepancies in education and terminology used in clinical practice. -Therapists use a variety of assessment and management strategies in clinical practice, predominantly focused on self-management.
Study 5 – Focus group study of healthcare practitioners' knowledge and experience	-Approaches to assessment and management varied independently of profession, department and setting. Participants highlighted the effect this may have on continuity of care and standardised approach. -Healthcare practitioners lacked confidence in their evidence-based knowledge due to the lack of easily accessible and high-quality literature. Their practice relied more heavily on experience. -Fatigue was often perceived as a symptom or exacerbator as opposed to a post-stroke condition. This could lead to questioning of the legitimacy of fatigue in some settings. -Stroke survivor lived experience accounts using acceptable terminology should feature in more fatigue resources.

Table 27. A synopsis of the PhD findings by study.

5.3 Strengths and Limitations

5.3.1 Study 1: A Systematic Search and Literature Review of the psychometric properties of fatigue measures used in a stroke survivor population

Limitations associated with the systematic review were outlined in the methods section of the thesis. Medline was the only database that was searched. Limiting data extraction to the Medline database, despite its wide reach and broad biomedical subject area, may have led to studies or scales being missed. Psychometric evaluation was limited to four measures of reliability and validity, namely internal consistency, test-retest reliability, face validity and concurrent validity. Although the four properties chosen were the most reported across the included studies, they are not the only important aspects of psychometric evaluation. Although a second individual carried out the initial search in 2017, only one carried out the full analyses and the review of included studies in 2019.However, at the point of extraction in 2017, agreement between the two reviewers was high and only 2 out of 13 studies were classified differently. The search strategy remained similar to the only published review of fatigue scales used with stroke survivors available (Mead et al, 2007).

5.3.2 Study 2: A thematic analysis of the TalkStroke Forum

This study was the first to explore post-stroke fatigue from the perspective of stroke survivors and supporters through an online forum. Previous qualitative studies have found online forums to constitute a rich and important data source, where patient perspectives are given in open discussion in the absence of a researcher (Jamison et al, 2018). As such, the insights into post-stroke fatigue provided a valuable contribution to the understanding of post-stroke fatigue. A further strength of this study is that it employed a ‘naturalistic’ data collection methodology. Using an archived online forum meant the data collected were created from natural interactions between fellow forum users, rather than from pre-defined or guided discussions with researchers, thus removing participant bias toward the research agenda (De Simoni et al, 2016).

A limitation of the study is that forum users may not be typical of all stroke survivors. The TalkStroke forum users tended to be younger and less severely affected by stroke (De Simoni et al, 2016; Balasooriya-Smeekens et al, 2016). The constructs of post-stroke fatigue derived from the analysis of the forum posts may be representative of the beliefs of a self-selecting group of forum users. Forum users may also not represent all social classes, as De Simoni and colleagues highlighted by identifying over half of the posters as holding professional occupations. Furthermore, the data collected were from archives dated before 2012, and it may be that patient experience has changed since then. Nevertheless, this study remains the most contemporary investigation of the topic within an online community.

By utilising a naturalistic data collection method, it was not possible to identify the underlying cause of the fatigue that participants were discussing on the forum. Further, there is a chance that not all forum posters under the age of 18 were excluded due to several participants having an unknown age.

5.3.3 Study 3: An interview study investigating lived experiences of post-stroke fatigue

Due to the qualitative nature of face to face interviews and the associated time constraints, the generalisability of study findings may be reduced. For example, stroke survivors with expressive dysphasia or severe aphasia may have felt unable to take part in an oral interview study. Initially, it was considered that individuals who had not received primary care input for a significant amount of time may not respond to an interview study invitation. However, following the data collection period it was clear that several individuals in this position felt it was an opportunity to reconnect with their general practice service. By carrying out all interviews myself, there were limitations to the time that could be spent on data collection. The interview structure only allows for a maximum of three individuals (researcher, stroke survivor, supporter) which allowed for thorough questioning but may have limited shared experience discussion. The interviews followed a predefined line of questioning, through the use of a semi-structured topic guide. When coupled with qualitative data collection this may leave the findings open to subjective bias as interpretation was carried out by one researcher only. Also, the semi-structured approach meant the same questions and wording of questions were not always asked, which could limit comparison between participants. However this could also be viewed as a strength, with the less structured conversation enabling participants to guide the direction of the interview themselves. Finally, although qualitative research allows rich data collection, there was not a chance to introduce a follow-up appointment and assess changes over time. Recounting previous experiences has an inherent subjectivity as it depends on how the individual interprets the situation they are discussing.

5.3.4 Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

The use of an online survey allowed respondents to participate from far-reaching geographical locations and removed the influence of an interviewer on responses collected. Nevertheless, the open nature of the majority of the survey questions may have resulted in different interpretations. Also, descriptive data collection is hindered by the inability to question respondents further (Kelley et al, 2003). Though the survey was targeted to specialised therapists and responses were submitted by a diverse demographic of healthcare practitioners across the UK, the response rate was low, at 8%. This could mean that responses were taken primarily by healthcare practitioners with greater interest and knowledge of post-stroke fatigue. Conversely, there were a relatively large number of respondents for a qualitative study, so it is unlikely that important themes were missed or not fully captured. Although physiotherapists and occupational therapists often lead fatigue management programmes, other members of the MDT were not invited to take part which may limit the generalisability of our findings to other healthcare practitioners. This perspective however was gained in Study 5. The qualitative analysis enabled the comprehensive and in-depth analysis of each response. However, the analysis approach precluded any broader generalisations about clinical practice as a whole.

5.3.5 Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

Within each focus group, there were up to 10 participants. This led to a broader range of information being collected. However, it could have led to some individuals feeling under pressure to agree with the dominant viewpoint or unable to voice their ideas (Mansell et al, 2004). It is also possible that these participants do not often get the opportunity to voice their opinions and experiences on the topics being discussed due to the limited literature and fatigue training in clinical settings. So, within the focus groups there were occasions where conversation became hard to control and discussion become unrelated to the questions posed.

Only 2 focus groups were carried out in demographically different areas of the UK; the overall participant number was low. This could lead to a lack of generalisability and certain viewpoints being missed. As noted in the methods section, no General Practitioners, or practice nurses attended either of the two groups. Focus groups also have the inherent disadvantage that more in-depth discussion and analysis into individual experiences cannot take place due to group management and time restraints. However, when considering the aim of the focus group study, talking to a range of healthcare practitioners across settings and professions was felt to be an efficient way to gain views from different settings and health care practitioners that had not necessarily been represented in the qualitative interviews and therapist survey. Finally, I transcribed the 2 focus groups (which were tape recorded) which allowed myself as chief investigator to fully understand and immerse myself in the dataset.

5.4 Research Question 1: How is Post-Stroke Fatigue perceived by stroke survivors, supporters, and healthcare practitioners?

5.4.1 Overview

Each of the studies carried out highlighted how stroke survivors, their supporters and healthcare practitioners working in stroke care perceive and conceptualise fatigue in a multitude of ways. All five studies within the PhD project explored the challenges of defining post-stroke fatigue. Within the studies, healthcare practitioners and stroke survivors demonstrated different approaches to the challenge and showed how their different experiences with the post stroke condition shaped their perceptions and lived experience.

5.4.2 Comparison to relevant literature

Post-stroke fatigue has been reported as one of the largest unmet needs that stroke survivors face (McKevitt et al, 2011). In 1971, McFarland stated that ‘fatigue’ is one of the most used and yet most poorly understood words in the English language (McFarland et al, 1971). The absence of guidance for healthcare practitioners working with this population is reflected in the absence of a standardised approach as was apparent in both the stroke survivor and healthcare practitioner studies within the thesis. Mechanistic work is ongoing, which may further strengthen healthcare practitioner and stroke survivor understanding (Doncker et al, 2018; Kuppuswamy, 2017; Chaudhuri and Behan, 2004). However, due to a lack of definitive answers and a paucity of investigations with strong methodological rigour, it is unsurprising that healthcare practitioner participants felt there was insufficient research addressing post-stroke fatigue.

Analysis of online community content is an under-used research design, despite being found to potentially offer additional insight to traditional interviews (Jamison et al, 2018).

Balasooriya-Smeekens' 2016 study found that residual impairments, including fatigue, affected stroke survivors' return to work. Forum users also discussed a multitude of other difficulties stemming from fatigue including feeling misunderstood and suffering from an 'invisible disability' (Balasooriya-Smeekens et al, 2016). My analysis found forum users referred to fatigue in this way and often referred to the lifestyle adjustments they had needed to make. Recent research has examined factors associated with post-stroke fatigue and found reduced independence in activities of daily living and higher anxiety levels had a direct association with the level of fatigue (Hawkins et al, 2017).

Several of the core characteristics identified by Eilertsens' model of stroke survivors' experiences of post-stroke fatigue resonated with how therapists understood and defined the condition in the national survey (Eilertsen et al, 2013). In both studies, individuals described post-stroke fatigue as an 'invisible disability', related fatigue to an 'abnormal' need to rest and highlighted the lack of understanding and definition regarding post-stroke fatigue. Indeed, the authors felt that the 'medicalisation' identified in this dataset was employed to combat the evident under recognition of post-stroke fatigue.

The extent to which healthcare practitioners legitimise a patient's symptoms can play a significant role in how the individual understands and navigates their condition. This is reflected often in the wider fatigue literature; patients with rheumatoid arthritis reported fatigue as overwhelming, uncontrollable and ignored, and indicate that it rarely forms a treatment target (Hewlett et al, 2005). By contrast, a survey of cancer-specialist therapists found that all professional groups overestimated the effects of fatigue compared to patient reports (Stone et al, 2003), though this may have been affected by the low response rate and degree of specialisation of the respondents involved. The extent to which healthcare practitioners engage with post-stroke fatigue may vary within a team. In the therapist cross-sectional survey, the open-ended question used to investigate the perception of post-stroke fatigue led to exposure of the tensions involved in managing fatigue within a multidisciplinary team. This could indicate that team dynamic may be a particularly pertinent issue.

Both the stroke survivor and the healthcare practitioner studies carried out within the PhD project demonstrated that the lack of a clear definition and understanding hampers the ability to tackle the problem. In particular, self-management strategies are hampered due to stroke survivors and their supporters not perceiving these strategies as legitimate treatments of post-stroke fatigue. This in turn could increase the viewpoint that fatigue is an invisible disability and continue to hinder progress in developing management strategies. In 1977, Bandura considered self-efficacy in the context of healthcare and proposed that it should be thought of as an intermediate step to self-management. Increased self-efficacy has been found to have a positive effect on several outcomes including quality of life, health status, depression, and ability to carry out activities of daily living (ADLs) (Jones et al, 2017). When designing resources aiming to inform stroke survivors and supporters, self-efficacy should be considered for these reasons.

5.4.3 Study Interpretation

Study 2: A thematic analysis of the TalkStroke Forum

For stroke survivors and their supporters, the TalkStroke forum provided legitimacy by fellow users acknowledging the existence of post-stroke fatigue, specifically detailed within the themes *Acceptance and normalisation of Post-Stroke Fatigue: "Part and parcel"* and *Medicalisation of Post-Stroke Fatigue: "A classic post-stroke symptom*". The engagement with others in the online community led to a feeling of understanding and support which forum users were possibly not receiving from other sources. Considering the symbolic interactionist perspective, how users engaged with each other in the forum could have affected how they then made sense of fatigue, their attitudes towards it as a condition and how they mentally or emotionally manage it. For example, detailed in the sub theme *Reassurance: "Exhaustion is normal",* some forum users asked whether fatigue was normal, seeking reassurance and support. Those users who received this affirmation often went on to reassure others in a similar way. The social interactions on the forum seemed to lead to shared meanings of fatigue and sickness behaviour developing.

The homogeneity of forum users' interpretations of post-stroke fatigue was of particular note – within the theme *Tiredness like no other,* the symptoms were repeatedly described as a 'legacy of stroke' and the existence of post-stroke fatigue in the TalkStroke online community was rarely if ever, questioned. In contrast, commonly included in such posts were quotes to the effect of post-stroke fatigue being 'not understood by the medical profession' (SS37). These posts were collated under the sub-theme *Lack of understanding: "It's not understood by them"* As a result, stroke survivors and supporters would seek out and offer their own, often metaphorical, explanations. Understanding and defining fatigue in clinical settings has proved to be a challenge for many decades due to the complex interaction of biological, psychosocial, and psychological elements, which makes understanding and management difficult for clinicians and stroke survivors (Aaronson et al, 1999).

Post-stroke fatigue was considered to be a legitimate problem after stroke in the forum and users continually told others the characteristics they believed separated it from other pathological and non-pathological types of fatigue. Individual perceptions of fatigue varied and were frequently guided by the individual's coping style and acceptance of the presence of fatigue in their day to day life.

The study provided novel insights into the terminology used by stroke survivors and their supporters when talking to others who they perceived to be in the same situation and not in a professional role either as an academic or clinician. Explanations were simple but clearly demonstrated what the forum users believed the cause of the fatigue was, often centred around the brain needing to heal. The terminology used when explaining a clinical problem has been shown to play a critical role in facilitating understanding (Wernick et al, 2016). Wernick and colleagues found that translation of medical terms led to better disease specific understanding whilst also improving the patients' perceived ability to manage their health condition. For this reason, insights into lay conversations could be valuable to healthcare practitioners working in stroke care settings. The explanations and advice given in the TalkStroke forum study could highlight terminology which the users understood and could make sense of. If similar terminology were used during consultations, patient-clinician communication could be improved. Taking a wider cost-benefit perspective, effective patient-clinician communication has been shown to improve outcomes, mood disorders and to reduce the use of health services (Woods et al, 2013).

Study 3: An interview study investigating lived experiences of post-stroke fatigue

Conducting an interview study offered a more detailed view of how stroke survivors and their supporters experience and perceive post-stroke fatigue, providing an opportunity to build upon and compare findings to the TalkStroke forum study. The majority of interview participants could not remember having post-stroke fatigue explained to them by a healthcare practitioner.   This might suggest unstandardised assessment and information giving or use of language with which patients and their families did not engage. Despite the interview participants not recalling post-stroke fatigue information provision, in the therapist survey and focus group studies, healthcare practitioners often said this was standard practice. This suggests a possible disconnect between the two groups. One reason which was mentioned by both the stroke survivor and supporter participants was receiving an expanse of information at one major time point. In many cases this was when discharged from acute settings. Healthcare practitioner information delivery often focuses on clinically defined outcomes which do not always encapsulate complex and diverse long term needs after stroke (Murray et al, 2003). Inappropriately timed information and lack of proactive follow up was found to be a common theme across qualitative studies investigating stroke survivor and caregiver experiences of primary care services in a recent systematic review (Pindus et al, 2018).

Metaphor and description of how the fatigue affected the stroke survivors' lives was often used when the participants were asked how they would describe their experience of fatigue, with examples from the interview study given within the theme *Difficult to articulate: " it's not just normal tiredness"*. Open questions enabled the participants to explain the effect fatigue had on other aspects of their condition, such as exacerbating aphasia, leading to memory difficulties and changeable mood state. For many, the relationship between their most pervasive post stroke co-morbidities had a large effect on how they experienced and explained fatigue to others. For example, participants with aphasia became anxious thinking about social situations which in turn would lead to an onset of fatigue. Within the theme *Role adjustment: "its different for both of us",* supporters commonly worried about the isolation which resulted from these difficulties. The unpredictable and variable nature of fatigue was seen as distressing and a barrier to routine, roles, and personal aspirations with stroke survivors and their supporters reflecting upon this within the theme *Comparison to expectations: "it shouldn't have happened to me"*. Stroke survivors felt that this was not frequently acknowledged by healthcare practitioners, which is discussed in greater depth under the Conclusions section *Perceived under recognition of fatigue*.

Family members and supporters of stroke survivor participants offered insightful explanations of their loved one's fatigue. The majority of stroke survivor participants demonstrated a level of dependence on their spouse, close friends or community within the theme *Outside support: "I don't know what I'd have done without him",* which was attributed to the changeability of post-stroke fatigue. They also highlighted the perceived value of healthcare practitioners engaging with supporters to understand the full lived experience of stroke survivors. Memory and information overload were two terms which often arose. Participants highlighted the benefit of sharing information with more than one person. Providing education to the stroke survivors supporters could enable the supporter figure to explain fatigue in the community setting where a healthcare practitioner was not present. Drawn upon within the theme *Healthcare system complexities: "getting back in touch isn't as easy as you think"*, there was a lack of certainty in the support that their healthcare practitioners could offer and this could have affected the stroke survivors' dependency levels on their supporters.

Interview participants rarely used medicalised language when describing post-stroke fatigue. Instead, as highlighted in the theme *Difficult to articulate: "it's not just tiredness"*, focus was placed on how the participants had adjusted their lifestyle to allow for their fatigue. The need to reconsider personal expectations and what they and their supporters considered to be "normal" was also highlighted within the theme *Comparison to expectations: "it shouldn't have happened to me"*. When attempting to articulate the feeling of fatigue, participants sought reassurance that they were being understood which could have been due to feeling like they had not been understood previously by healthcare practitioners involved in their care.

Lack of certainty was a concept that ran throughout the stroke survivor study themes. Participants were uncertain of the reason for the onset of fatigue, its prognosis, and its longer-term effects. Both stroke survivor and supporter participants displayed hesitancy to approach others with questions if the topic was not raised first. Visible impairments were viewed as more debilitating or worthy of healthcare practitioners' time. The interview study brought the participants internalisation of post-stroke fatigue to the forefront. Some of these ideas are explored further within the Synthesis of Study Findings section in the next chapter.

Sociological Interpretation

A Symbolic Interactionist Perspective

The symbolic interactionist approach allows articulation of the patient experience. Taking this approach enables a deeper analysis of the ‘lived experience’ of post-stroke fatigue. The perspective has been used by many medical researchers, particularly considering key principles of biographical disruption and loss of self. Core texts maintain that inquiry must start from a patient's standpoint or understanding. How illness experience is described within interview studies can be used to frame theoretical conceptions.

A key finding from the interview study was stroke survivors and their supporters made sense of their fatigue by considering their lifestyle and roles within this. We can consider this differently and call their stable set of beliefs, values and attributes the self-concept. An individual's self-concept affects their sense of self, which symbolic interactionists view as an unfolding changing process. When an occupational or societal role is lost, this can cause the individuals' self-concept to change and narrow, along with sources for further construction of their identity. This narrative was told by many of the study participants and could have led to further complexity when trying to deal or cope with the fatigue.

Referring to a new normal or being unsure they would ever be normal again was another common topic in the interviews, offered mostly by the stroke survivor describing their own experience. Charmaz referred to this comparison in wider terms theorising “illness frames a life but occurs within a life” (Charmaz and Belgrave, 2013). She referred to the loss of self which occurs following stroke and how for many, it is not a one-off occurrence. Taking several of the interviewees, for example, they experienced the immediate life-changing effects of the stroke which was the first loss of self. In the weeks after, their major concerns led to further setbacks- often functional or visible deficits. For many of the participants, fatigue only became a core concern once back in the community. The symbolic interactionist theory suggests that there is an identity hierarchy. Each individual’s identity is made up of several different roles and perspectives they have in different settings and situations they find themselves in within their daily life. These identities have different levels of importance to the individual. They may move between these different identities freely dependent on the setting, but each tier of the hierarchy remains the same. The lack of stability in the post-stroke condition and variability of post-stroke fatigue specifically may lead to improvements and then setbacks. Individuals with milder strokes may regain a pre-stroke or new role and then lose this as a result of the fatigue.

This perspective places importance on the role of others through communication, interactions, and social situations. McKenzie and Crouch (2004) believe this core concept is visible in many conditions, taking cancer as their example. Even when an individual is not sick from a societal viewpoint, they may feel deep uncertainty about becoming ill again or dying and often suffer from others disallowing expression of these feelings which the authors felt in turn increases stigmatisation. This theoretical perspective can be related poignantly to the experiences of the participants within this study. This was clear either implicitly through confirmatory language use or explicitly where participants said they felt misunderstood by their family or healthcare practitioners.

The perspective also adds weight to the assumption of under recognition from another angle. Naming and defining a syndrome or condition, such as post-stroke fatigue, helps an individual evaluate and deal with it by setting an outline or boundaries around it. It may legitimise it or shape its meaning. By not using one term, the person’s relationship with the fatigue is adjusted. Renaming can recast its meaning and revise actions. For some, when the term is changed to a more medicalised definition or given a name where there was not one before, it can adjust what they believe is their social identity. This has been shown in Multiple Sclerosis when previously considered ‘clumsiness’ is termed ‘loss of proprioception’ by a trusted healthcare practitioner (Charmaz and Belgrave, 2013). Another phenomenon that also has been shown to exist within post-stroke fatigue management pathways is a lack of recognition of a syndrome or condition (Walsh et al, 2015). This perspective believes that unsurity or lack of a diagnosis can undermine the sufferers' credibility to self as well as their perceived credibility to others. This may explain why several of the interviewees reported not discussing their fatigue with healthcare practitioners or attending support groups after saying it had never been discussed with them previously.

The perspective can also be considered when analysing responses on management and coping strategies. Charmaz suggests that routine is an important part of an individual's life and a source of relative stability. An individual is unlikely to change a routine or habit unless it becomes problematic. (Charmaz and Belgrave, 2013). Their routine must change significantly after the stroke and this can be accepted with more ease. When fatigue becomes chronic and is still highly variable, this lack of set routine could cause issues. Routine changeability was mentioned by several participants when they were asked to recollect their lived experience of fatigue. When considering future effective management programmes, a standardised routine to build upon could be a successful strategy, considering this societal norm.

Study Comparison: TalkStroke Forum Analysis & Interview Study

The interview study provided an opportunity to gain a broader insight into how stroke survivors perceive post-stroke fatigue. Participants in both studies explained that post-stroke fatigue varied in its characteristics when compared to general pathological fatigue. It was viewed as a legitimate problem, adversely affecting their quality of life. The descriptors used for fatigue were predominantly based on its impact on their lives or an explanation provided by a healthcare practitioner. Similar to the TalkStroke forum users, many of the interview participants exhibited different coping styles where they either accepted the fatigue as a 'normal result of stroke' or they tried to fight the fatigue including resisting rest. Stroke survivors perceived as struggling to cope by themselves or their supporter commonly reported feeling unsupported by healthcare practitioners or unsatisfied with support.

The interview study helped gain a greater insight into patient- healthcare practitioner communication and how the dynamic of this professional relationship affected the way individuals made sense of post-stroke fatigue and their willingness to seek support from this source. The perceived under recognition of having an invisible condition also became clear in the interviews, with those viewing post-stroke fatigue as a less legitimate effect of stroke, also reporting they were unlikely to seek professional advice or support during medical consultations.

Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

Therapist respondents to the cross-sectional survey portrayed post-stroke fatigue as a highly debilitating condition, deserving of greater attention. There was notable variation between different therapists' definitions and characterisations of the condition in the contradictory views expressed regarding key features of the condition. There was a lack of clarity among therapists' approaches towards the definition and appropriate use of the terms 'tiredness' and 'fatigue'. Collectively, this suggests that there may be variation in the understanding of post-stroke fatigue between therapists, which could suggest inconsistencies in education and terminology used in clinical practice, perhaps as a result of current training and research.

Linking these findings to the stroke survivor and supporter interviews, several further assertions can be made. Both clinician and patient populations conceptualise and approach post-stroke fatigue in a variety of ways. However, both use terminology aiming to legitimise and medicalise the condition. Bridging the gap between the two populations, to provide education, may reduce the proportion of stroke survivors who view post-stroke fatigue as an unmet need and believe that it is a post-stroke condition which is misunderstood by therapists. Respondents often referred to a lack of confidence in their knowledge of post-stroke fatigue which may make them less likely to feel able to educate their patients. The findings from the two studies also show that coherent unambiguous terminology would be more acceptable to stroke survivors and their supporters than a standardised 'one size fits all' approach which does not fully encapsulate individualised presentations.

Respondents portrayed post-stroke fatigue as a highly debilitating condition that deserved greater attention. Medicalisation was viewed positively, as it reduced the under recognition associated with this 'invisible' condition. Metaphor was used to convey the serious and debilitating nature of post-stroke fatigue in a way that stroke survivors and their supporters would understand. There was a lack of consistency regarding key features of the condition, in particular over terminology use (e.g. ‘tiredness’ or ‘fatigue’), treatment (e.g. the role of exercise), and prognosis (e.g. time taken to ‘recover’).The study found that respondents in the acute setting typically used ‘medicalised’ terminology compared to those working in the community, among whom metaphor and patient expression were more common. Throughout the survey responses from community therapists, metaphor and simplified descriptive language were commonly used to emphasise the impact of post-stroke fatigue on stroke survivors. This was reflective of healthcare practitioners considering patient experience in their clinical thinking around post-stroke fatigue.

Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

The focus group study supported previous findings, highlighting healthcare practitioners feelings of uncertainty over their level of knowledge around post-stroke fatigue and their ability to give an educated explanation to their patients. A particular challenge across all stages of the pathway was the variable presentation of stroke survivors and its effect on several other post-stroke symptoms.

Throughout the study, the importance of understanding post-stroke fatigue from both the healthcare practitioner and stroke survivor perspective became apparent. From my earlier studies, there was an expectation that there would be multiple different responses to the challenge of defining post-stroke fatigue. Individuals working in a community setting with greater clinical experience noticeably took the lead in this section of the focus group in both locations. Similar to the therapist views within the national survey, participants felt strongly that fatigue was a commonly occurring consequence of stroke and should be explained and considered as part of a patients' wider management programme in a consistent manner. Although the importance of using analogies and examples stroke survivors and their supporters could relate to was reiterated in the early stages of the focus groups, both sets of participants felt more could be done to capture the stroke survivor perspective when providing information. Specifically, both groups gave examples from their places of work where different healthcare professions gave different levels of input around fatigue to their patients. Standardising the education given and using language which the patient and their supporters connected with were areas that were reported as needing consideration moving forward.

Focus group participants felt uncomfortable and ill-equipped to discuss post-stroke fatigue with their patients. Several attributed this to a lack of confidence in their understanding of post-stroke fatigue mechanisms. This could be considered as a similar sociological occurrence to the high occurrence of stroke survivors reporting feeling ill-equipped or rating fatigue as a high un-met need. Although research is being carried out and a case definition has been proposed, the participants described the post-stroke fatigue evidence base as being difficult to access and not available enough for the standard healthcare practitioner. The relative absence of fatigue in major Stroke guidelines could contribute to this perceived lack of available information and recommendations.

Supporting the findings from the national therapist survey, the majority of participants recalled personal experiences with patients when defining fatigue. When asked about their knowledge of the evidence in the field, several of the participants reported that they did not think it was readily available and so often did not use the literature to inform their clinical decision making. Taking an experience-based approach, the participants from focus group 1 agreed that one definition could not fully encompass post-stroke fatigue due to individual variation. Understanding how to effectively assess fatigue was viewed as more important than incorporating a standardised definition into clinical practice. This viewpoint was supported during reflections on clinical training. Although the value of ensuring new staff had a baseline knowledge was reiterated, many of the therapists participating in the focus groups asserted that theoretical knowledge needed to be aided by practical experience with patients.

Study Comparison: Therapist Survey & Healthcare Practitioner Focus Group Studies

The focus group study allowed for a larger range of healthcare practitioner experiences and perceptions to be investigated, building upon the descriptive dataset collected in the therapist cross-sectional survey. In both studies, participants described post-stroke fatigue in a variety of different ways, rarely being informed by definitions reported in the literature and instead guided by experience and members of the multidisciplinary team with a specialist interest in post-stroke fatigue. The focus group participants gave further insight into perceived reasoning for this variation, citing settings worked in, professional role and the individualised presentation of post-stroke fatigue. Across both studies and all professional roles represented, the common nature of post-stroke fatigue was well known and often used as a way to normalise the condition to patients. The focus group study also allowed for discussion around how post-stroke fatigue fits into the ‘package of symptoms’ many patients experience following a stroke. Focus group participants gave valuable insight into how fatigue is rarely viewed as a condition in its own right. Instead, healthcare practitioners reported incorporating information provision and management into a wider rehabilitation or medical plan. Although this approach is suggestive of a holistic patient-centred approach, it could mean that fatigue is missed or information provision isn’t sufficient for the stroke survivor and their supporters.

Comparison between perspectives: Stroke survivors and healthcare practitioners

Considering the Importance of Sense-Making model, it is important to compare the similarities and differences in how stroke survivors, their supporters and healthcare practitioners perceive and explain post-stroke fatigue. Four different study designs were utilised, to gain a more in depth picture.

Across the three groups investigated, similar to the published literature, a variety of different explanations and experiences were reported. Stroke survivor and supporter definitions of post-stroke fatigue were predominantly informed by their lived experiences, whilst healthcare practitioners based their definitions on a combination of the literature and patient presentations. All groups felt they could be better informed and were unsure of the pathophysiological causes of post-stroke fatigue. Healthcare practitioners often offered a variety of systematic approaches to the challenge, for example ‘there is usually a primary (i.e., central or disease-specific) mechanism and a secondary (loss of fitness/function, mood/sleep related etc) mechanism at work’. Many of the interview participants could not remember having fatigue explained to them, and the terminology used could possibly have contributed to this issue. One characteristic of post-stroke fatigue was mentioned by stroke survivors, supporters, and healthcare practitioners of various professions; its common nature following stroke. The use of the term ‘normal’ was also often used, however this was perceived in different ways by stroke survivors specifically. Some stroke survivors said they would ‘never feel normal again’ and often portrayed other characteristics of an individual fighting or not coping well with the fatigue. Others justified adjusting their lifestyles by saying they needed to ‘adapt to the new normal now’. This demonstrates how different individuals interpret different terms, justifying why individualised knowledge transfer is important.

5.4.4 Summary

Considering the findings from all four studies, the multi-faceted presentation of fatigue presents challenges to stroke survivors, their supporters and healthcare practitioners. Stroke survivors considered fatigue as a condition that had various symptoms, triggers and alleviators affecting their lifestyle through its pervasiveness and unpredictability. In contrast, healthcare practitioners often viewed fatigue as an exacerbator of other post-stroke conditions, and part of a broader range of symptoms. Information provision and explanations reflected this. Although it was viewed as important to incorporate fatigue management into care pathways, fatigue was often made sense of by considering its medical attributes before its broader patient impact. This was seen as important by healthcare practitioners to increase the legitimacy of the condition. Metaphor was used by stroke survivors, supporters, and healthcare practitioners within explanations to aid patient understanding. Stroke survivor lived experience was employed by all, to varying degrees.

5.5 Research Question 2: What are the psychometric properties of current measurement scales available for post-stroke fatigue?

5.5.1 Overview

To investigate this research question, a systematic review was carried out into the psychometric properties of measures evaluating fatigue in a stroke population. By assessing each scales' psychometric properties, different measures of reliability and validity could be evaluated. Condition specific measures and broader neurological fatigue measures were searched for, to give a broader picture of the use and psychometric properties of each fatigue scale evaluated in a stroke population.

Considering across study psychometric property evaluation, there was a large amount of variety in scoring of reliability which could have resulted from the differences in methodological rigour. Face validity was not consistently reported on within the selected studies, despite previous reviews highlighting the wording of several scale items as a potential issue for stroke survivors. Almost all studies however compared scale results to another measure or population to check validity. Due to there being little guidance on the most used or psychometrically sound scales for neurological populations, the comparison measures varied which makes reaching a conclusion difficult. Overall however, this aspect of validity was rated moderate to high within most studies which could be due to the overlap of items used and the constructs being measured by each scale. Due to the small number of studies assessing each included measure, it is not possible to make sound conclusions on each individual scale. Further investigation is required.

5.5.2 Comparison to relevant literature

Despite several studies developing new condition-specific scales, there is still no recommended patient reported outcome measure or measurement scale for post-stroke fatigue within national and international clinical guidelines. Multi-dimensional general fatigue scales are commonly used to assess fatigue in the literature and although this is often noted as a limitation, it does allow comparison with related neurological and chronic conditions (Drummond et al, 2017).

Use of measurement outcome scales and tools alone has not been found to accurately reflect the experience of suffering a stroke, due to the complex and variable nature of post-stroke recovery (Mayo et al, 1999). Given that this study was published over twenty years ago, this limitation with objective measurement has been acknowledged for some time. Much like wider stroke recovery, this thesis has shown the multi-faceted nature of post-stroke fatigue.

The thesis has also touched upon the complexities of perception when measuring a condition like fatigue. The information derived from self-report outcome measures will depend on the questions being asked, the scale developers conceptualisation and the patients understanding of the question being asked (Dittner et al, 2004).

O'Connell and colleagues considered the difficulties faced by healthcare practitioners when trying to measure and understand the complex nature of lives post stroke. Their study identified that organised care for this vulnerable population was lacking and several of the losses and frustrations stroke survivors were feeling had not been addressed by their healthcare providers (O'Connell et al, 2001). O'Connell's' study once again points to the challenges associated with a focused approach to outcome measurement for debilitating, subjective conditions such as post-stroke fatigue.

Suggestions have been made by some research teams that a combination of measures addressing different aspects of post-stroke conditions may be the answer to this problem. However the expensive and time-consuming nature of this approach in clinical settings would mean it is impractical (Murray et al, 2009). Further to this, post-stroke outcome measures which aim to assess multiple dimensions, do not always cover fatigue, such as the Fatigue Impact Scale. Despite the consistent evidence that fatigue does have a broad and debilitating impact on stroke survivors, this scale fails to assess it.

Similar to the challenge of defining fatigue, the unresolved issue in condition specific fatigue measurement is the creation of items which encapsulate all aspects of the subjective fatigue experience. Skogestad and colleagues found that scales which are currently used assess over 45 different constructs, however many are confusing or unrelated to stroke survivors experiencing fatigue (Skogestad et al, 2019). Further, the number of studies using Rasch Analysis highlights a change in how measures and scales are being evaluated (Hobart et al, 2013; Lundgren-Nilsson et al, 2014; Mairesse and Neu, 2016) .

5.5.3 Interpretation

Due to a lack of consistent psychometric analysis across studies, it was not possible to directly compare each of the included measures. Interpretation of the reliability and validity scores also varied, with authors using the term “excellent” to describe the same numerical figure as another study describing the score as “adequate”. From reviewing the literature on scoring recommendations when using Cronbach’s a and Intraclass Correlation Coefficient (ICC), guidance on condition-specific interpretation is not easy to find, when looking in clinical guidance documents. Another source of variation was found when analysing the different constructs of fatigue that were measured. The Fatigue Severity Scale (FSS) has been psychometrically analysed most often in neurological populations and remains the most used scale to measure post-stroke fatigue in the field (Skogestad et al, 2019). However, its face validity has been questioned as well as its specificity to stroke (Mead et al, 2008). Leegard and colleagues adapted the FSS by removing Items 1 and 2. Prior to the 2 items being removed, the scale demonstrated unacceptable high mean-square validity, in turn reducing the measures overall validity. The investigators carried out face to face interviews with stroke survivors to assess the measure’s face validity Leegard et al, 2011). However, despite the removal of items 1 and 2, the FSS lacks a validated cut-off score which means the measure cannot yet identify clinically significant fatigue after stroke (Drummond et al, 2017).

The FSS is one of the most widely used fatigue scales across chronic conditions and so one possible reason for it being the most commonly assessed scale may be for comparability between conditions (Hewlett et al, 2011). In a field where gold-standard assessment and management options are still not clear, learning from other chronic and neurological conditions could be advantageous. Few of the included studies accounted for the multidimensional nature of post-stroke fatigue which may be due to the high number of scales used in the literature which are not condition specific.

5.5.4 Stroke Survivor and Supporter Perspective

No posts within the forum analysis study included terms pertaining to measurement of fatigue or named specific scales or outcome measures. Within the interview study, although no questions were asked specifically about measurement and assessment, very few participants remembered receiving a verbal explanation or self-reported scale to quantify their post-stroke fatigue. For those who had received healthcare practitioner input regarding post-stroke fatigue, it was given either in the form of information provision or was a topic raised as a result of the stroke survivor or their supporter asking about it first. These insights highlight the perception of stroke survivors that the approaches taken to fatigue assessment and measurement are limited and unstandardised.

5.5.5 Healthcare Practitioner Perspective

Data collected from the cross-sectional therapist survey gave insights into barriers and facilitators when using measurement scales in the clinical setting. For those who answered that they *would not use a scale*, barriers included being unaware of scales as a measurement tool, a scale not being indicated following clinical reasoning and a lack of resources or time.

This supports the concerns regarding face validity within our findings and the two major reviews carried out on post-stroke fatigue measures (Mead et al, 2007; Skogestad et al, 2019).

5.5.6 Summary

To investigate this research question, a systematic search and review was carried out into the psychometric properties of measures evaluating fatigue in a stroke population. By assessing each scales' psychometric properties, different measures of reliability and validity could be evaluated. Several condition-specific measures have been developed since the last major published review of fatigue measurement in stroke (Mead et al, 2007). The Fatigue Severity Scale is now the most evaluated scale in the literature. Despite this, my systematic search and review of the literature highlighted concerns with its concurrent validity and no clear evidence that the previously highlighted issue of face validity has been sufficiently addressed. When considering each psychometric property, the Fatigue Assessment Scale scored highest consistently across studies (Cronbach's a= 0.91), followed closely by the FACIT-Fatigue Scale (Cronbach's a= 0.95). The Fatigue Assessment Scale and Fatigue Severity Scale-7 were found to be the most appropriate scales for use with stroke survivors out of the currently available fatigue scale options, when considering the consistency in scoring across the validity and reliability measures evaluated within and between studies When this data was considered alongside the other thesis studies, it became clear that use of measurement scales is not standardised practice in clinical settings. This was reported to be for a variety of reasons by healthcare practitioners including applicability to all patients and the lack of clear guidance on the use of objective measures in national and international guidelines as well as the broader literature.

These were the 2 most commonly used scales by therapists who participated in the online survey, apart from the Visual Analogue Scale. They were also the most cited in the literature review. Individuals who used a scale to assess post-stroke fatigue in practice cited the benefits as providing an objective baseline to which they could then refer back to. The variable and multi-faceted nature of post-stroke fatigue means that use of a scale or outcome measure in isolation would not be suitable in clinical practice. However, the benefits described above make the use of scales valuable within academic studies researching management interventions. In the absence of a recommended definition and clear mechanism of fatigue, focusing on the content of scales and high-quality studies investigating the impact of post-stroke fatigue seems to be important moving forwards. Readily available information on the constructs different scales measure and how they should be interpreted could help inform researchers and healthcare practitioners inform their choices.

5.6 Research Question 3: How do healthcare practitioners assess post-stroke fatigue in clinical practice?

5.6.1 Overview

Effective management of a condition relies on a thorough assessment which accurately reflects the problems reported by patients (Dittner et al, 2004). Excluding wider neurological reviews and measurement evaluation studies, few papers have investigated post-stroke fatigue assessment. The cross-sectional survey and healthcare practitioner focus groups asked targeted questions on the topic of fatigue assessment. Although measurement scales are used in clinical practice, the healthcare practitioner studies indicated that subjective history taking to understand the impact of fatigue on the patient was more common and seen to be more valuable than using a measurement scale alone. The key themes from the stroke survivor and supporter studies were reviewed to ensure their perspectives were also incorporated.

5.6.2 Comparison to relevant literature

Assessing an inherently subjective condition will always pose a challenge to healthcare practitioners and researchers alike. How an individual perceives their symptoms and conceptualises sick behaviour will affect the assessment parameters (Hunt and McEwen, 1980). Respondents in Kaplan and Baron-Epels' study investigating health evaluation methods were more likely to report tiredness and pain if they identified as having sub-optimal health. Understanding how individuals evaluate their own health status helps with the conceptual development of being able to assess subjective health (Kaplan and Baron-Epel, 2003).

National and international guidelines are developed to work towards standardised care for common medical conditions. Guidance has been created on the assessment of fatigue in Multiple Sclerosis and Cancer which in turn informs clinical training and patient education resources (Berger et al, 2015; Braley and Chervin, 2010). The absence of evidence on post-stroke fatigue assessment means no guidelines to date have suggested best practice methods. It is however a requirement that health and social care needs are assessed and reviewed following stroke at regular interviews (Department of Health, 2005; Duncan et al, 2005). With post-stroke fatigue being reported as a common un-met need, it arguably should form part of these reviews (McKevitt et al, 2011; Mullis et al, 2019).

However, in conditions such as fatigue and pain which are multi-factorial and subjective in nature, Piper and colleagues suggest that there are barriers hindering translation of major guidelines in oncology care (Piper et al, 2013). Similar to post-stroke fatigue, as shown in the stroke survivor and supporter interview study, cancer patients often do not initiate discussion about fatigue and this may be due to the belief that it is an inevitable part of the condition

(Borneman et al, 2007). Further barriers to implementation were suggested by Borneman and colleagues which arise from the fact that routinely used documentation does not include a reminder to document the symptom’s presence, severity, or management. Without this, despite presence in guidelines, consistent assessment and documentation cannot be assumed (Piper et al, 2013).

Although there are complexities associated with subjective assessment including challenges with creating and carrying out replicable measurement, asking a patient to self-report their fatigue level at standardised time intervals has been shown to be an effective assessment strategy (Mock et al, 2007). The NICE Guidelines for assessing Myalgic Encephalomyelitis (ME) suggest a full history should be taken with focus placed on exacerbators and alleviators of the individuals’ fatigue, supplemented by a battery of blood tests and an assessment of psychological wellbeing (NICE Guidelines, 2007). The multi-factorial approach taken allows all potential causes of fatigue to be considered. However, the approach suggested for ME may be less feasible in routine clinical settings due to the time needed.

In the focus group study, participants cited time pressures as a reason fatigue was either not assessed or often not assessed in a standardised manner. Lerdal and colleagues attempted to categorise the fatigue experience to aid assessment, citing five main areas which encompass post-stroke fatigue. These were intensity, quality, timing, fluctuation, and long-term trajectory (Lerdal et al, 2011). Finding a middle way between open subjective history taking and objective measurement which encompasses the main characteristics of post-stroke fatigue could optimise assessment of fatigue.

5.6.3 Interpretation of thesis findings related to how post-stroke fatigue is assessed

Within the therapist survey and healthcare practitioner focus group studies, participants discussed the importance of understanding the individual being assessed and the complexity of carrying out post-stroke fatigue assessments due to the variability in patient presentation. It was unclear whether stroke survivors were fully aware of when fatigue assessment was taking place but there was agreement that it was important for the stroke survivor and their supporter to be given information to inform their understanding. This would then help them identify and adapt self-management strategies.

Within the interview study, open-ended questions regarding fatigue were asked. Several of these may replicate those asked within a clinical assessment. When answering these questions, the stroke survivor gave a broad account covering different areas of their life such as mood, routine, and social interaction. When therapists and healthcare practitioners were asked about assessment, their responses revolved around their professional competencies and perspective. This meant that their assessment approach could miss key aspects of the patients' story, reducing the ability to deliver patient-centred care. Although both healthcare practitioners and stroke survivors considered the effect of post-stroke fatigue on activities of daily living over a 24-hour period the participants in the therapist cross-sectional survey and healthcare practitioner focus groups focused their assessment on improving tasks within the daytime or improving the quality of rest. In contrast, stroke survivor participants focused upon the negative effect fatigue had on their sense of self, routine and role in the home and community.

These data provide an insight into how the clinical assessment of post-stroke fatigue is carried out by UK therapists. The disparity between studies reporting on this topic in the literature and current clinical practice has been further demonstrated by the findings of the therapist cross-sectional survey study. Validated scales, commonly used by academics as an outcome measure, were reported to be used by therapists but often not as their standardised practice. The majority of therapists who responded to the survey took a subjective history of their patients for post-stroke fatigue, with some then following this up with an objective outcome measure often to quantify a baseline. Many therapists mentioned the perceived benefits of subjective assessment when justifying the choice not to use a scale. Subjective assessment, through taking a detailed history from the stroke survivor, was reported to provide a more holistic view of the patients' fatigue than a scale, whilst also giving scope for further questioning. There were variations between clinical settings, with many acute therapists citing the use of a scale as impractical and not in the patients' best interests at that point in their recovery. Throughout responses to survey questions 7 and 8, the influence of the therapists' clinical team was clear. Many respondents justified their chosen answer by explaining that it was the standardised practice in the setting they worked.

The therapist survey design allowed for the collection of descriptive data responses on several aspects of post-stroke fatigue assessment; subjective history taking, measurement use, and the associated clinical reasoning. The responses suggested that in the absence of clinical guidelines, therapists most often assess fatigue through subjective questioning. Patient-reported outcome measures were used by some, mostly to provide an associated objective measure alongside the findings from taking a more detailed history to assess baseline and progression. Although responses demonstrated a knowledge of the cognitive effects of post-stroke fatigue, adjustment of assessment to allow for these associated factors was rarely mentioned. Similar to the questions asked to ascertain therapist understanding, there were marked differences between assessment styles of acute and community-based respondents.

In the therapist survey, tensions between individuals in different professions were noted. As a result, a secondary research question within the healthcare practitioner focus group study was centred around the role of the individual within post-stroke fatigue assessment and management. The responses to this set of questions revealed an underlying ambiguity surrounding who led fatigue programmes within the multidisciplinary team. It was important to consider the effect both a clear leader and a lack of leader may have on assessment and management. On the one hand, in some settings, all healthcare practitioners considered fatigue in relation to their profession. In contrast, in a team where there is a named role or individual who handles fatigued patients, the remainder of the multidisciplinary team may not discuss fatigue with their patients or factor it into their clinical decision making. Both of these scenarios could lead to less effective assessment and variation in clinical practice. Another area of variation was between settings. Both the therapist survey and the healthcare practitioner focus group found that different approaches were taken in the acute and community settings. This discrepancy is not unique to post-stroke fatigue or indeed stroke care (Higgs et al, 2001). The fast-paced environment in an acute ward leads to time pressures and different prioritisation within the multi-disciplinary team to that which is found in a community setting. These are important factors to consider and may provide some answers as to why the variation found in the two studies may exist.

The focus group study supported the findings from the national therapist survey. Measurement preferences were not standardised, even within the same trust. The chosen tool or approach was often guided by a healthcare practitioner with an interest in post-stroke fatigue and their choice as supported by reading or experience. The patient-specific variability of fatigue was voiced as a challenge and this was echoed across settings. Clinicians who tried a scale as a result of reading evidence in the field recalled that although the literature supported the use of the chosen PROM, they were not suited to their specific clinical setting. This suggests that there is still a disconnect between the scales that have been developed and evaluated in the current literature and clinical practice. The most agreed-upon measurement tool was a simple VAS scale which was adapted to each patient and incorporated aspects of an activity or fatigue diary.

5.6.4 Stroke Survivor and Supporter Perspective

Although assessment of fatigue was not directly investigated within the TalkStroke forum analysis or the stroke survivor and supporter interview study, the themes arising from these studies can still be considered to gain a broader insight into some of the barriers and complexities when creating and evaluating fatigue assessment strategies. When the stroke survivor participants discussed the experience and effect of fatigue, they often recounted stories or events personal to them to contextualise the condition. In contrast, the two healthcare practitioner studies suggest that those in medical roles consider fatigue as a symptom or exacerbator as opposed to a condition in its own right. This may mean that the approach taken to assessment and education which healthcare practitioners take may contrast with or not meet the needs of stroke survivors and their families who are most concerned about the ways fatigue affects their activities of daily living and social interactions. Understanding discrepancies between these approaches is valuable as fatigue has been reported as an unmet need in several large studies (McKevitt et al, 2011; Mullis et al, 2019).

Another complexity which healthcare practitioners may unknowingly be faced with is the perceived under recognition associated with fatigue. In the stroke survivor studies reported on in this thesis, often the participants felt unable to approach a clinician about their fatigue which may be due to the lack of legitimacy individuals with invisible deficits may perceive. This could be exacerbated by healthcare practitioners who consider post-stroke fatigue as a trigger, barrier or aggravator of other post-stroke complications and adjust their treatment accordingly, but without discussing fatigue with the stroke survivor or their supporters.

5.6.5 Summary

The findings presented in the online therapist survey provide an insight into how UK-based therapists carry out clinical assessment of post-stroke fatigue . The disparity between studies reporting on the psychometric properties of fatigue scales in the literature and current clinical practice has been further supported by the findings of this thesis. Validated scales, commonly used by academics as an outcome measure, were reported to be used by therapists but often not as their standardised practice. The majority of therapists who responded to the survey took a subjective history of their patients for post-stroke fatigue, with some then following this up with an objective outcome measure often used to quantify a baseline. Many therapists mentioned the perceived benefits of carrying out a short patient interview to assess fatigue when justifying the choice to not use a scale. This form of subjective assessment was reported to provide a more holistic view of the patients' fatigue than a scale, whilst also providing scope for further questioning. Variation appeared between settings, with many acute therapists citing the use of a scale as impractical and not in the patients' best interests. Throughout responses to the survey, the influence of the therapists’ clinical team was clear. Many responses justified their chosen answer by explaining that it was the standardised practice in the setting where they worked.

Assessment is an important part of patient care. The above studies have highlighted there is a differing focus between academics and clinicians. Over the past decade, there has been a sharp increase in studies developing and evaluating fatigue scales and measures. However, in the clinical setting, measurement tools are used as an addition to extensive subjective assessment. Linking a clinically sound assessment strategy to appropriate management interventions must be a priority to progress patient care in this field, independent of professional practice or setting.

5.7 Research Question 4: How is post-stroke fatigue managed by stroke survivors, supporters, and healthcare practitioners?

5.7.1 Overview

Although literature has focused on the management of fatigue after stroke, little research has been conducted of sufficient quality to inform recommendations. For this reason, management of post-stroke fatigue was investigated across 4 of the thesis studies. Stroke survivor, supporter and healthcare practitioner perspectives were considered as well as the perceived value of experienced management interventions. The studies found that accessible and clear information provision was valued across all studies, when used alongside patient specific assessment to inform adaptable management strategies applicable to the patient.

5.7.2 Comparison to relevant literature

The reported lack of medical consensus over approaches to post-stroke fatigue reflects an absence of a standardised approach to post-stroke fatigue in the medical setting. Ambiguity extends to understanding of how fatigue after stroke occurs and what factors influence its onset and longevity. This holds true in literature exploring fatigue management with Wu's

2015 Cochrane review being the only review to seek answers to whether any intervention reduces the proportion of people with fatigue, fatigue severity or both (Wu et al, 2015). Self-management strategies were most commonly reported by therapist respondents to the online survey and frequently raised within the focus group study. A large amount of literature has investigated the benefits and application of this management strategy. It is a core management strategy employed by health systems globally (Lorig and Holman, 2003). Lorig and Holman concluded that self-management is especially important following stroke due to it being a lifelong condition mostly without healthcare practitioner input. Effective self-management was found to lead to the patient exhibiting greater knowledge of their condition, behaviour, self-efficacy, and health status (Barlow, 2002).

Within the thesis all three groups studied (stroke survivors, supporters, and healthcare practitioners), demonstrated a knowledge or awareness of the difficulties faced by healthcare services providing on-going psychological and rehabilitation support. This has been well documented in the literature, audits and the news showing that increasing pressures on the NHS and associated resources are compounding the problem (O’Connell et al, 2001). O’Connell and colleagues noted the importance of informative discharge education materials, the need to consider the stroke survivors’ dependency on their supporters and the wider impacts of social isolation. The same issues emerged from this thesis, suggesting that despite awareness of the issues for at least 19 years, they are still to be adequately addressed (O’Connell et al, 2001).

5.7.3 Interpretation

5.7.3.1 Comparison between perspectives: Stroke Survivors, Supporters and Healthcare Practitioners

Several important similarities and differences between these three perspectives became clear in the five thesis studies. Many of the similarities were identified in the Talkstroke forum analysis. Each subsequent study reinforced the findings that stroke survivors, their supporters and healthcare practitioners all shared a desire to better understand the aetiology and symptoms of post-stroke fatigue . Stroke survivors and their supporters expected this information to come from healthcare practitioners and healthcare practitioners expected to be informed through evidence and training. A lack of appropriate and effective information giving was highlighted in all the studies. Stroke survivors and healthcare practitioners viewed fatigue as a variable condition and this was shown in the management strategies employed. In both the stroke survivor and healthcare practitioner-focused studies, a wide variety of strategies were employed by participants to cope with fatigue. This further emphasises the lack of a standardised approach to post-stroke fatigue care. It was unclear if the participants were aware of the variety of strategies but despite this, there was a shared hope for proven management strategies in the future.

Differences arose when approaches to management were considered. Within the stroke survivor and supporter studies, the tendency to accept or fight the fatigue was often raised. The symbolic interactionist analysis further highlighted this. Healthcare practitioners considered the different aspects of the stroke survivors' lifestyle however rarely discussed the importance of considering whether they were accepting or fighting the fatigue when putting together a management plan. Within the interview study, stroke survivors often used terms such as ‘us’ or ‘we’ as opposed to ‘I’, symbolising the importance of their supporters.

In contrast, the inclusion of supporters was not raised by all healthcare practitioner participants. Many of the supporter participants said they felt the stroke survivors’ priorities and emotional concerns were not fully considered when discussing fatigue which could result from the proposed symptom management profession-specific approach often taken by healthcare practitioners.

5.7.3.2 Study Interpretation

Study 2: A thematic analysis of the TalkStroke Forum

Captured within the theme *Involvement of healthcare practitioners*, forum users consulted healthcare practitioners regarding post-stroke fatigue and more general stroke-related concerns, however reported variable satisfaction with the advice and support they were given. This does demonstrate that healthcare practitioners are still often the first point of reference with healthcare concerns and so clinicians must be confident in education and management. The majority of discussion regarding management on the forum offered advice to the recipient on self-management tools and coping mechanisms including ‘listening to the body’ within the theme *Mental vs physical recovery* and activity pacing within the theme *Lifestyle Changes*.

Many of the forum users were looking for reassurance that their experiences were normal or seeking out other stroke survivors' experiences. This supports the TalkStroke Forum and Interview Study findings for research question 1 that stroke survivors and their supporters often want to seek out information and affirmation from others in the same position as them. Healthcare practitioners were seen as a valuable source of education whilst peer support was seen as a way of legitimisation.

Study 3: An interview study investigating lived experiences of post-stroke fatigue

Within the theme *Effective Information Giving: "they were really helpful"*, stroke survivors and their supporters expressed a desire to be able to contact their primary care clinicians for education or advice. Those who expressed most gratitude for the support they had received mentioned continuous care and positive relationships with their clinicians. These two areas of discussion were captured within the themes *Healthcare System Complexities: "getting back in touch isn't as easy as you think*", and *Clinician Understanding: "They showed me. That was good"*. Often when asked if the stroke survivor had reached out to a primary care practitioner to discuss their fatigue they expressed feeling like it was inappropriate and not being "worthy" or being a "burden".. This may be a reason for fatigue being reported as an un-met need which is not being addressed (McKevitt et al, 2011). This is discussed in further detail in the next chapter, within the under recognition of post-stroke fatigue section.

Fatigue seemed to be an after-effect present from the time of stroke but often not fully considered until the stroke survivor was trying to re-adjust to life after discharge and reintegrate into society. Self-management strategies, found within the themes *Individualised Goal Setting: you've got to go for it… nobody is going to help ya*" and *Routine: "you can't put your life on hold*", such as routine planning, adjustment, and goal setting were common successful approaches. The emotional impact of the variable and unexpected onset of post-stroke fatigue was clear for many participants with some feeling unable to leave the house alone in case they could not find a place to rest. Often this was discussed on a trivial basis without fully realising the impact this was having on the person and their families' quality of life.

Attitude towards the fatigue and presence of supportive family were viewed as two of the most important factors associated with coping, with education and follow-up care viewed as lacking currently in clinical practice. The themes *A Clear Pathway: "sometimes you have questions"* and *Enhanced understanding of the patient: "they haven't been through it"* support these assertions.

Within the interview study, the opportunity was taken to gain an insight into the perceived role of healthcare practitioners within fatigue management. Supporting the viewpoint within the TalkStroke forum analysis, participants looked to their primary care practitioners as a source of education and initial advice. No participants reported carrying out healthcare practitioner-led management for their fatigue. This could, however, signify a lack of understanding of what a fatigue management programme is.

Study Comparison: TalkStroke Forum Analysis & Interview Study

Building upon a novel research design without researcher influence in the stroke survivor and supporter interview study enabled greater insight to be gained. The interview study supported many of the findings from the forum analysis, despite the increased researcher involvement. In both studies, participants reported mixed value of healthcare practitioner involvement. The perceived value of the interaction was largely due to the clarity of communication and relevance to the individual stroke survivor. Practitioners who were able to explain fatigue in a way that was clear and original, such as using a model of the brain or illustrative language, were valued highly.

Management strategies often were centred around the stroke survivor and supporters' ability to adjust their lifestyle to allow for the stroke survivor to still feel like they were progressing and had a purpose. The symbolic interactionist theory supports this finding, suggesting that individuals who perceive their 'self' as valuable to loved ones and their community cope better with chronic conditions and hardships. In both the Talkstroke forum analysis and interview study, the supporter voice was important. There were excerpts from posts and transcripts where the stroke survivor was not aware they were managing or progressing until their supporter reminded them of the steps forward they had taken. As the literature supports, there are clear links between post stroke depression, anxiety, and fatigue. Supporters played a clear role in motivating stroke survivors to set goals, find purpose in day to day life and reminding them of the positive changes they had made. Especially in the interview study, this was seen as vital to stroke survivors when managing the variability of post-stroke fatigue.

Study 4: A cross sectional survey of UK therapists experience with post-stroke fatigue

The survey study provided an initial descriptive data set on management strategies in answer to survey question 9; "*What treatment techniques have you employed in helping stroke survivors manage their fatigue and which were the most useful?*". Responses highlighted the vast variation in treatment and management techniques being employed in clinical practice by therapists. There was a clear follow on between topics therapists discussed within their subjective assessment and those they went on to target with management strategies. This is valuable to know, as despite there being widespread variation in practice, a standardised approach could be taken and then built upon to ensure patient-centred care was achieved.

The strategies that were described were mostly broad and generic, for example, education and pacing within the theme *Daily Routine*. Despite respondents considering cognitive strategies and implications of the fatigue in the theme *Cognitive Impact*, few respondents indicated that they would adjust the strategies listed depending on the individual in question although the survey design did not enable us to know if this was an implicit assumption made by the therapists who took part. Another rarely mentioned area that has featured heavily throughout the thesis was input from supporters or care-givers. With the time availability of healthcare practitioners in the current economic and political climate, utilising informal caregivers could be a valuable tool.

Study 5: A healthcare practitioner focus group study investigating post-stroke fatigue management

Within the theme Creating an educated baseline: “patients will feel able to talk”, differences were highlighted between clinical decision-making dependent on professional role and setting within the focus group study. This finding supports research carried out by the Institute of Medicine in 2001 (Institute of Medicine, 2001). Clinicians working in acute settings were found to have a reactive approach, focusing on curing or improving conditions by considering the symptoms displayed. In contrast, many of the management and treatment strategies carried out by community clinicians were found to be planned and considered proactively. There was a higher level of team working and many management programmes had a goal of the patient self-managing by the point of discharge, noted in the theme *Self-management: “looking to build their own awareness”*. These are important differences to consider when looking to develop management strategies which are acceptable for stroke survivors expressing a fatigue related unmet need but also acceptable for the healthcare practitioner tasked with carrying it out.

Although this question could be answered differently for each setting considered, there were key ideas put forward by both focus groups. Clinical approaches that were taken varied independently of the clinicians’ profession, department, and setting. An experience-based approach was taken more readily than being guided by evidence, however participants felt that further clinical education was a priority going forward in the theme *Creating an educated baseline: “patients will feel able to talk”*. In the acute setting fatigue was perceived as a symptom or exacerbator of other post-stroke complications that affected clinical decision-making, however this was not the case in all settings and participants voiced needing *“to all be on the same page”* in the theme *Healthcare practitioner support*. There was unanimous consensus across the groups, within the theme *Patient empowerment: “there is almost an invisible barrier”,* that stroke survivors and supporters lived experience should feature more in educational resources.

Education was viewed as an area that could be improved, both for healthcare practitioners and stroke survivors and their families. Currently, there is no consensus on how post-stroke fatigue should be explained, assessed, or managed and having a standardised toolkit or information booklet could help improve this by *Creating a standardised baseline: “patients will feel able to talk”*. Following the presentation on findings and interpretation of the first 4 thesis studies, several practitioners who were present said that they would find it useful to be able to use language and explanations which stroke survivors use to explain their fatigue, with different ideas forming the theme *Patient empowerment: “there is almost an invisible barrier”*. There was not a clear consensus on one management strategy in alleviating fatigue which supports the view that post-stroke fatigue is multidimensional and patient-specific. This focus group study highlighted the importance of clinical staff needing to be confident in their knowledge and clinical decision making.

Many similarities can be drawn between the method healthcare practitioners took to assessment and management of post-stroke fatigue. *Multi-factorial subjective assessment, information giving and self-management* strategies were employed, irrespective of profession. Fatigue management was often centred around the 24 hour picture, especially in the acute setting. Management was guided by experience due to the lack of clear advice in guideline documents and often was agreed upon and developed within a team. This alongside a lack of standardised clinician education leads to further variation in practice.

The areas of management which participants in the healthcare practitioner focus groups felt needed further development were utilising stroke survivor case studies to aid patient education, a standard baseline education for healthcare practitioners across the stroke care pathway and tools to facilitate carry over between clinical settings.

Study Comparison: Therapist Survey & Healthcare Practitioner Focus Groups

Healthcare practitioner experiences assessing and managing post-stroke fatigue in the clinical setting have received limited attention in the literature despite how important this evidence base is to inform ongoing intervention development and evaluation. Across both studies, there were no clear approaches to management that were adopted by a majority of clinicians. Information provision was seen as valuable to the patient by all healthcare practitioners, however the focus group study design allowed for further interrogation of this concept. Healthcare practitioners participating in the focus groups viewed information provision as important to help the patient begin to understand their own fatigue early on in the rehabilitation process. This was implemented more consistently by clinicians in the community setting as opposed to acute care wards, however was considered of value and something that all healthcare practitioners participating in the study strived towards.

Healthcare practitioners were found to lack confidence in consistently incorporating post-stroke fatigue into their clinical reasoning, which they believed was due to a perceived lack of communication within multi-disciplinary teams and the associated literature not being easily accessible. This was due both to the limited presence of post-stroke fatigue in clinical guidelines and the small evidence base when compared to other post-stroke conditions. Varied leadership and ‘ownership’ of training, education, and management of post-stroke fatigue dependent on setting and team were evident in both the therapist national survey and healthcare practitioner focus groups.

In both focus groups, participants in acute, sub-acute and community settings found the study enlightening and valuable in considering how their colleagues differed in their approaches and clinical treatment plans. Possible strategies to reduce this variation were discussed, such as consistent handovers and multidisciplinary team discussion independent of profession. Participants in the therapist survey did not have the opportunity to engage in this reflection on reasons for variations in practice.

Comparison between stroke survivor and healthcare practitioner perspectives

Three key similarities emerged, independent of study or population. These were the importance of understanding the patients lived experience, the need for an individualised approach to management and the value of effective information provision. Stroke survivors and their supporters recalled negative experiences with healthcare practitioners who they perceived not fully understanding their difficulties. The value supporters can have in gaining a full picture of how the fatigue presents in day to day life was also emphasised, with many of the interview study participants using pronouns such as ‘us’ and ‘we’.

Although the use of metaphor, acronym and patient-friendly terminology was apparent in both healthcare practitioner studies, following the presentation at each focus group of the TalkStroke Forum analysis and the stroke survivor and supporter interview study, participants noted a need to incorporate lived experience more in assessment and education of fatigue. This was echoed by stroke survivors and supporters throughout, with many feeling a disconnect between themselves and the healthcare practitioners they engaged with. Utilising a symbolic interactionist perspective highlighted the importance of healthcare services supporting the stroke survivor and supporter to understand and deal with the wider changes in lifestyle, role, and meaning of self as well as fatigue specific changes.

Healthcare practitioners also felt that thorough assessment was vital when creating a fatigue management plan, to ‘link that with learning whats important to them’, ensuring better patient practitioner communication and individualised care based off their experience. However, despite saying this was important, few examples were given of situations where this had been executed successfully. Within the TalkStroke forum analysis and interview study, most individuals who were coping well with their fatigue discussed the use of self-management strategies and taking a trial and error approach which led to them understanding their own body. The most common strategies listed by therapists when asked about management interventions were also largely self-management related. One way to achieve this might be by supporting stroke survivors with e-resources or remotely by providing the appropriate education to allow them to take this approach. However, the opinion and advice given by healthcare practitioners were still highly regarded by stroke survivors and their supporters and many wished to receive face to face contact where possible.

The final area that was seen as important across all studies was effective information provision. Healthcare practitioners, stroke survivors and their supporters felt they could be better informed and that information exchange should form the basis of ongoing fatigue management. Ideas about what effective information provision means varied, with benefits and disadvantages of verbal and written communication discussed.

5.7.4 Summary

All of the thesis studies focused on different elements of the management of post-stroke fatigue by encapsulating lived experience, objective measurement for future interventions and current management by healthcare practitioners. Similar to lived experience and assessment, a variety of management techniques were being carried out by stroke survivors and their supporters independently and by healthcare practitioners across the care pathway. There was a lack of consensus on what the most effective ways to manage fatigue were and how best to support stroke survivors.

Section 4 Part 2: Conclusions

Conclusions

-Implications for Research

-Implications and recommendations for clinical practice

-Thesis recommendations

-Creation of a lived experience resource

-Conclusion

Chapter 6 – Conclusions

6.1 Synthesis of Study Findings

6.1.1 Definition of post-stroke fatigue

The working definition that has been used throughout this thesis is; 'Since their stroke, the patient has experienced fatigue, a lack of energy, or an increased need to rest every day or nearly every day. This fatigue has led to difficulty taking part in everyday activities' (Lynch et al, 2006). Lynch's case definition remains the only validated definition of post-stroke fatigue. However, considering the data collected and discussed in this thesis, it is concluded that the definition cannot be generalised to all post-stroke fatigue sufferers. This body of work has added weight to the perspective that post-stroke fatigue is a multidimensional biopsychosocial condition.

If Lynch's case definition is used, it is suggested that it is supplemented with additional information provision or considerations depending on who is interpreting it. The studies within this thesis have highlighted that stroke survivors, healthcare practitioners and academics perceive and interpret post-stroke fatigue information in different ways. For example, the interview study suggested that stroke survivors and their supporters want information that is tailored to them. A definition that does not include all the biopsychosocial elements of the lived experience of post-stroke fatigue would make this challenging. If a stroke survivor or supporter was told Lynch's definition they may struggle to see its relevance to their own lived experience. This may reflect negatively on the healthcare practitioner and be perceived as a breakdown of communication. In contrast, healthcare practitioners often want structured medicalised explanations, to give them confidence in their understanding and ability to treat their patients.

This means that the two groups are looking for different outcomes from a post-stroke fatigue definition or pathophysiological explanation.

Despite attempts to create an operative definition for fatigue and more specifically post-stroke fatigue for many decades, the findings in this thesis supports the view that this may not be possible. Improving stroke survivor and supporter understanding is a priority due to the high numbers of individuals who report post-stroke fatigue as an unmet need (McKevitt et al, 2011; Mullis et al, 2019). In clinical settings, it is paramount that the lived experience of stroke survivors is incorporated into education programmes and resources. The use of simple terminology such as "the brain needs time to heal" has been shown to legitimise the presence of post-stroke fatigue and reduce the perceived under recognition attached to the debilitating post-stroke condition. Depending on what aspect of fatigue is being assessed or studied, simple explanation can then be individualised. National guidelines in other common debilitating conditions support this (Berger et al, 2019; Multiple Sclerosis Clinical Practice, 1998). If the stroke survivor and their supporter form an understanding from the information they are given by a healthcare practitioner, they will be able to consider effective management and coping strategies. The role of the healthcare practitioner is thus to guide them on this journey. In summary, in the absence of another validated definition, Lynch's definition remains the most appropriate current post-stroke fatigue definition. However, it should be supplemented with additional information or assessment relevant to the individual being communicated with.

6.1.2 Under recognition of post-stroke fatigue

Throughout the thesis, the idea of under recognition has arisen; reported by stroke survivors, supporters, healthcare practitioners and also voiced as a concern in academia.

Under the *Enhanced Understanding of the Patient* theme in the stroke survivor interview study and the *Involving Healthcare Practitioners* theme in the forum analysis study, stroke survivors described healthcare practitioners displaying either a lack of interest; “GP doesn’t really have any opinion on my tiredness”, or a perceived lack of knowledge of the individuals lived experience of fatigue; “they haven’t been through it”. When asked if their GP or healthcare practitioner had discussed fatigue with them, the majority of participants responded by saying they either had not, or it was a conversation they did not remember. Participants in both the forum analysis study and interview study described an unwillingness to raise their concerns as they felt there were more important issues after stroke. This perception, coupled with a lack of regular consultation on post-stroke fatigue could lead to an increased under recognition of post-stroke fatigue. This would support McKevitt et al’s 2011 study findings, concluding that fatigue is the most common unmet need after stroke.

When considering this from the healthcare practitioner perspective, in the cross-sectional survey study and the focus group study, interestingly healthcare practitioner participants reported reduced confidence in their fatigue clinical knowledge. As a result, fatigue was described as not being consistently discussed within clinical teams or with patients and this in turn could increase the perception of fatigue being a less important or talked about post-stroke symptom. The Symbolic Interactionist perspective supports this hypothesis, suggesting that healthcare practitioner recognition and labelling would contribute to normalisation of the topic of fatigue as a post-stroke condition.

To target this reduced recognition of post-stroke fatigue, in the interview study stroke survivors consistently described how important their closest supporters had been when helping them adapt to and accept ongoing fatigue. Other participants demonstrated caring deeply about their loved ones by becoming upset or distressed when they felt they were becoming a burden. This was a particular issue when they felt their loved ones did not recognise the effect fatigue was having or if they did not take it seriously. This arose in the *Role Adjustment* theme within the interview study, with one participant saying her children did not openly show any concern, dismissing discussion of her fatigue experiences.

6.1.3 Medicalisation of post-stroke fatigue

The concept of medicalisation has also arisen through this thesis, more prominently within the studies investigating the healthcare practitioner perspective. However, similar to definition and under recognition of post-stroke fatigue, there are implications on all stages of the fatigue management pathway.

Medicalisation as a concept has been widely investigated and considered by social scientists to refer to the processes by which social phenomena come to be perceived and treated as illnesses or diseases (Ballard & Elston, 2006). Previously, medical practice took a reactive doctor led approach with doctors predominantly deciding the legitimacy of conditions and in doing so were the main arbitrators of medicalisation (Gray et al, 2015). Over the last two decades, care and assessment has shifted and now often puts the patient at the forefront. This thesis has shown however that this, and the concept of medicalisation more broadly, is multi-faceted due to its complexity.

Although therapists in the cross-sectional online survey often attempted to apply a framework and medicalised language in the absence of an existing formal classification, a specific pathological process was not identified within the study responses. As Dittner considered in 2004, a lack of unambiguous evidence that has widespread acceptance by the scientific community may lead to debate over a conditions legitimacy despite its clear associations with ill health and disability (Dittner et al, 2004). As the findings from the survey suggested, and the stroke survivor interviews and forum analysis supported, medicalisation of fatigue could be reassuring and enabling due to healthcare practitioners giving the common post-stroke condition a name and legitimacy.

6.1.4 Patient-Practitioner Communication

This thesis project has demonstrated the importance of clear informative patient-practitioner communication. As has been discussed in this section, the complex and multi-factorial lived experience associated with post-stroke fatigue has been evidenced to make communication between different groups challenging.

In the TalkStroke forum analysis study, a key theme was the medicalisation of post-stroke fatigue. Within this, the sub-themes demonstrated the different ways individuals made sense of fatigue. For example, some explained it to others by comparing to other conditions, others spoke about how “all-consuming” it was and focused on the effects it had on their every day life and others posted about how they perceived healthcare practitioners did not understand the fatigue. This thesis has demonstrated that there could be many reasons for this, and it likely centres around the many different ways individuals experience and cope with fatigue.

In contrast, healthcare practitioners participating in the cross-sectional survey and focus group study demonstrated high variability in how post-stroke fatigue is defined, assessed and managed. This lack of standardisation and differentiation in clinical approach likely carries across to how health care practitioners are communicating with their patients and supporters.

In addition, during the focus group study several other areas of disparity arose. Several participants exhibited a lack of self-confidence in their clinical understanding of fatigue, which meant they often chose not to discuss it with patients so they were not giving false or incorrect information. Setting also had an influence. Acute care clinicians who participated in the focus group study explained how due to the complex and constantly changeable presentations they were working with, issues such as fatigue were often viewed as a low priority in the clinical team and so were not regularly discussed.

6.2 Implications for research

The thesis has highlighted methodological weaknesses and sparsity of post-stroke fatigue focused investigations in the literature. Although interest in the field has grown considerably in the last decade, the focus has not been placed on the lived experience of stroke survivors. Qualitative investigations that have been carried out have not yet influenced national and international guidelines. Although learning from fatigue in other conditions is important, creating an informed understanding of how post-stroke fatigue affects an individual's sense of self, feelings of legitimacy and perceptions of the world must be a priority for researchers moving forward to reduce the number of stroke survivors reporting fatigue as an unmet need.

Targeted research into the causes of post-stroke fatigue must remain ongoing as these investigations directly advise healthcare practitioners and researchers developing assessment and management strategies. Currently, the majority of the mechanistic articles to have been published are based on untested hypotheses rather than empirical evidence. Although testing theory is an important step to guide the direction of future studies, it does mean that current findings cannot be used to advise healthcare practitioners on information provision or clinical decision making.

In the therapist cross-sectional survey and healthcare practitioner focus group, participants mentioned the merit of national and international guidelines to guide clinical practice. Post-stroke fatigue still features a minimal amount in many major stroke guidelines, which needs to change. The current situation is likely to reflect the low number of methodologically sound studies, across the field, that have been completed with large sample sizes. Inclusion of post-stroke fatigue in national UK guidelines would increase the condition's visibility as a common post-stroke problem and also start to reduce the lack of standardisation across the care pathway.

6.3 Implications for clinical practice

The array of conceptualisation and approaches to managing post-stroke fatigue identified in this thesis highlights the need for better evidence on how to optimise the recovery process for stroke survivors with fatigue and their supporters. Within the TalkStroke Forum analysis, the construct of post-stroke fatigue as a 'tiredness like no other' that 'everybody seems to suffer with' suggested a requirement for a consistent understanding and explanation to be provided by healthcare practitioners, reducing the reliance of sufferers to seek informal explanations and reassurance from within the stroke community and other informal support services. Capturing the most prevalent beliefs in the initial exploratory studies within the thesis, largely that fatigue is 'due to the brain healing' also enables assessment of the gap between clinical and community knowledge. The insights gained could inform the education required to better inform survivors.

The importance placed on informal support from supporters and loved ones in the stroke survivor and supporter interview study highlighted the value these individuals may have when considering reducing the burden on primary care services. Discussion and information provision around post-stroke fatigue should become more frequent in clinical settings, and this study suggests that it should also include stroke survivors supporters where appropriate.

Throughout all the studies, an underlying theme emerged. Stroke survivors, supporters and healthcare practitioners all viewed post-stroke fatigue as a perceived unknown, primarily due to the limited availability of information and accessible support. Better understanding by health care practitioners of lay beliefs may help them support their patients and work towards standardised baseline information provision. Another problem identified which compounds the view that fatigue is an unknown entity or invisible disability, is the perceived under recognition which is often associated with the condition. Many stroke survivors and supporters did not feel able to start a conversation about their fatigue in clinical settings. This has been found across the fatigue literature and an approach similar to the oncology discipline may help improve this perception. Oncology healthcare practitioners are taught to ask their patients a simple fatigue question frequently throughout their care.

The thesis findings suggest that part of the problem may be that healthcare practitioners explain and manage post-stroke fatigue in different ways. By drawing on the three perspectives focused on within this thesis, guidance could be developed to support clinicians assessing and educating their patients on post-stroke fatigue, at all stages of the care pathway. This task would be made easier by a strong evidence-based framework for explaining and assessing post-stroke fatigue in clinical practice and if there was a widely adopted definition of post-stroke fatigue. There is now a proliferation of fatigue measurement scales, which all measure different aspects of the fatigue experience alongside numerous constructs (Skogestad et al, 2019). As such, it is important that healthcare practitioners ensure they choose a scale that measures the right aspect of fatigue for their purposes (Dittner et al, 2004). Research into causes and management of post-stroke fatigue remains a priority.

6.3.1 The below recommendations could be considered in response to the thesis findings:

1. **Increased visibility of post-stroke fatigue**

   Stroke survivors, supporters and healthcare practitioners all described the presence of under recognition of post-stroke fatigue; "an invisible disability". To reduce the presence of under recognition in the clinical setting, simple changes could be introduced to stimulate discussion. When other common post-stroke problems are assessed, post-stroke fatigue could also be reviewed as part of standard practice. This could be on assessment forms across settings, handover paperwork where applicable and on multidisciplinary team meeting agendas. Having educational "toolkits" displayed in clinical spaces could help increase the presence of post-stroke fatigue cues in the workplace. To reassure post-stroke fatigue sufferers, its 'common' and 'normal' nature could be reinforced by incorporating stroke survivor lived experience accounts into educational resources. Within the interview study, participants felt this was currently missing. Many stroke survivors and supporters expressed not wanting to hassle their primary care practitioners about fatigue, despite the significant impact it had on their quality of life. If it were discussed more openly within clinical consultations, more individuals experiencing fatigue may receive support.

2. **Improved continuity of care and communications between settings**

   Stroke survivors and their family members often described a feeling of isolation or inability to “get back into the system” following discharge from active care. Active care is here defined as an acute stay, early service discharge team input or following a period of community care. Stroke survivors and their supporters felt uncertain over who they could approach regarding their fatigue and how they would contact them. This could be improved by signposting becoming standard practice at the point of discharge either with a phone number for the team where care was ending or to a secondary appropriate service such as a stroke group. Within the focus group study, healthcare practitioners suggested the addition of a prompt or question about post-stroke fatigue on handover forms between care settings. They believed this would ensure that fatigue was not missed, no matter the stroke survivor’s route along the pathway.

3. **Lived experience terminology and education**

   A recurring theme within the thesis was the importance and value of using language and resources which the stroke survivor and their supporter or care-giver could understand and connect with. The forum analysis provided a useful insight into the terminology used by stroke survivors when explaining their fatigue to others who were not necessarily from a medical or academic background. Many participants who were interviewed did not remember post-stroke fatigue being explained to them by a healthcare practitioner, although within the focus group study most attendees reported that fatigue information provision was a standardised practice. This could mean that giving patients information at the point of discharge is ineffective or could mean that stroke survivors and their supporters were not fully making sense of the information received on fatigue.

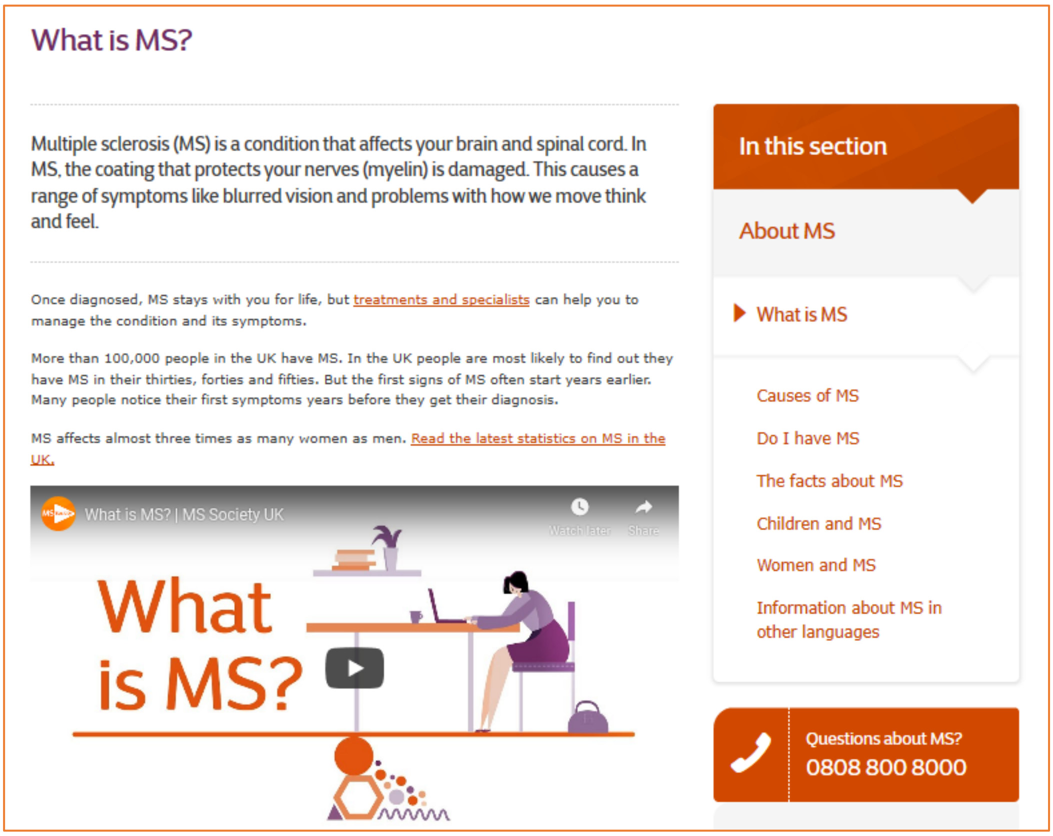
A secondary benefit of incorporating stroke survivor accounts into information provision could be a reduction in the perception that healthcare practitioners do not fully understand the stroke survivors experience. Often in the interview study, participants recalled their healthcare practitioner not fully understanding. This could help with the perceived disconnect between patient and clinician. It could also help stroke survivors explain fatigue to their supporters and improve the legitimisation of the condition.

4. Standardised ‘baseline’ information provision and resources

Information provision was viewed as an important aspect of post-stroke fatigue management by healthcare practitioners, stroke survivors, and supporters. Although post-stroke fatigue is variable in its presentation, having ‘baseline’ resources could begin to standardise care and improve healthcare practitioners confidence when discussing post-stroke fatigue with their patients during consultations:

For healthcare practitioners: A training resource, preferably online or in the form of an e-learning package. All healthcare practitioners working with stroke survivors could complete basic training alongside core competencies, independent of the NHS Band they are in or setting they work within.

For stroke survivors and supporters: Incorporating stroke survivor and supporter accounts into standardised booklets given to all stroke survivors at the point of hospital discharge. Further detailed information could be provided in an online e-resource similar to the ‘What is MS?’, seen below.



What is MS?

Multiple sclerosis (MS) is a condition that affects your brain and spinal cord. In MS, the coating that protects your nerves (myelin) is damaged. This causes a range of symptoms like blurred vision and problems with how we move think and feel.

Once diagnosed, MS stays with you for life, but treatments and specialists can help you to manage the condition and its symptoms.

More than 100,000 people in the UK have MS. In the UK people are most likely to find out they have MS in their thirties, forties and fifties. But the first signs of MS often start years earlier. Many people notice their first symptoms years before they get their diagnosis.

MS affects almost three times as many women as men. Read the latest statistics on MS in the UK.

6.4 Creation of a guidance resource

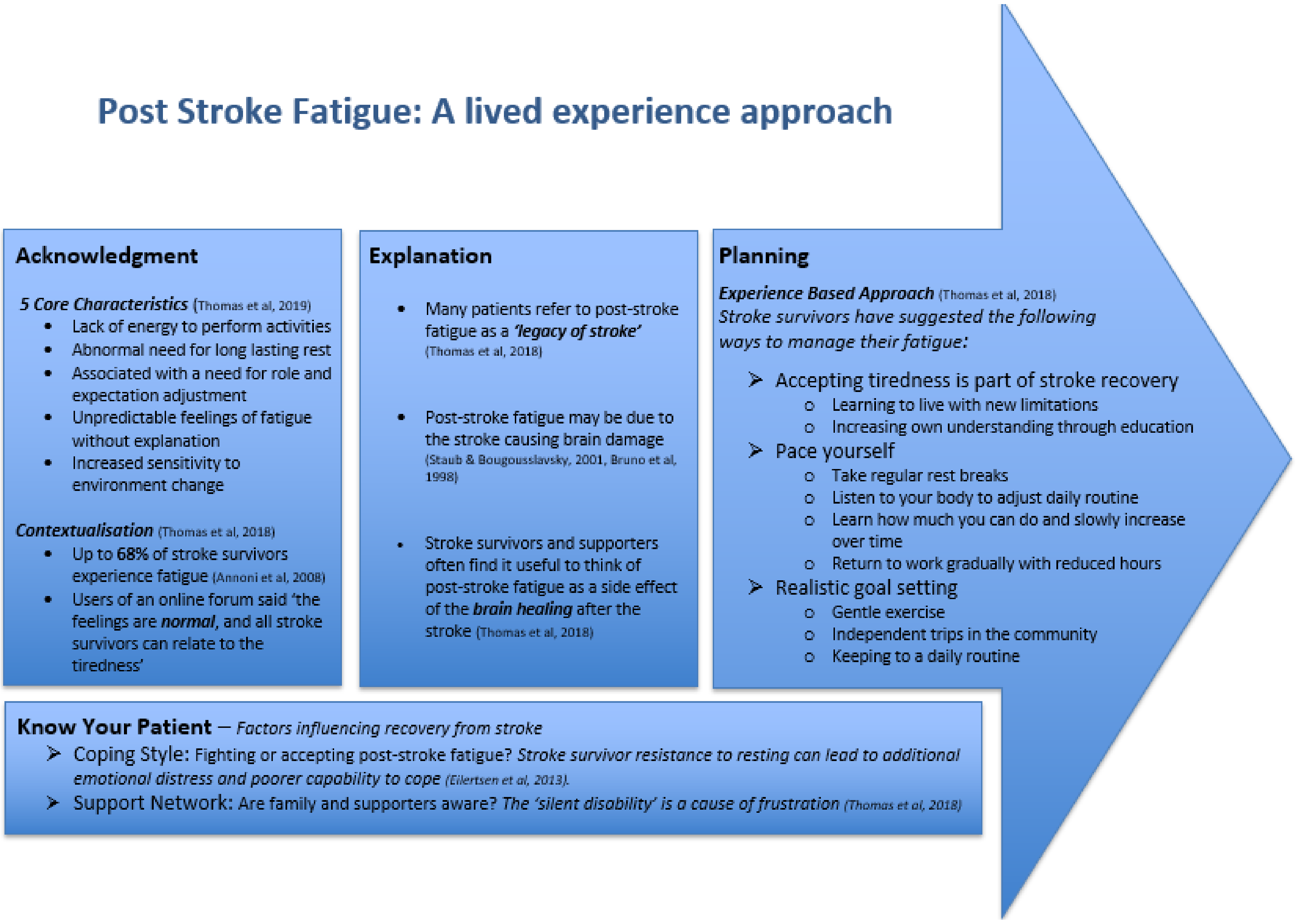
Following analysis of the TalkStroke forum study, a resource was drafted with the aim of assisting healthcare practitioners to incorporate stroke survivors' lived experience into their clinical practice (Figure 18, Page 263). Following discussion at the Society of Academic Primary Care Conference in 2018, it became clear that primary care clinicians wanted a tool or resource that was simplistic, easy to follow and could be adapted. Throughout the thesis project, there has been an evident disconnect between clinical practice and academia. This could be for several reasons.

Within the healthcare practitioner focus groups, participants felt that evidence was not easily accessible or signposted within clinical guidelines or on major resource sites such as the Stroke Association.

Following completion of all five studies making up the PhD thesis, the resource was adjusted and shown to healthcare practitioners at conferences and within in-service training sessions to receive feedback.

The response was overwhelmingly positive and healthcare practitioners from various disciplines felt it was a resource that would be utilised within their teams if it were available to them. Practitioners gave feedback on aesthetic value, purpose, and readability.

One drawback of the resource is its format. Throughout the thesis, the advantage of using e-resources has become clear. For this reason, a justified next step to improve understanding and management of post-stroke fatigue following completion of this thesis would be the development of a sense-making focused tool or training module for healthcare practitioners and stroke survivors which could be made readily accessible.



Post Stroke Fatigue: A lived experience approach

Acknowledgment

5 Core Characteristics (Thomas et al, 2019)

- Lack of energy to perform activities
- Abnormal need for long lasting rest
- Associated with a need for role and expectation adjustment
- Unpredictable feelings of fatigue without explanation
- Increased sensitivity to environment change

Contextualisation (Thomas et al, 2018)

- Up to **68%** of stroke survivors experience fatigue (Annoni et al, 2008)
- Users of an online forum said 'the feelings are ***normal***, and all stroke survivors can relate to the tiredness'

Explanation

- Many patients refer to post-stroke fatigue as a ***'legacy of stroke'*** (Thomas et al, 2018)
- Post-stroke fatigue may be due to the stroke causing brain damage (Staub & Bougousslavsky, 2001, Bruno et al, 1998)
- Stroke survivors and supporters often find it useful to think of post-stroke fatigue as a side effect of the ***brain healing*** after the stroke (Thomas et al, 2018)

Planning

Experience Based Approach (Thomas et al, 2018)
Stroke survivors have suggested the following ways to manage their fatigue:

- Accepting tiredness is part of stroke recovery
  - Learning to live with new limitations
  - Increasing own understanding through education
- Pace yourself
  - Take regular rest breaks
  - Listen to your body to adjust daily routine
  - Learn how much you can do and slowly increase over time
  - Return to work gradually with reduced hours
- Realistic goal setting
  - Gentle exercise
  - Independent trips in the community
  - Keeping to a daily routine

Know Your Patient – *Factors influencing recovery from stroke*

- Coping Style: Fighting or accepting post-stroke fatigue? *Stroke survivor resistance to resting can lead to additional emotional distress and poorer capability to cope* (*Eilertsen et al, 2013*).
- Support Network: Are family and supporters aware? *The 'silent disability' is a cause of frustration* (*Thomas et al, 2018*)

Figure 18. A lived experience resource developed following Study 2, a TalkStroke forum analysis.

6.4 Conclusion

Several aspects of post-stroke fatigue care need further development and presence within national and international clinical practice guidelines. Within this thesis, the variation and lack of standardisation across the pathway already apparent in the fatigue literature, has been further exhibited. Moving forward, a greater emphasis must be placed on post-stroke fatigue education for healthcare practitioners, stroke survivors, and their supporters. This should be informed by high-quality studies investigating fatigue assessment and management. Incorporating lived experience into development and evaluation projects could provide valuable insights that are necessary to guide best practice and improve stroke survivors' quality of life, when experiencing fatigue.

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