



**Experiences of fatigue in
long-term health conditions
- what patients say**

SUMMARY

Fatigue is one of the most challenging and problematic aspects of chronic health conditions – and also one of the most tricky to treat. One reason why fatigue is so difficult to measure, and by extension manage, is the variability in how different patients experience fatigue. In order to delve deeper into this patient experience, we conducted a small-scale feasibility study into:

- **how patients experience their fatigue**
- **living with fatigue: how patients manage**
- **treatments: patients' concerns and considerations**

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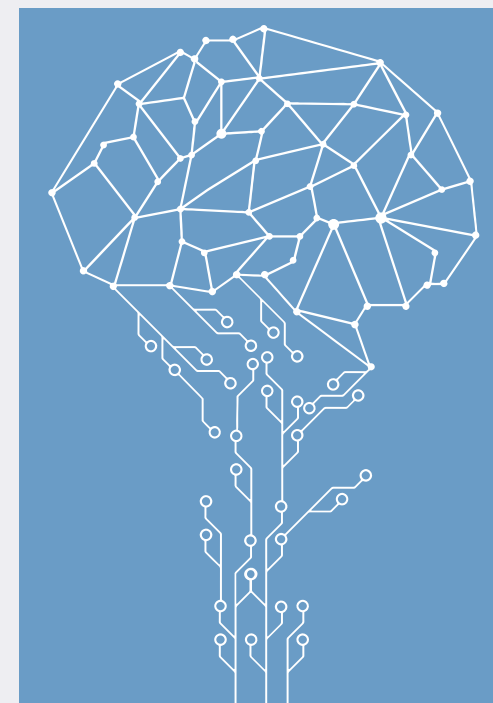
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CHAPTER 1

What is fatigue and why is it challenging to treat?

In scientific reports, fatigue has been described as whole-body exhaustion not proportional to recent activity, and often accompanied by decreased strength, weariness, sleepiness, and irritability, and cognitive problems [1,2]. These experiences often interfere with daily activities and social activities, and contribute to distress and low quality of life [3].

Persistent fatigue is recognised as a clinically important, but subjective and clinically non-specific part of living with chronic long-term illness [4]. Fatigue is associated with many chronic diseases, including but not limited to multiple sclerosis, heart failure, liver disease, systemic lupus, cancer, rheumatoid arthritis and depression [5]. In patients with chronic health conditions, fatigue is often rated as one of the most challenging and problematic aspects of their disease [6]. Qualitative research suggests that fatigue is overwhelming, but hard to describe [2]. This, along with its subjective nature and non-specificity may make it particularly challenging to assess and treat.



CHAPTER 1

What is fatigue and why is it challenging to treat?

How is fatigue measured?

There are a wide range of questionnaires that can be used to assess fatigue, and many are developed to be used only in specific diseases [7]. Many scales tap into various facets of fatigue, including for example, sensory, mood, cognitive, motivation, physical, and activity related impairments [5]. However, if fatigue differs from one patient population to another, measures developed for one clinical patient group may not be informative in another [7].



CHAPTER 2

Research report: How do patients experience their fatigue?

Interested in how patients with long-term health conditions and severe fatigue experience and manage their fatigue, as well as their experiences with treatments, Cambridge Cognition recently completed a small-scale feasibility study. The study included a written survey and used open-ended questions. These asked about:

- how they experienced fatigue
- what the most significant symptoms of fatigue were
- how patients managed their fatigue
- how patients selected treatments and therapies
- downsides to treatments and difficulties accessing treatments

The following report presents the results of this study, which we examined using a qualitative thematic approach, completed in three stages: (1) data familiarization; (2) identification of key issues and concepts; (3) clustering and organizing themes, defining the main concepts and mapping the ways in which different parts of the data relate to each other.

CHAPTER 3

Who took part and what was measured?

Who took part in the study?

We approached patients with long-term health conditions and fatigue using a crowdsourcing website (<https://www.prolific.co/>). We selected only adults with long-term health conditions and high levels of fatigue. Eighty-three people completed the survey, with a broad age range, and good representation across different age categories (Figure 1). Information on participant sex and geographic location was not available.

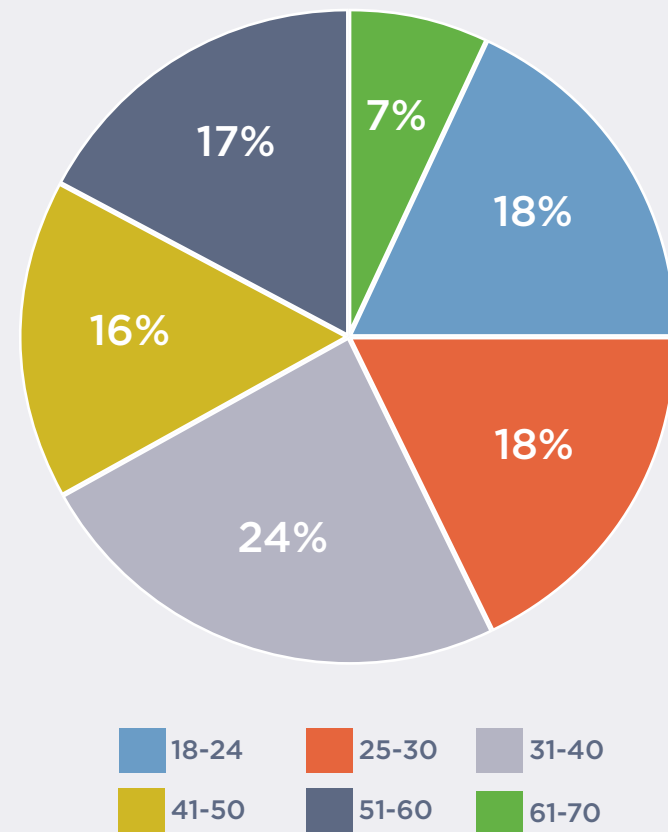


Figure 1: Age range of participants

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Who took part and what was measured?

Which health conditions did patients report?

We asked participants if they had ever been diagnosed with a range of specific health issues, and to describe any other health conditions that they had experienced.

Most patients had been experiencing their health issue(s) for a long time (figure 2). Over 50% reported that they had lived with their health issue(s) for over 10 years, and just under 90% reported three or more years of living with their health issue(s).

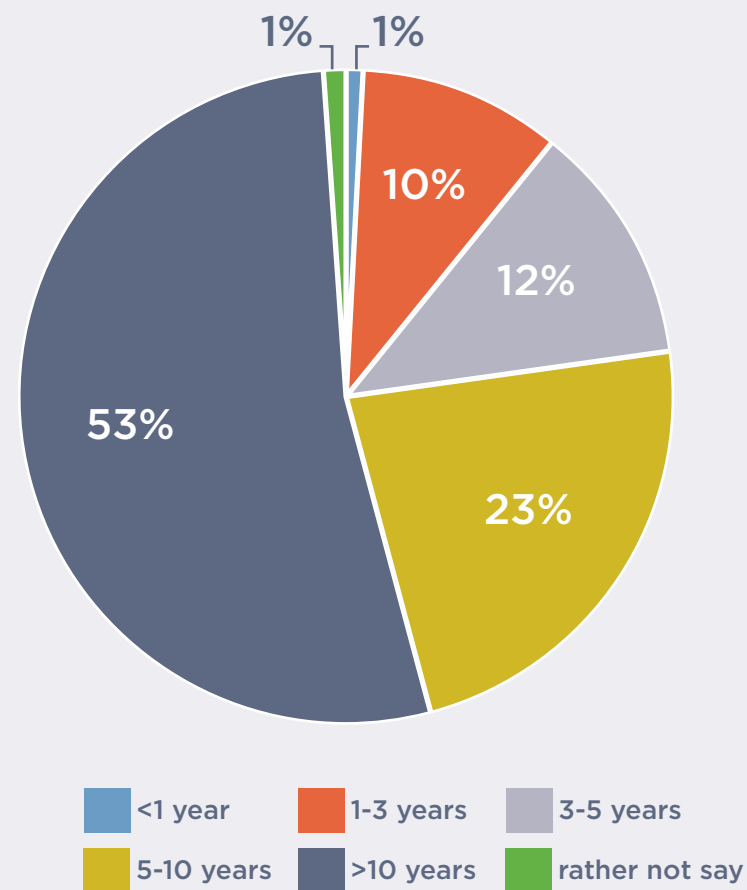
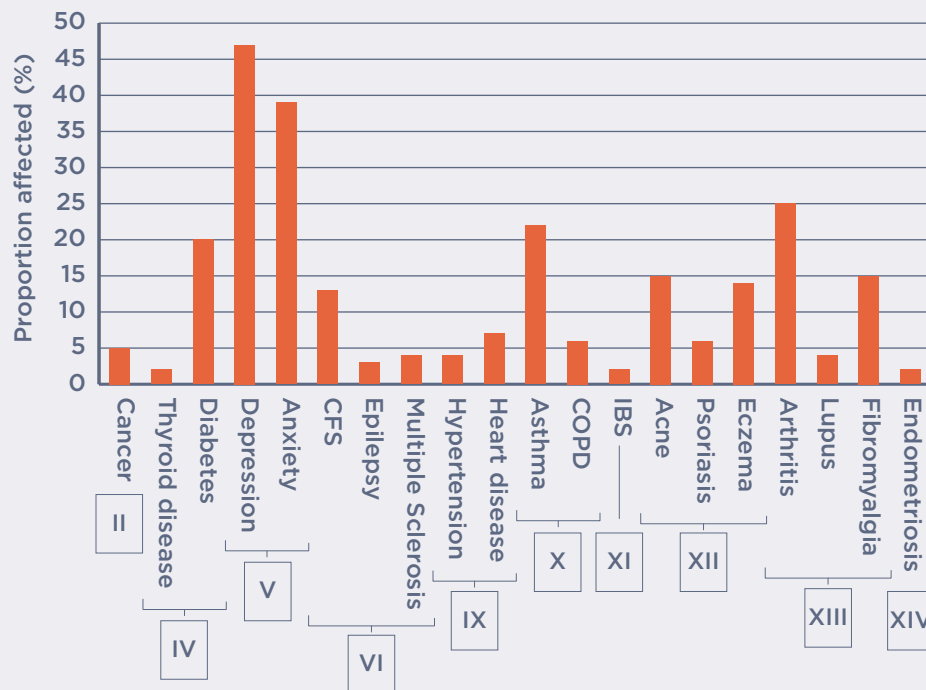


Figure 2: Duration of health issue(s)

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Who took part and what was measured?

Patients reported health conditions that spanned a range of parent disease classes in the World Health Organisation’s International Classification of Diseases (ICD) 10: version 2019 (<https://icd.who.int/browse10/2019/en>). Figure 3 shows the frequency of reported conditions, along with ICD-10 parent disease classes.



ICD-10 Disease category

- II. Neoplasms
- IV. Endocrine, nutritional and metabolic disease
- V. Mental and behavioural disorders
- VI. Diseases of the nervous system
- IX. Diseases of the circulatory system
- X. Diseases of the respiratory system
- XI. Disease of the digestive system
- XII. Diseases of the skin and subcutaneous system
- XIII. Diseases of the musculoskeletal system and connective tissue
- XIV. Diseases of the genitourinary system

Figure 3: Health conditions reported with ICD-10 classifications (numbered)

CFS=chronic fatigue syndrome,
 COPD= chronic obstructive pulmonary disease,
 IBS=Irritable bowel syndrome.
 Roman numerals corresponds to ICD-10 disease parent directory.

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Who took part and what was measured?

Only a quarter of participants reported just one health condition, all others reported two or more (figure 4A). This means that there was overlap between health conditions, which crossed ICD-10 disease categories (figure 4B). Given the phrasing of the question, it is not clear whether these diseases co-occurred at the same time, or during different periods in participants' lives.

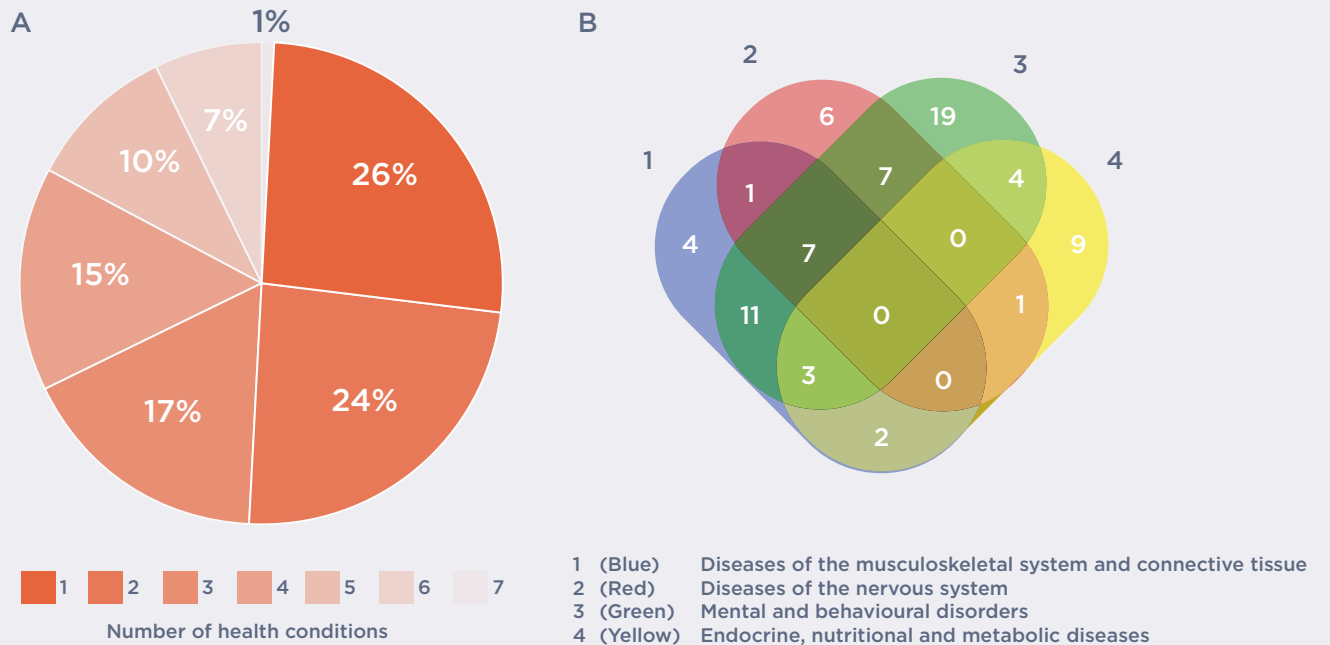


Figure 4: Health condition(s) ever experienced by participants.

A) Number of health conditions reported,

B) Venn diagram showing overlap between four disease categories, selected for display purposes

(created in <http://bioinformatics.psb.ugent.be/webtools/Venn/>). Overlap with other disease categories was also common.

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

What does fatigue feel like?

We asked how fatigue appears and changes over time. Most participants reported some changes over time: some had periods without fatigue, some with sudden, or more subtle onsets, or fatigue worsening over time (figure 5).

Participants described their main symptoms of fatigue, which we categorised into common themes and experiences. This resulted in ten main themes: depressive symptoms, subjective tiredness, movement, anxiety and stress, pain, cognitive symptoms, muscular control, emotional lability, sleep and sensitivity, each described in at least 10% of people surveyed.

We also identified seven additional themes, described by a smaller proportion of people as a main symptom of fatigue. These included problems with eating (appetite changes, digestive problems), restlessness, impatience, difficulty with routine tasks, light-headedness or dizziness, thirst (dry mouth, dehydration) and overheating (fever, hot flashes). **Figure 6** shows a fine-grained breakdown of descriptions provided.

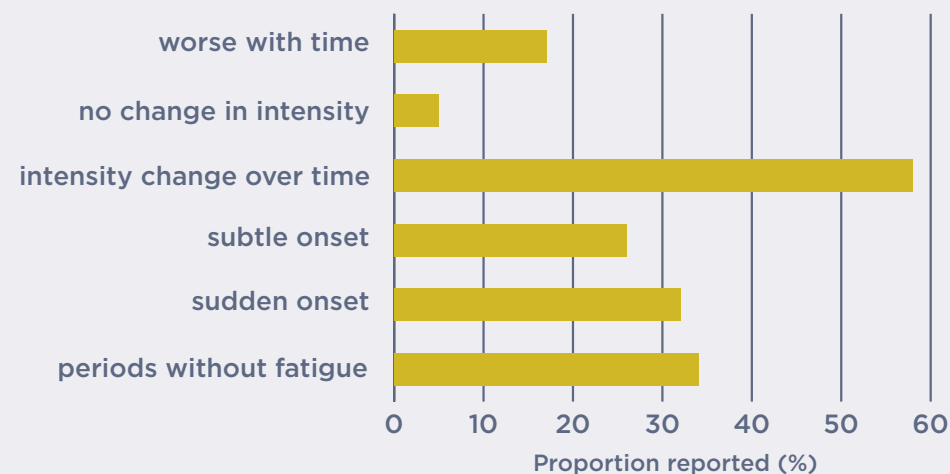
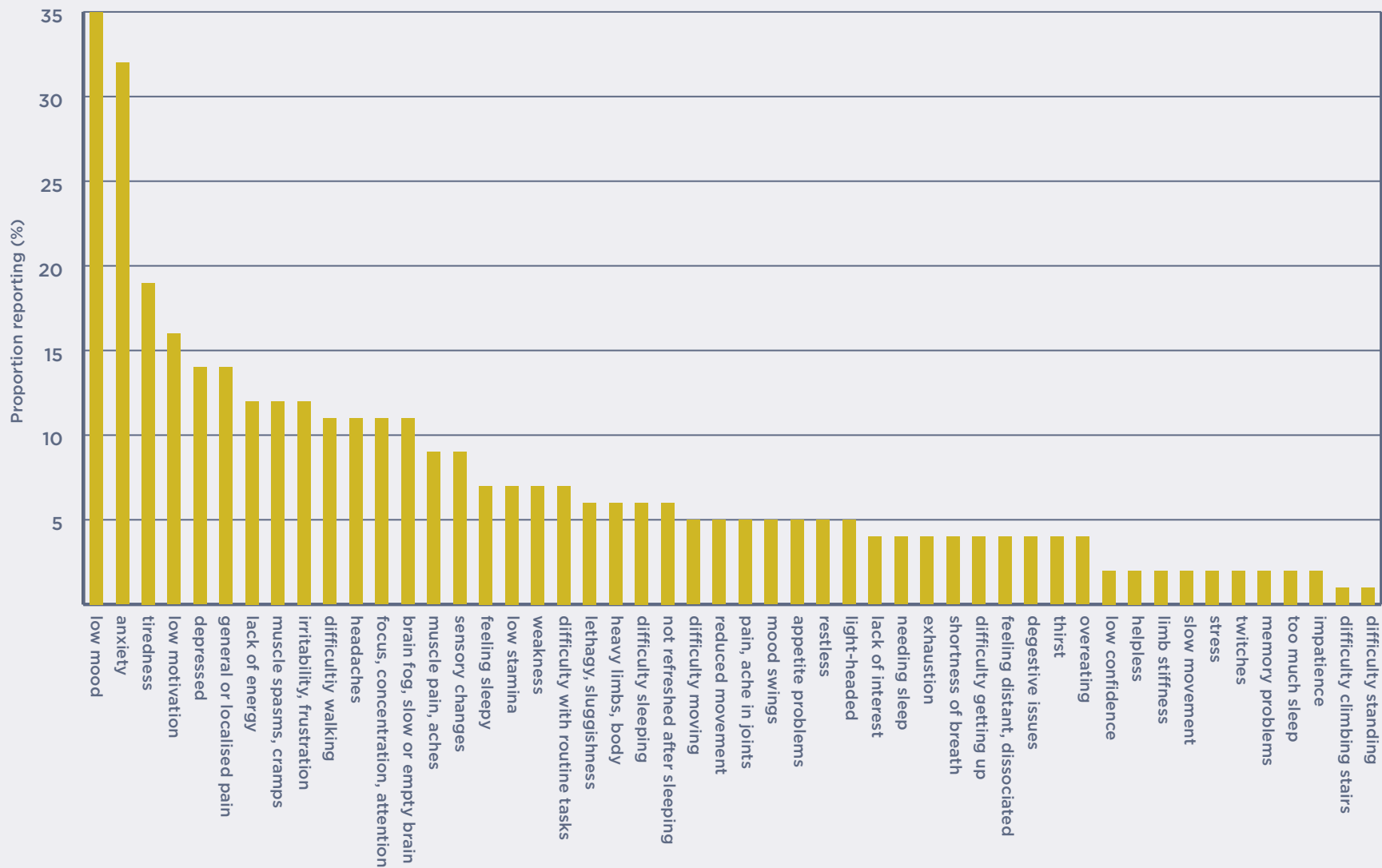


Figure 5: Pattern of fatigue over time

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Experts by experience: key concerns and priorities for treatment

Figure 6: Symptoms of fatigue: detailed descriptors



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Experts by experience: key concerns and priorities for treatment

The 10 most commonly described symptoms of fatigue

Depressive symptoms



Described in 64% as feeling depressed, low mood, low confidence, low motivation, low interest and/or helplessness.

Subjective tiredness



Described in 40% as exhaustion, sleepiness needing to sleep, lack of energy, lethargy and/or sluggishness.

Movement



Described in 37% as sensation of heaviness, stiffness, movement difficulties, shortness of breath, no stamina, restricted and/or slow movement.

Anxiety and stress



Described in 35%, mainly as feeling anxious, anxiety, but also as stress.

Pain



Described in 34% as localised or general pain, joint pain, muscular pain or aching and/or headaches.

Cognitive symptoms



Described in 25% as 'brain fog', feeling distant or dissociated, problems with focus, attention, concentration and/or memory.

Muscular control



Described in 19% as spasms and cramps, twitches and/or weakness.

Emotional lability



Described in 17% as mood swings, irritability and/or frustration.

Sleep



Described in 13% as difficulty sleeping, oversleeping, and/or not being refreshed from sleep.

Sensitivity



Described in 10% as increased sensitivity to taste, light or sound and/or localised tingling.

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Experts by experience: key concerns and priorities for treatment

Many participants had a history of more than one health condition (**Figure 4B**), and this increased the apparent similarity across health conditions. Whilst we do not have enough data from individual patient groups to tease out experiences of fatigue that may be specific to one or another patient group, it would be helpful in future research to examine whether there are subtle differences in the presentation of fatigue between different health conditions.

Our initial findings show that people with musculoskeletal system or connective tissue diseases experience more frequent movement, pain and sleep problems linked to their fatigue. Sleep problems and subjective tiredness were more often reported in those with endocrine, nutritional or metabolic diseases (primarily diabetes). More frequent sensory changes were described in patients with diseases of the nervous system (mainly chronic fatigue syndrome), and more anxiety and stress in those with mental, behaviour and neurodevelopmental diseases (primarily anxiety and depression).

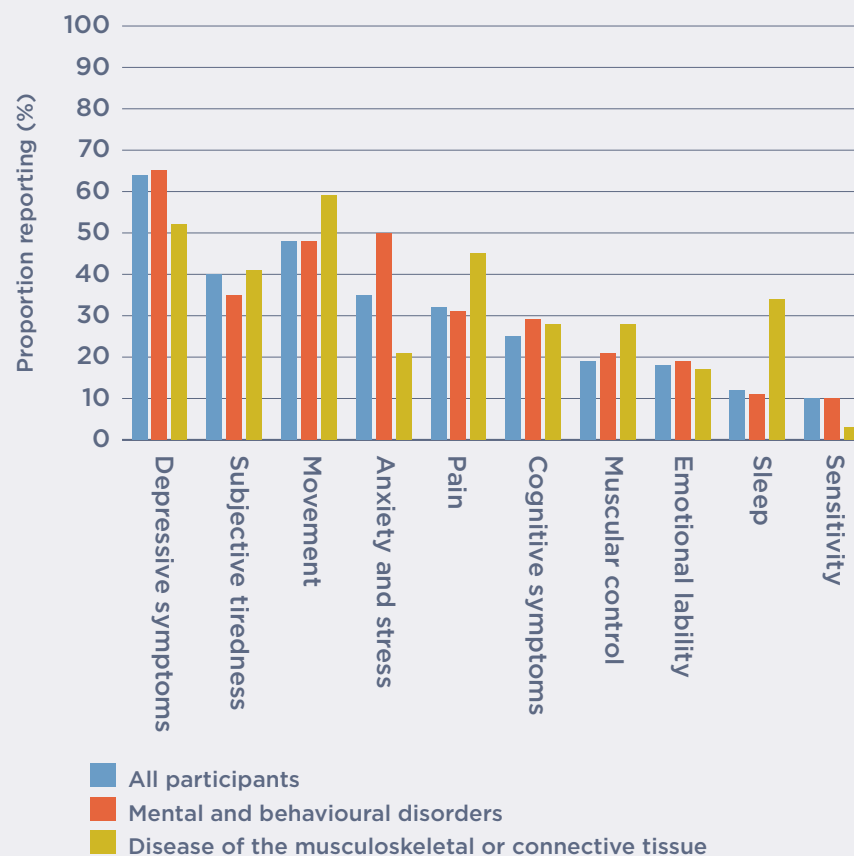


Figure 7: Frequency of 10 main symptom categories in different disease groups

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

Table 1: Descriptions of fatigue

“My mood gets really low, I can get moody and less patient, even be rude at other people. I become anxious and start worrying, everything makes me sad, I can cry for no reason. Sometimes I feel as I have no energy and I just lie down and do nothing. Some days even showering seems too much.”

Age 18-24 with history of heart disease, depression, anxiety and acne.

“Headache, sleepiness, muscle pain, sensitivities to light, difficulty with memory, fever, thirst, heart rate issues”

Age 25-30 with history of chronic fatigue syndrome, diabetes, and polycystic ovary syndrome.

“low mood, low energy, lack of interest in working or doing daily chores, always feeling tired even though I just woke up, restlessness when trying to sleep, bad mood.”

Age 41-50 with history of diabetes and hypertension.

“Low mood, anxiety, muscle weakness, general tired feeling, low motivation, feeling unable to do any activity that requires a lot of movement, trouble concentrating, trouble focusing.”

Age 31-40 with history of depression and interstitial cystitis.

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Experts by experience: key concerns and priorities for treatment

How does fatigue affect everyday life?

Impairments due to fatigue touched many aspects of daily life, including work and education, daily life demands such as housework and cooking, physical activity, the ability to socialise and engage in free-time activities.

Similar impairments were described across different health conditions (figure 8, **table 2**), albeit with slightly different patterns in the frequency for different types of complaints. For example, individuals with musculoskeletal system and connective tissue diseases described impairment more frequently across almost all of these areas, and reported more frequent restrictions on basic physical activities and walking (figure 8). However, again, the high level of overlap between conditions, and the small groups preclude detailed analysis or firm conclusions relating to differences between health conditions.

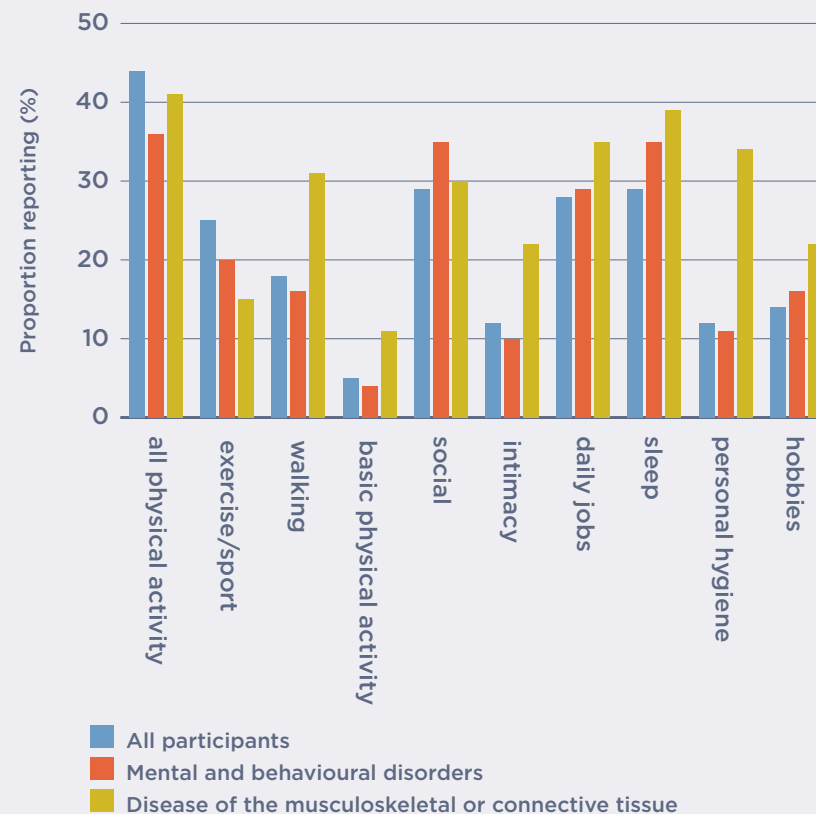


Figure 8: Areas of impairment in daily activities

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Experts by experience: key concerns and priorities for treatment

Just under half of participants described difficulties with physical activity, but impairment ranged widely: from problems with basic physical activities (standing, sitting, getting into the shower), to difficulties walking or dog walking, and difficulties in taking part in sports or exercise. Some reported that sustained activities (e.g. walking longer distances, sustained concentration) were particularly challenging.

Many people reported difficulty keeping up with demands of daily life. This included problems in vocational or education functioning, difficulties with daily household chores and activities, including cooking, cleaning, shopping, household administrative duties, and personal hygiene and grooming.

Around a third of participants described social and interpersonal problems, including socialising, seeing friends or keeping social engagements. Around 5% reported that they had trouble leaving their home at all. Some complained of problems with intimacy with partners or spouses.

Participants often reported problems with sleep. They also reported having trouble in engaging in activities that they enjoy, including sports and physical activities – as described above, and engaging in hobbies such as reading and gardening.

“Just under half of patients described difficulties with physical activity”



CHAPTER 4

Experts by experience: key concerns and priorities for treatment

Table 2: Descriptions of how fatigue affects everyday life

“I cannot really do cardio exercise I just cannot have any energy for it. I also cannot do anything that requires strong concentration such as important admin or finances. I also cannot go out socially.” Age 25-30 with history of anxiety disorder and irritable bowel syndrome.

“Often feel too tired to do even the most basic activities such as washing and at times difficult to face up to going out.” Age 51-60 with history of diabetes.

“I love hiking but am not able to walk very far because of it I get worn out easier.” Age 31-40 with history of acne, anxiety disorder, depression, and chronic kidney disease.

“I cannot work currently because of the fatigue also cannot walk very far have to pace all activities to avoid overexertion schedule recovery time after activities.” Age 51-60 with history of rheumatoid arthritis and anxiety disorder.

“Unable to go to work/school. Struggle with daily tasks and social activities.” Age 18-25 with history of postural orthostatic tachycardia syndrome (POTS) and chronic fatigue syndrome.

“I am not able to do much of anything. I fall asleep at the drop of a pin. Sleeping through the night, daily hygiene, participation in sports or social activities. Increasingly difficult to sit up. VERY limited walking with a walker. Unable to do any self-grooming” Age 61-70 with a history of acne, asthma, chronic fatigue syndrome, arthritis, chronic obstructive pulmonary disease, and lymphedema.

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

How do people manage their fatigue?

Drugs



Diet



Sleep



Rest



Scheduling & pacing



Exercise



Therapy & physiotherapy



Meditation



Herbal remedies & supplements



CHAPTER 4

Experts by experience: key concerns and priorities for treatment

People used medical, psychological, health, lifestyle, herbal and holistic approaches for managing their fatigue. Many combine a range of approaches.

Just under a tenth of the group did not manage their fatigue in any way, either because treatments only addressed their chronic health condition, because they simply lived with fatigue, or because previous treatments were not successful.

Many (46%) described using drugs, including sleeping pills, pain medication and cannabis (each described by 3-7%). Around 8% of the patients were obtaining counselling or therapy, and 2% were treated with physiotherapy. However, it was often unclear if the reported drugs or therapies treated the underlying chronic health conditions or were used for fatigue. This could be because managing fatigue depends in part on effectively managing the underlying chronic health condition. A more detailed survey would be needed to tease apart treatments for fatigue, which are separate from, or in addition to, those for other health conditions.

“46% of patients reported using drugs to manage their health conditions”



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Experts by experience: key concerns and priorities for treatment

Around a third of participants reported increasing sleep and rest, or using specific sleep patterns or schedules. Some (6%) described pacing themselves and moderating activity to ensure they can achieve important tasks when needed. A small proportion of respondents (2%) used sleep apnoea machines.

Dietary management was described by 20% of the sample, mainly with healthy eating, but also with diets or dietary techniques (gluten-free, low carbohydrate, sugar-free or low sugar, fasting). A similar proportion (18%) described using supplements or herbal remedies. A smaller group (6%) used caffeine or caffeinated drinks, or increased or reduced alcohol intake (2%).

Around 18% said that they managed their fatigue with exercise. A smaller proportion of respondents managed their fatigue through meditation or meditation-like approaches (8%), or changing work arrangements to help to accommodate fatigue (reducing workload and working from home).

**“Around a third
of patients use
rest to manage
their fatigue”**



CHAPTER 4

Experts by experience: key concerns and priorities for treatment

Table 3: Example descriptions of what participants do to manage their fatigue

“I take meds for my health problems that contribute to fatigue (several prescription medicines). I work hard to maintain a strict sleep schedule and respect my limits. I try to eat healthy and exercise.” Age 18-25 with history of acne, depression, anxiety disorder, heart disease.

“Medications and a bedtime routine” Age 30-35, with history of anxiety disorder, arthritis, depression and diabetes.

“I obviously have various treatments for the diabetes but no specific ones for the fatigue. Just try to get enough sleep and rest.” Age 51-60 with history of diabetes.

“I keep low carb diet I don’t eat sugars I walk 5-8km everyday I take medicines: metformin.”
Age 25-30 with history of diabetes.

“Nothing really. Honestly it’s never really been something any of my doctors have addressed.”
Age 25-30 with history of anxiety disorder, arthritis, asthma, eczema and mitochondrial disorder.

“I have medication for the pain antidepressants anxiety meds and sleeping pills. I try to sit down and close my eyes when I feel overwhelmed by tiredness. Pace myself throughout the week knowing that if I do too much one day I will need a couple of days to recover.”
Age 51-60 with history of anxiety disorder, fibromyalgia, depression, cancer, arthritis, and psychosis/schizophrenia.

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

What are the main downsides to treatment?

Most participants felt that their current treatments did not manage their fatigue particularly well (figure 9).

We asked participants what the main downsides to their treatment or therapy for fatigue were, and a third responded that there were currently no downsides to their treatment. This was overall a younger group (mostly under age 40) with only a quarter feeling that their fatigue was poorly managed.

A further 8% reported that the question was not applicable to them - all by individuals not treated with any form of medication or therapy, but who used behavioural approaches to managing their fatigue (limiting work, taking breaks, and dietary supplements).

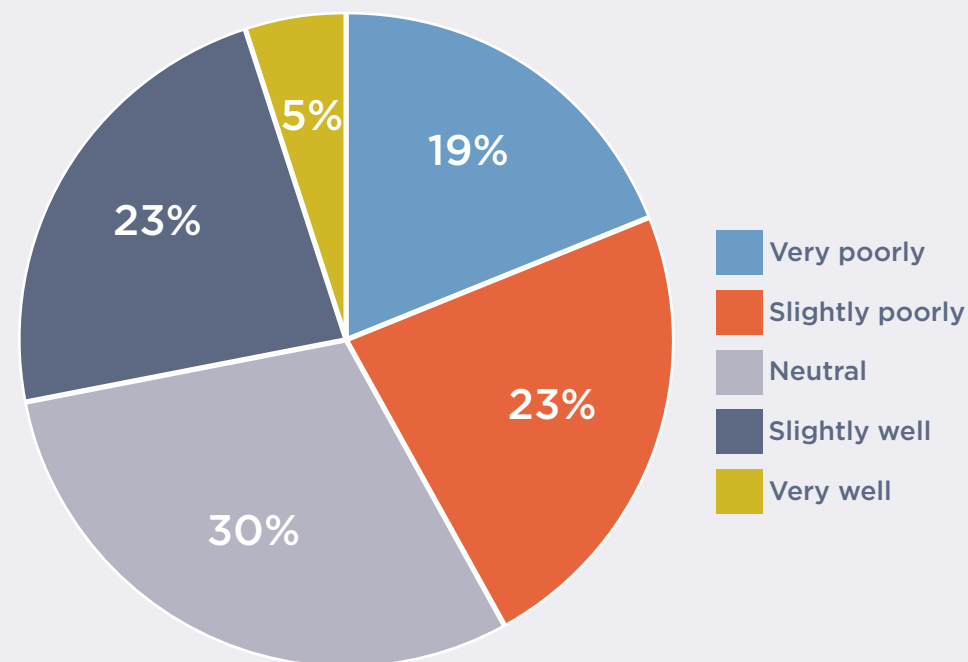


Figure 9: Participants' ratings of how well current treatment regimen manages fatigue

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

People with fatigue who reported downsides to their current treatment, often described medication side effects (20%): such as feeling tired, groggy, dizzy and having brain fog. Some felt that these problems arose because of their use of sleeping pills, in others these side effects were linked to treatments for their underlying chronic health conditions, and in yet others the source of side effects was unclear. 12% of the group complained that efficacy was poor, and 4% reported limitations of activities due to medication-taking routines. Prohibitive treatment cost was described in 5%.

For those who managed their fatigue through resting, over a quarter (28%) reported that this took up a lot of their time, making them unproductive, reducing their ability to take part in other activities and resulting in them missing out on things they would be interested in.

Other, more infrequent complaints of downsides to treatment (each affecting 1-4% of the sample) included low energy, being isolated due to retraction from daily life or being house/bedbound, aching and pain, problems with sleep, breathing, stress or worry, and dietary problems or restrictions.

Which medication side-effects do patients report?

- **tired**
- **groggy**
- **dizzy**
- **brain fog**

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

What do patients consider when selecting treatments and therapies to try?

We asked participants which factors they consider when selecting a treatment or therapy. Overall, they showed a willingness and openness to new treatments, or had already tried a number of different treatment options. Around 7% of participants said that they would be willing to try anything that could help. Some stated that nothing worked (2%), and others that they simply lived or coped with their fatigue (5%).

The three main criteria for selecting the treatment were cost (reported by 21%), side effects (19%), and efficacy (18%). Around 8% of patients also described the importance of ease of access to treatments, including distance and time it takes to travel for appointments or treatment.

What do patients value in fatigue treatments?

- **effective**
- **affordable**
- **no side-effects**

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

A reasonable proportion of participants (14%) did not want to take more medication, or wanted to use natural options. Some participants stated they would be concerned about the effect of fatigue medication on their chronic health condition(s), or interactions or interference with current medications.

When seeking treatment, 16% of participants reported that they were likely to select treatments recommended by their medical professional. Around 10% found ways to inform themselves of their treatment options, either through research in medical journals, through reading books or on the internet. Information exchange with community (friends, family, or disease community networks) were also important information sources for identifying treatments for some participants (6%).

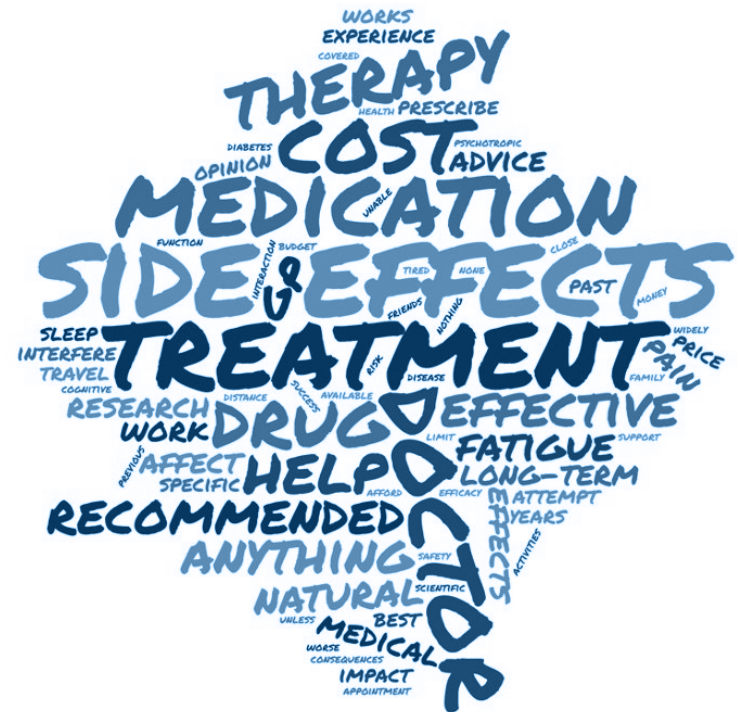


Figure 10: Word map of terms used by patients to describe how they select treatments for fatigue

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

When asked about their ideal treatment for fatigue, similar themes arose: treatments should be effective (35%), affordable (24%), and without side effects (26%). Many wished to move over to natural treatments (15%), others reported that they wanted to reduce or stop medication (4%) or use medications as needed rather than regularly (2%). Ease of access, use and management of treatments was also considered important, as well as treatments being comfortable or non-invasive.

Some participants described particular areas they wanted to target, such as reducing pain, tiredness, increasing alertness and energy, improving sleep, lifting or stabilising mood, and improving cognitive function, and physical and mental wellbeing.



Figure 11: Word map of terms used by patients to describe ideal treatment

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

What stops patients from accessing treatments?

Approximately a third of participants reported that there was nothing stopping them from accessing treatments for fatigue. These were overall a younger group, reported better treatment efficacy (figure 12A) and experienced fewer chronic health conditions than the remainder of the sample (figure 12B).

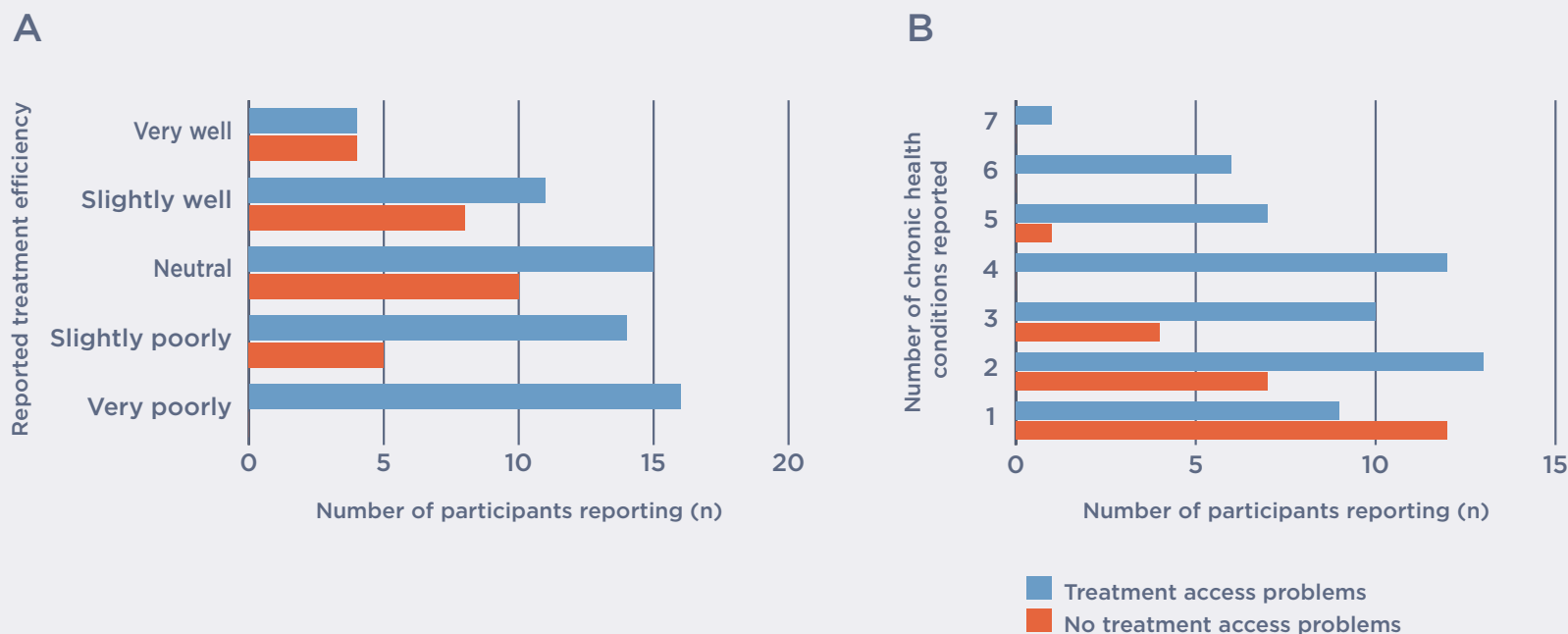


Figure 12: Number of participants reporting problems accessing treatment, by A) reported treatment efficacy, and B) number of chronic health problems

CHAPTER 4

Experts by experience: key concerns and priorities for treatment

For the participants who reported problems with accessing treatment for fatigue, these limitations included cost, access to information and support, expected or perceived support, and physical restrictions. Within this group, almost half (47%) reported cost limitations or related problems with health insurance. This was associated with how well participants felt their treatment was managed: those who described cost as a major barrier to treatment also reported that their fatigue was managed more poorly.

A smaller proportion were unaware of options for treating fatigue (20%), or reported that they had difficulties obtaining information or support through their medical practitioner (16%). Other issues raised were problems with obtaining physical access to treatments, due to mobility restrictions (10%) or long waiting times for appointments (5%).

A few participants described limitations in terms of beliefs around fatigue. A small proportion (5%) felt there was no point in trying to treat their fatigue problems. Although stigma was voiced explicitly by only one participant, there was a general sense that access to support was limited more broadly by stigma, either because medical practitioners did not provide support or treatment options, or because they considered fatigue as a secondary, or unimportant features of ill-health **(Table 4)**.

“For patients with problems accessing treatment, 47% said that cost was a contributing factor”



CHAPTER 4

Experts by experience: key concerns and priorities for treatment

Table 4: Example descriptions of limitations in access to treatment

“The UK is useless and offers no help whatsoever. Especially with supposed ‘universal’ healthcare being different per NHS trust. Waiting times of 6-9 months between appointments, I become overly negative about things very stressed.” Age 25-30 with history of anxiety, eczema, asthma and irritable bowel syndrome.

“Most doctors in my country don’t believe that CFS exists.” Age 25-30 with history of diabetes, chronic fatigue syndrome and polycystic ovary syndrome.

“Not knowing what therapies there are that could help. Not having my doctors recommend or refer any.” Age 31-40 with history of depression and interstitial cystitis.

“I don’t know of any to try. Going to the doctor seems like a waste of time as fatigue is such a general symptom.” Age 41-50 with history of acne, asthma and arthritis.

“Cost. The NHS only covers a tiny amount of stuff and I can’t afford to pay for anything in addition” Age 41-50 with history of depression, asthma, chronic fatigue syndrome and fibromyalgia.

“I am housebound and only leave for mandatory medical appointments for my lymphodema, lipodema, wound care needs. I’m in hospital bed, wheelchair, or lift recliner 23 hours a day or more. I am unable to walk without walker and only very limited.” Age 61-70 with a history of acne, asthma, chronic fatigue syndrome, arthritis, chronic obstructive pulmonary disease, and lymphedema.

CHAPTER 5

Four ways to better understand fatigue

This patient involvement research has highlighted a number of things we need to bear in mind when we try to assess and understand fatigue. These are summarised in four main points below.

1. The research shows the complex clinical history of people with fatigue. Fatigue affects people from a wide range of health conditions. Many experience more than one clinical condition in their lifetime, and these conditions are chronic and long lasting. The more complex the disease presentation, the more challenging it is for people to identify treatments and successfully manage their fatigue.
2. Fatigue itself presents as complex and multifaceted and changes over time. It affects a range of functions: mood, anxiety, pain, movement and muscular functions, sleep, cognition, and sensation and subjective tiredness. Often fatigue affects more than one of these areas at once. Fatigue leads to impairments in many aspects of daily life, including in work and education, managing daily demands, the ability to socialise and engage in enjoyable activities.

CHAPTER 5

Four ways to better understand fatigue

3. Whilst fatigue affects a similar array of experiences and activities across individuals and disease categories, it does so at varying levels of impairment. Common experiences of fatigue interacted with underlying chronic conditions in certain symptoms (e.g. severe motoric impairments in fatigue were more common in people with musculoskeletal or connective tissue diseases, and anxiety and stress more common in those with mental, behavioural and neurodevelopmental diseases). Whilst in some, fatigue affects their ability to enjoy more stimulating and vigorous activities, in others fatigue leads to making even basic social and physical activities more challenging.

4. People actively manage their fatigue through a range of medical and non-medical approaches, but many are not satisfied with existing treatments. People are motivated to try a range of different approaches. However, they often describe problems with low efficacy and side effects. They note that medications used to treat fatigue or chronic health conditions can exacerbate sleep problems and worsen fatigue. Cost limitations also constrain access to treatment, as do problems with mobility restriction and pain. People report that support is limited, either because clinicians and patients themselves view fatigue secondary to underlying health conditions, because it is non-specific, or not important enough to warrant further support.

CHAPTER 6

Learnings, limitations and future action

Limitations and next steps

This qualitative study provides hints of possible differences in the experiences of fatigue in different chronic diseases, and provides a rare glimpse into the qualitative patient journey for those living with fatigue and chronic conditions. Future work in this area could help drug makers, healthcare providers, and regulators to consider a holistic approach to treating chronic ill health, and should address some limitations in this report.

The exact wording of questions should be clear and specific. For example, this report includes patients with a history of different health conditions who experience fatigue. However, it is not clear which of the reported health conditions are current and which are historical. Furthermore, when we ask about treatments to manage fatigue, responses from our participants often include treatments of co-occurring chronic health conditions. Whilst this is a key limitation in this study, it also highlights that for many patients there is an important interaction between the management of their health condition and fatigue. We now need further research to disentangle experiences of managing of chronic health conditions and fatigue.

This report spells out the frequency with which patients describe specific problems or experiences, but it is important to bear in mind that our data is qualitative in nature with a small sample size compared to quantitative studies. The proportions reported therefore provide only a rough indicator of the size of each problem described. There may be other experiences of fatigue not reported by the patients surveyed in this report.

CHAPTER 6

Learnings, limitations and future action

Conclusions and future directions

Overall, our research suggests a variety of themes in the experiences of fatigue that are relevant to the development and application of our health technology:

- A clear overview of patients' experiences of fatigue can help us to further refine clinically valuable assessments and develop sensitive patient reported outcomes (PROs), using concepts and descriptions that patients themselves use.
- Our research shows that fatigue almost always changes over time. This signposts the need for time-sensitive assessments, such as technologies supporting repeated assessment.
- Cognitive problems are common, and cognitive assessment could deliver objective and sensitive data in patients affected by fatigue. High-frequency cognitive assessments could help to examine fluctuations in these objective measures over time.

CHAPTER 6

Learnings, limitations and future action

- The way in which patients with fatigue describe managing daily activities is indicative of problems with sustained attention, concentration or exertion. This can be linked to concepts of moderation or energy management, described in previous research [4]. Further work is now needed to identify whether tasks of sustained effort are too taxing for this group, or whether these tasks may be particularly sensitive to impairments in fatigue.

- People with fatigue and chronic health conditions are overall very pro-active in managing their health, but often feel that their fatigue is not managed well. They find it difficult to obtain information on treatments or support from medical professionals. This indicates a gap in health provision, and points to the value of including fatigue indicators as key secondary clinical outcomes in trials for chronic health conditions. This could help to inform medication selection for patients experiencing fatigue, and reduce clinical perceptions of fatigue being secondary, unimportant or too non-specific to warrant attention in disease management.

- Our research suggests that patients with fatigue show strong motivation to manage this key and impairing feature of their chronic disease. Acknowledging, and including assessments relevant to this experience could help to improve their motivation and engagement in research and trials, by providing insights into key outcomes that are of interest to them.

CHAPTER 7

Who can I speak to?

Why do we do patient-centred research at Cambridge Cognition?

Patient-centred research is key to understanding what matters most to the patients themselves, which can help us to better understand:

1. their experience of illness and treatment
2. the difficulties they face day to day
3. what they find most unmanageable or bothersome
4. outcomes that matter most to them

In turn, this places patients at the forefront of our assessment and technology development, and helps us to develop measures that have value to patients themselves, and that can best serve their needs.

This eBook has covered our patient-centred research efforts into fatigue: one of the most challenging and problematic aspects of chronic health conditions, and also one of the most tricky to treat.

CHAPTER 7

Who can I speak to?

If you have any questions about our research, please do get in touch:
info@camcog.com

If you are a person living with fatigue, and are looking for advice and support in managing your condition, we would encourage you to speak with your GP. You can also obtain more information from these charities:

- [The Brain Charity](#)
- [ME Association](#)
- [Stroke Association](#)
- [Multiple Sclerosis Trust](#)
- [MS Society](#)
- [Brain and Spine Foundation](#)
- [Versus Arthritis](#)

If you live in the UK, you can also find Chronic Fatigue Syndrome services in your area [here](#)

REFERENCES

1. Louati K, Berenbaum F. Fatigue in chronic inflammation - a link to pain pathways. *Arthritis Res Ther* [Internet] *Arthritis Research & Therapy*; 2015;17(1):1-10. PMID:26435495
2. Whitehead LC, Unahi K, Burrell B, Crowe MT. The Experience of Fatigue Across Long-Term Conditions: A Qualitative Meta-Synthesis. *J Pain Symptom Manage* [Internet] Elsevier Inc; 2016;52(1):131-143.e1. [doi: 10.1016/j.jpainsymman.2016.02.013]
3. Bootsma TI, Schellekens MPJ, Woezik RAM, Lee ML, Slatman J. Experiencing and responding to chronic cancer-related fatigue: A meta-ethnography of qualitative research. *Psychooncology* 2019;(August):1-10. [doi: 10.1002/pon.5213]
4. Wilson L, Whitehead L, Burrell B. Learning to live well with chronic fatigue: The personal perspective. *J Adv Nurs* 2011;67(10):2161-2169. [doi: 10.1111/j.1365-2648.2011.05666.x]
5. Hjollund NH, Andersen JH, Bech P. Assessment of fatigue in chronic disease: A bibliographic study of fatigue measurement scales. *Health Qual Life Outcomes* 2007;5:1-5. [doi: 10.1186/1477-7525-5-12]
6. Swain MG. Fatigue in chronic disease. *Clin Sci* 2000;99(1):1-8. [doi: 10.1042/cs0990001]
7. Dittner AJ, Wessely SC, Brown RG. The assessment of fatigue: A practical guide for clinicians and researchers. *J Psychosom Res* 2004;56(2):157-170. [doi: 10.1016/S0022-3999(03)00371-4]

The survey questions, which formed the basis of this study, can be viewed here [here](#)

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