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# Subacute fatigue in primary care – two sides of the story

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**Objectives.** Fatigue is a common symptom in primary care. Chronic fatigue research highlights the value of preventing chronicity, but little research has investigated the early, subacute stage of the fatigue trajectory (<3 months). We aimed to examine patient and general practitioner (GP) perspectives of subacute fatigue in primary care: (1) to gain a better understanding of fatigue during this stage and (2) to explore how management could be improved.

**Design.** A qualitative study design was used. In-depth, semi-structured telephone interviews were conducted with 14 patients and 14 GPs (non-dyadic), recruited from 19 primary care practices.

**Methods.** Interview transcripts were thematically analysed. Initially, patient and GP accounts were analysed separately, before themes were merged to identify shared and independent perspectives.

**Results.** Three main themes were identified. Within these, subthemes from patients', GPs', or shared patient/GP perspectives emerged. The main themes encompassed the following: (1) Change from normal – the impact of fatigue; (2) The challenges of managing fatigue; and (3) The consultation GPs' knowledge was often not reflected in patients' accounts, even for those reporting positive experiences, suggesting knowledge was not effectively translated.

**Conclusions.** Some findings, such as impact, mirror those described in chronic fatigue. New insights into early-stage fatigue management also arose, including mismatches in patient and GP perceptions on negative tests and not re-presenting. These highlight the need for better communication and shared understanding. GPs should pre-emptively present a biopsychosocial model of fatigue and keep communication channels open, particularly in the light of negative physiological tests.

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## Statement of contribution

# What is already known on this subject?

- Patients with chronic fatigue retrospectively report lack of understanding from GPs in early stage of illness.
- Little research has investigated the early stages of the fatigue trajectory.

#### What does this study add?

- Consequences of an episode of subacute fatigue are similar to those reported for CFS.
- There is discordance between GPs' positive view of negative tests and patients' need for explanation of symptoms.
- The length of appointments is a significant barrier for creating shared understanding.

Fatigue is a common symptom in primary care with 5–7% of people presenting with a primary complaint of fatigue (Hamilton, Watson, & Round, 2010). Acute fatigue can be associated with a wide range of triggers, including viral illness, disrupted sleep/wake cycle, and emotional stress. Fatigue is defined as subacute when  $\leq 3$  months in duration, and chronic after persisting for 4 months in the United Kingdom (NICE, 2015) or after 6 months in the United States (CDC, 2015). Only around half of people with tiredness/ fatigue as a major or concurrent symptom recover within 1 year. This means around half still have chronic fatigue a year later (Nijrolder, van der Horst, & van der Windt, 2008; Nijrolder, van der Windt, & van der Horst, 2008). A small percentage will have been diagnosed with chronic fatigue syndrome (ME/CFS), which has more stringent diagnostic criteria including fatigue that is disabling in nature, has a sudden onset, and is not alleviated by rest (CDC, 2015; NICE, 2007). A review of studies from around the world suggests the average prevalence of chronic fatigue is 10% and that of chronic fatigue syndrome is 1% of the population (Son, 2012). The pervasive and fluctuating nature of chronic fatigue and the associated physical and emotional symptoms and reduction in capacity have been documented (Storkmorken, Jason, & Kirkevold, 2015), as have the difficulties of it being an unknown illness and 'losing' elements of life (Jelbert, Stedmon, & Stephens, 2010). This highlights the value of preventing acute fatigue becoming chronic.

Current guidance in the United Kingdom for managing tiredness/fatigue suggests targeting modifiable psychological, social, and general health factors, but includes little specific information about how to best do this (NICE, 2015). One way to guide early treatment is to understand risk factors associated with moving from acute to chronic fatigue. A recent systematic review of risk factors following an acute infection (Hulme, Hudson, Rojczyk, Little, & Moss-Morris, 2017) supported existing biopsychosocial models of chronic fatigue which suggest a complex interaction of predisposing, precipitating, and perpetuating factors in the aetiology of chronic fatigue (Deary, Chalder, & Sharpe, 2007; Surawy, Hackmann, Hawton, & Sharpe, 1995). The data suggest that pre-existing health issues, lack of fitness, and distress/stress may predispose individuals to be vulnerable to post-infectious fatigue. Vulnerable individuals may have a heightened immune response to infection, resulting in more severe acute symptoms. In turn, this may result in increased bed rest, sick certification, and time off work. Prolonged inactivity may result in a rebound response to rush back to previous levels of activity, only to find this 'boom' behaviour produces further symptoms. If these symptoms are attributed to a psychological or physical illness, rather than normalizing these in relation to pushing too hard after a time of bed rest or severe symptoms, patients may develop a negative representation of their symptoms and illness. The response may be to rest again rather than risk activity. This in turn produces more symptoms and an ongoing vicious cycle (Hulme et al., 2017).

Another factor not measured in medical studies included in this review is the role of the therapeutic doctor–patient alliance in alleviating or contributing to ongoing fatigue (Deale & Wessely, 2001). The biopsychosocial model described above could help provide patients with a clearer understanding of their fatigue and help structure behavioural strategies to assist recovery, such as a careful, graded return to activity. However, there is very little work exploring doctor–patient relationships in the earlier stages of fatigue and whether these models are indeed used in practice.

Qualitative studies of patients with established CFS frequently described negative patient experiences, relating to not feeling believed and having no clear 'next step' (Hannon *et al.*, 2012; Hareide, Finset, & Wyller, 2011). Conversely, doctors seem to view CFS as a difficult condition to deal with, in part due to discordance with patients' views regarding cause and management (Raine, Carter, Sensky, & Black, 2004) and the discrepancy between the 'ideal' doctor role of providing a cure versus the 'reality' of the consultation (Asbring & Narvanen, 2003). However, eliciting accurate information about early fatigue experiences is limited by the retrospective data collection.

This qualitative study aimed to examine patient and general practitioner (GP) perspectives of fatigue in primary care, to gain a better understanding of fatigue during the subacute stage from both perspectives and provide insights into how subacute fatigue management in primary care specifically could be improved.

## **Methods**

## Design

Qualitative methods using semi-structured telephone interviews were conducted with all participants.

#### **Participants**

This study was nested in the FAME (Fatigue: acute fatigue Assessment and Management in Everyday practice) NIHR development programme, an ongoing feasibility cohort study investigating risk factors of CFS/ME, based in the south of the United Kingdom. Patients are recruited either by their GP during consultation or by general practice mail-out. Three basic clinical presentations are included: (1) glandular fever, (2) other infective precipitants, and (3) no clear infective precipitant. Patients were screened for inclusion: score 4+ on the Chalder Fatigue Scale (Chalder *et al.*, 1993) for <3 months. Exclusion criteria were as follows: unable to give informed consent, or presenting with a clear non-infective and short-term cause for fatigue (e.g., pregnancy, clinical hypothyroidism, drug induced).

At enrolment for FAME, patients consented to be contacted regarding this study. GPs were recruited by email via general practice research managers; if willing to participate, they were asked to contact the researcher. All participants were recruited from 19 GP practices. All were publicly funded National Health Service, primary care GP practices with practice population sizes ranging between 6,132 and 24,616 (mean = 9,939).

Patients and GPs were not directly matched, and although there may have been overlap between patients and GPs, this was not explicitly ascertained so we cannot assume any dyadic relationships were included. Patient recruitment commenced in September 2015 and finished in March 2016, and GP recruitment occurred from November 2015 to May 2016.

Nineteen of the 22 patients recruited to FAME during the recruitment period consented to be contacted. Of these, 16 agreed to take part, two of whom were subsequently found to be ineligible as their current fatigue exceeded 3 months. The three who declined cited ill health. Fourteen GPs expressed initial interest, all of whom completed the telephone interview (see Table 1 for participant characteristics). Patient interviews lasted approximately 45 min and GP interviews approximately 20 min.

#### Materials

The patient interview schedule (Appendix A) included questions relevant to FAME in the first section, for example, 'How did you feel about the questionnaires you completed?' The second section included questions specific to this study, for example, 'Can you tell me what you did when you first noticed your fatigue?' The GP interview schedule questions were focussed specifically on fatigue presentation in primary care for this study, for example, 'How do you tend to deal with patients with symptoms of fatigue?' (Appendix B). Both schedules included open questions to gather in-depth, participant-led data, and probes were used to explore responses.

#### **Procedure**

Participants were contacted to arrange an interview after receiving further information and consenting to take part. Participants received an information sheet including aims of the study; however, they were not told personal details about their interviewer. Prior to the start of interviews, the interviewers (both students either studying or intercalating in the Health Psychology faculty) received the same in-house training about interview and qualitative research techniques from experienced members of the academic research department. This included becoming familiar with the interview schedule, conducting practice interviews, and receiving continuous feedback, measures taken to increase consistency and reduce interviewer bias. All interviews were conducted by phone. The interviewer (A.B. for patients, A.J. for GPs) outlined the study and answered any questions before proceeding. All interviews were audio-recorded with participants' permission and handwritten notes were made as necessary, as a reminder for further exploration and to aid later analysis. Interviews were transcribed verbatim and thematic analysis commenced.

Table 1. Participant characteristics

	Patients $(n = 14)$	GPs $(n = 14)$
Gender		
Female	H	9
Male	3	5
Age (years)		
Mean	52	46
Range	29–70	30–55
Fatigue score		
Mean	7	
Range	4–11	
Years qualified		
Mean		21.5
Range		6–32

Ethical approval was obtained from a local National Research Ethics Service (NRES) Committee.

## Data analysis

Interviews were thematically analysed using principles outlined by Braun & Clark (Braun & Clarke, 2006). An inductive approach was taken, conducting the interviews and exploring the data in the absence of pre-defined hypotheses or theoretical frameworks using data-driven codes. The aim was to promote in-depth interpretation of the data and to gain an understanding of the interactions and experiences of fatigue in primary care, fully grounded in participants' accounts of their understanding of the topic. Recruitment and data collection continued until saturation was reached, at which point new themes were no longer arising in the data (Mason, 2010). Similar patterns were emerging after 10 patient and 8 GP interviews; however, the additional interviews were conducted to enrich the depth of the preliminary analysis and check that no new relevant themes were appearing.

Analysis occurred in line with the steps outlined by Braun and Clarke (2006).

Phase 1: data familiarization. The lead author (K.H. – DHealthPsy) listened to all interviews and read all transcripts, to maximize data familiarization and immersion, check transcription accuracy, and check interviewer consistency and biases. Transcripts were read multiple times, each time noting ideas and potential patterns of interest. Each interviewer went through the same process with their respective interviews (i.e., patient or GP). The lead author and individual interviewers continued this pattern of working throughout the remaining phases, meeting to discuss and corroborate codes and themes.

Phase 2: generating initial codes. Initial ideas were compiled as provisional codes, by working through the full interviews and noting all features of interest by manually highlighting and annotating the text. A data-driven approach was used, rather than coding data in the light of existing theoretical frameworks. After independent familiarization and coding of the first five transcripts, the interviewer and lead author met to discuss initial codes. Regular discussion enabled the corroboration of codes and ensured the data-driven approach was upheld.

Phase 3: searching for themes. Provisional codes were then systematically reviewed across the whole data set and mapped into potential themes under broader headings. Both the interviewer and lead author continued to independently analyse and code the further nine transcripts and began to map emerging themes.

Phase 4: reviewing themes. Themes were reviewed in the light of the whole data set to ensure everything of relevance had been captured and the thematic maps were refined to identify distinct and coherent themes and subthemes. This occurred in research team meetings, where discussion of the emerging themes and subthemes helped the refining and defining process.

Phase 5: defining and naming themes. Themes were refined and allocated an identifying title describing the essence of the data captured.

Analysis occurred on two levels. Initially, data from both groups were analysed separately, identifying themes in each party's accounts. The second level of analysis involved merging the analyses, identifying shared and independent perspectives.

Throughout the analysis process, triangulation occurred, whereby the interviewer, the lead author, and another member of the research team read and discussed the transcripts and codes, to ensure emerging themes were accurate and grounded in the data and to minimize risk of bias.

## Results

As illustrated in Figure 1, three core themes were identified: (1) Change from normal – the impact of fatigue; (2) The challenges of managing fatigue; and (3) The consultation. Within each theme, perspectives from patients and GPs formed subthemes, some independently and some shared. Additional quotes can be found in Appendix C.

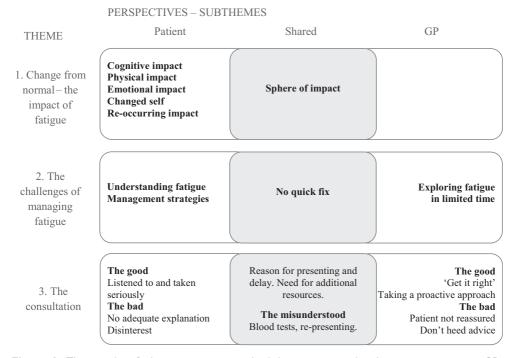
# 1. Change from normal – the impact of fatigue

#### **Patient**

Patients described the significant impact of fatigue on them and their daily lives. This impact spanned multiple domains and often seemed similar to that previously documented for chronic fatigue. The impact was particularly marked when comparisons were made to what patients deemed 'normal' or how they used to be.

*Cognitive impact.* Patients described concentration difficulties, worsened memory, and organization problems, labelling it as 'brain fog' and 'cloudy head'. This impact had a knock-on effect for daily activities requiring these skills, for example, reading, working, and driving.

It feels like your head is just really cloudy; you can't really think straight, because all you can think about is -I'm so tired. (P0052)



**Figure 1.** Themes identified across accounts and subthemes, some related to patients, some to GPs, and some shared. Subthemes are bolded, with extra information to provide context.

*Physical impact.* Others experienced a more physical manifestation of fatigue, described as 'insides have gone to jelly' (P0065). Typically, people described symptoms such as having no energy, feeling tired all the time, aching, and a feeling of heaviness.

*Emotional impact.* Emotional consequences arose not only as a direct result of fatigue, that is, the fatigue making them feel low or less positive, but also as a secondary consequence; the fatigue prevented them doing the things they wanted or felt they should be able to, triggering feelings of irritation and frustration.

It's quite frustrating and upsetting . . . Yeah I try and have a little pep talk with myself and just go "you used to be able to do it, you can go and do it". . . but it doesn't work. (P0061)

Changed self. As the statement 'I was never, ever like that' (P0052) demonstrates, the fatigue affected individuals by altering their core concepts of 'self'. Patients frequently compared themselves to how they had been, stating that 'it wasn't like them' or that they 'used to do [an activity] all the time', which also affected them emotionally.

*Re-occurring impact.* When discussing fatigue onset, it became apparent that many patients had experienced fatigue previously or had experienced an underlying fatigue for longer than 3 months. Within the subacute time frame, the fatigue may then have worsened or become problematic. It seemed that patients were possibly vulnerable to fatigue:

... it was like fatigue on top of fatigue... I was probably working on about 50% energy the 6 months prior to the flu, and then when the flu came along it was just like I went right down to about 5%. (P0034)

## Shared

*Sphere of impact.* As well as affecting the person at a purely individual level, the fatigue affected the wider sphere of work and social life. People described adjustments made to accommodate fatigue, for example, considering working part-time, Internet shopping, and reducing social activities. They prioritized what *had* to be done, in an effort to uphold responsibilities such as job commitments and caring for others.

I'm kind of finding bits of my life that I can kind of just not do whilst I'm just feeling tired'. 'I'm sort of hibernating. (P0071)

GPs were aware of other consequences patients experienced, but their accounts predominantly described the consequences in the context of the sphere of impact as the main driver of presentation, that is, the wider picture:

They don't like being fatigued and not coping with day to day living... it's generally family commitments, commitments to partners that they are not being able to fulfil because they're feeling tired. (GP2)

As this overlapped with patient accounts of the sphere of impact and was a shared perspective, no subthemes specifically relating to GP accounts emerged.

# 2. The challenges of managing fatigue

For both parties, the difficulty of classifying and managing such a complex and heterogeneous symptom was apparent: 'it just doesn't seem like something with edges' (P0001). They described different challenges which culminated in the overarching, shared perspective that there is no quick fix.

#### **Patient**

*Patients' understanding.* It became clear that patients strived to find a cause, but that attributed triggers varied greatly. Considerations ranged from biological (e.g., medication, thyroid problems) and emotional (e.g., relationship stress, family death) to external lifestyle factors (e.g., 'rush rush society' (P0100)).

*Patients' management strategies.* The lack of a clear understanding posed challenges for subsequent management. Patients could not identify what was wrong in order to make the changes necessary to minimize the impact.

... could it be down to work, could it be down to possibly social life the evening before or could it be done to what I'm eating or something – and I just can't pinpoint what actually triggers it off. (P0101)

This is not to say that patients did not utilize management strategies. They described trying numerous things to lessen fatigue, both before the appointment and afterwards, with varying degrees of success. Helpful strategies included improving diet, getting people to come round to talk things through, resting/taking a nap, and exercising.

Resting was one of the more common strategies: '...keep topping up the battery, so you've got to keep resting' (P0065), with the concept of pacing occasionally arising in conversation, both explicitly described and inexplicitly implied. A few patients described positive effects of engaging in increased physical activity, which seemed to be unexpected initially.

I don't feel as bad after sport. When I do more sport I actually feel better. (P0100)

Unhelpful management strategies centred around not accommodating the fatigue.

I suppose I was fighting it, I was resisting it and trying to sort of, produce some energy from somewhere... (P0034)

A commonality across these management strategies was that individuals seemed to have learnt or deduced for themselves what worked for them and what did not:

I've discovered over time that if you over do it, it makes things worse, so just to pace it. (P0083)

GP

*Exploring fatigue in limited time.* For GPs, the challenge was the complexity of fatigue in the context of appointment times. Although common, GPs described a number of

medical conditions and problems fatigue can be associated with. On the one hand, possible physical causes needed to be explored at initial presentation:

that's why it's tricky, because you almost have to cover with the first "I feel tired" conversation all of the organs in the body to work out if any of them are defective or causing the problem. (GP8)

On the other hand, psychological causes also need to be considered:

It can point to all sorts of problems – may be emotional, may be depression, may be family problems, financial problems...(GP7)

GPs described the extensive process of trying to get an answer. From a 'physical' point of view, techniques consisted of blood tests and asking about secondary symptoms. Psychological or 'psychosomatic' factors were usually considered a more common alternative, elicited through questioning about life circumstances:

The way I think that most of us do it is if the bloods come back normal the first time around, then they've got no other kind of symptoms to go along with anything, then you probably go down the psychological root of tiredness. (GP8)

Whether fatigue was attributed to psychological, physical, or a combination of factors depended on the patient's presentation and also the GP's stance towards the symptom and experience/intuition. Often, the conclusion was that fatigue is multifactorial. As such, ascertaining all the relevant information required was extremely difficult to do.

## Shared

*No quick fix.* Across both parties' accounts, the ultimate issue was that there was no quick fix; immediate resolution and relief was not possible.

I suppose if they can give you a tablet to take and it would take it away, that's the only thing I think that would make it – but there isn't anything. (P0106)

It's always easy when you have a medical problem which you can treat, you can prescribe a medication ... you've only got 10 min and often with those sort of people, those are the people you actually need to spend longer with, to sort of get down to the nitty-gritty of what needs to change. (GP12)

## 3. The consultation – the good, the bad, and the misunderstood

Both parties had clear views about what constituted a 'good' consultation and, conversely, what was unhelpful. Shared understanding was demonstrated, but often discordance between accounts arose, suggesting mismatches in perspectives.

#### The good

*Patient.* For patients, it was clear that a positive relationship with their doctor (e.g., perceived as supportive and approachable) was key for a positive experience during consultation.

I've got a lovely doctor and he's actually talking it through, you know, he's listening to me and he's taking it seriously, he's not just kind of brushing it off and saying, oh go and get some more sleep, because that's not the issue. (P0071)

*GP.* From GPs' perspectives, there was a clear consensus about the importance of 'getting it right'. This involved validating symptoms, presenting a clear picture of fatigue, and not overmedicalizing it; the overall aim being patients take advice on-board and self-manage.

... if you've got the first consultation right and you've taken them seriously, you've communicated clearly, not too many come back... I wasn't always very good... It was just – oh, get out of my surgery really, because there's clearly nothing wrong with you that a doctor can do. And so under those circumstances people just bounced back, progressively more pissed off because doctors weren't taking them seriously. (GP10)

Some GPs described pre-emptively preparing patients to set up successful consultations. For example, clear blood tests were proactively broached in an effort to avoid later disagreement and psychological factors were discussed together with physical ones early in the consultation. Analogies, such as car batteries, were deemed useful (i.e., 'topping up' by managing energy through planned periods of activity and rest, rather than completely draining the battery and then needing to 'recharge').

But also introduce at that stage and say "look – if this blood test comes back as normal, it doesn't mean that I don't believe you're tired, it just means that there's not a biochemical reason for that; we can then explore that next time" – which then sets you up next time for when they come back. (GP8)

#### The bad

*Patient.* Other patients did not report such positive experiences, for example, not seeing the same doctor consistently, perceived disinterest, or no adequate explanation (especially if a mental health issue was indicated). These encounters contributed to the difficulty of making sense of an already complex symptom.

Yeah I mean it may have not been half-hearted, he may have been honest, we might not find it but it didn't feel like there was much interest I suppose . . . I wouldn't say he was particularly bad or off or anything, it just felt like "oh it's all a bit vague". (P0083)

*GP.* For GPs, consultations were described as more difficult when patients were unwilling to accept the involvement of non-physiological components, for example, lifestyle, diet, work patterns, and stress, mainly when the GP suspected the involvement of factors labelled as more 'psychological', 'emotional', or 'psychosomatic', particularly if not broached sensitively.

 $\dots$  whereas if you kind of jump in with – do you think you're depressed, it will put people's backs up. (GP8)

Reassuring patients was often spoken about in terms of 'persuasion', indicating a certain unwillingness of patients to accept that 'nothing is wrong'.

*Shared.* Patients and GPs were in agreement about the driver of initial presentation. Patients rarely presented to GPs in the very first weeks of fatigue if this was their primary health complaint. Both groups described a sentiment of 'normalness'. Only once fatigue persisted for a month or two, did concern arise, or the impact on daily living became unmanageable.

...just constantly thinking 'God, I'm tired', until it got to a point where I thought this is ridiculous. (P0071)

- ...4–8 weeks, I think people probably put up with fatigue for a matter of weeks, but once it goes into anything beyond that, then it gets to a stage where they feel happy to come and highlight it and see if there's anything that can be done or anything underlying. (GP2)
- ... it's come to the realisation that their degree of tiredness is actually more than their partner's, their mum, you know, the people around them. (GP8)

Both parties also shared a need for more resources. Patient suggestions included group workshops, leaflets, posters, forums, and video, for extra support, information, and possibility of reducing the fatigue.

I don't wat to sit around going, 'oh, I'm so tired' – but I'm really interesting in sharing information and finding out what has worked for people... (P0071)

GPs also reacted positively to the suggestion of fatigue resources. Few GPs were aware of recent guidelines [2], and most did not allude to a care pathway strategy, rather employing a 'watch-and-wait' approach or expecting multiple follow-up appointments. All but one GP were very much in favour of extra resources: (1) to address topics they did not have time to cover in the consultation, (2) to provide a platform for discussions in consultations, and/or (3) to give patients something to take away and help self-management. The most dominant topic was simply the need for more time.

 $\dots$  giving them something in their hand which they can actually go away and read and look at  $\dots$  because it's difficult to explain and get everything you want to in the time that you have. (GP12)

#### The misunderstood

If no underlying physiological cause was identified, GPs tried to equip patients with helpful information, for example, pacing, CBT, meditation, and lifestyle changes. Non-return was seen as indicative of fatigue reduction.

I'm assuming it must be working because they're not – they're not coming back to me. If it wasn't working I'm assuming they would come back to me...(GP11)

However, non-return did not necessarily signal a resolution of the problem. On the contrary, patients' fatigue was still present, but they thought that doctors cannot do anything. This was not a reflection on the doctors, but rather patients' difficulty in understanding their fatigue and lack of distinct cause.

 $\dots$  If they check your bloods and there's nothing there – there's nothing more they can do – is there? (P0100)

Another discordant topic was that of blood tests. GPs used blood tests to exclude various health conditions and ensure they were not missing something, despite possibly having suspicions of non-physiological factor involvement. Clear blood tests were interpreted as positive and reassuring and led to psychosocial factors becoming the focus of conversation.

Well often you have a suspicion that it is psychological and there's nothing really wrong, but you end up doing the tests anyway because you need to exclude them for, you know, your own peace of mind and also patient reassurance. (GP1)

However, clear tests often seemed to add to the confusion for patients and did not necessarily reassure them:

they look at my results and say, wow, this is good for a 70 year old, you've got nothing to worry about... So then when you start feeling tired and all the rest of it, you think – oh my word – what is this? (P0124)

## **Discussion**

## Summary

To our knowledge, this qualitative study is the first to combine patient and GP perspectives of subacute fatigue in primary care. Three main overarching themes were identified across both parties' accounts describing the impact of fatigue, the challenges of managing fatigue, and characteristics of the consultation. Patients and GPs shared the viewpoint that the heterogeneous nature of fatigue was problematic; exploring the aetiology of the fatigue, and doing so in the limited appointment time available, was difficult, as was the fact that the symptom could not be 'fixed' quickly. Discordance in perspectives arose when trying to understand the factors involved. GPs often shifted to psychological explanations, especially once clear physiological test results were received. Patients described ongoing confusion about what was causing the fatigue though, suggesting that GPs' knowledge was not necessarily transferred. Patients not representing was seen as indicative of the resolution of the issue. However, non-return tended to be because patients thought the doctors could not do anything for them.

## Comparison with existing literature

Interestingly, subacute fatigue appears phenomenologically similar to chronic fatigue, with similar consequences described to those reported in CFS, for example, 'brain fog', exhaustion, and the transformation of identity (Asbring & Narvanen, 2003; Jelbert *et al.*, 2010; NICE, 2007; Ocon, 2013). Although patients stated at entry to this study they were experiencing subacute fatigue (<3 months), many described fatigue as a long-standing problem, experienced around periods of illness, for example. This is not surprising as premorbid fatigue has been shown to be a significant risk factor of post-infectious fatigue (Petersen, Thomas, Hamilton, & White, 2006; Wessely *et al.*, 1995). Thus, findings from this study should potentially be interpreted in relation to a 'subacute episode' of fatigue. Patients also commonly normalized fatigue, resulting in delayed help seeking. Patients'

fatigue history should be discussed during consultation, which may help identify individuals vulnerable to prolonged fatigue.

On the whole, GPs were aware of various biopsychosocial factors involved in fatigue and potential management strategies. However, patients seldom reported receiving clear explanations for their fatigue, even for those reporting positive experiences. As Kirmayer et al. (2004) describe, sense-making is a process occurring between a patient, publically occurring illness narratives, and the health care professional. However, patients' consideration of lots different causes, difficulty managing the symptom, desire for extra resources, and, in some cases, not returning to the doctor, suggests this two-way sensemaking process was not occurring. Such discordance is common in multifactorial conditions where explanations may be deemed insufficient by patients (Salmon, Peters, & Stanley, 1999) and perceived patient resistance may mean an understanding acceptable to both parties is not reached (Raine et al., 2004). Differences in how negative tests and nonreturn were perceived exemplify this mismatch. GPs viewed clear blood tests as reassuring and interpreted non-return as fatigue having resolved, but clear blood tests were confusing for patients and not returning was a product of the belief that doctors could not provide a resolution. This mirrors conclusions drawn from a systematic review and meta-analysis (Rolfe & Burton, 2013); diagnostic tests as exclusion tools for a range of symptoms do little to reassure patients or reduce their anxiety or symptoms and may reduce subsequent GP visits.

Burton, Lucassen, Aamland, and Hartman (2015) and Dowrick, Ring, Humphris, and Salmon (2004) advocate a rational and effective explanation for 'unexplained' symptoms. Physical and psychological factors should be linked by combining patients' lived experience with clinical knowledge, a practice which requires a shared understanding between the two parties. This is in line with the move away from the traditional biomedical model of health care in which the GP holds a relatively paternalistic role, towards a more individualistic approach (Fong Ha & Longnecker, 2010). This seems particularly important after a negative medical test. However, findings from this current study suggest doctors seemed to shift focus to purely psychosocial factors after negative tests, as opposed to including other non-pathological biological factors (such as the stress response or circadian rhythms) in a truly biopsychosocial model of fatigue.

Additionally, patients are also likely to have tried some management techniques before presenting; eliciting this is an important part of listening to the patient and creating a coherent narrative (Burton *et al.*, 2015). However, the time required for the shared understanding and patient-centred approach may be in stark contrast to allotted consultation time, which in the United Kingdom is typically around 10 min for routine appointments (Oxtoby, 2010). Hannon *et al.* (2012) reported the same issue in CFS, with GPs describing that 10-min consultations meant getting an understanding of varied and potentially complex symptoms was a challenge. It should be noted that Hannon *et al.* (2012) study was also conducted in England. Therefore, it is worth considering that in countries where appointment times are longer, for example, Sweden and the United States where average primary care consultation time is over 20 min (Irving *et al.*, 2017), it may be easier to move towards a shared and individually relevant understanding.

Hannon *et al.* (2012) subsequently suggest providing leaflets which outline management options and the opportunity to return to discuss information in more detail. These suggestions provide a potential avenue for early intervention following this study, namely to prevent the possible perpetuation of subacute fatigue to longer lasting fatigue. As described in the cognitive behavioural model of fatigue (Deary *et al.*, 2007), addressing factors such as excessive rest, unhelpful illness attributions, and sensitization in patient

information materials may help support the sense-making process and disrupt perpetuating cycles (if they exist), within the consultation time constraints.

## Strengths and limitations

A strength of this study is its novel focus on the early stages of fatigue. Findings suggest mismatches in GP and patient perspectives may arise at initial presentation, as opposed to in the latter stages. Appointments at this early stage may, therefore, be important in determining the trajectory of fatigue. However, GPs and patients were not directly matched; some GPs may not have treated any of the patients included and, conversely, some patients may have visited a GP who did not participate. Thus, only general conclusions can be drawn, rather than drawing direct comparisons. Also, GPs worked at surgeries which were part of the larger FAME study, leading to potential bias due to increased levels of understanding around fatigue. Additionally, this study was conducted in primary care practices in the United Kingdom which, as Oxtoby (2010) points out, are under strain when it comes to appointment time allocation. Therefore, findings should be interpreted with caution in the context of other health care settings and other countries' health care systems.

## Implications for research and practice

Future research could compare perspectives from matched GPs and patients in other primary care sites, to further these findings and investigate what consultation components underlie the knowledge transfer gap (e.g., lack of time, expectation mismatch, communication style).

It is important to note that GPs seemed well-informed but are likely to be time-constrained in imparting information to patients. In the absence of lengthening consultations, data suggest a number of useful considerations, summarized in Table 2. For example, our findings suggest that addressing fatigue in a multifactorial and personally relevant manner (e.g., taking patient experience into account and proactively providing an overview of the interlinking and biopsychosocial nature of fatigue) may increase the knowledge transfer occurring between the two parties, in essence providing coherent 'symptom stories' that can lead to practical, individual management advice (Burton *et al.*, 2015). Importantly, although in line with literature and previous findings, these

**Table 2.** Considerations from current research and existing literature findings for subacute fatigue management in primary care

#### Consideration

- Ascertain patient's fatigue history, potential risk for chronicity, and previous management techniques (Fong Ha & Longnecker, 2010)
- 2. Pre-emptively discuss the meaning of negative physiological tests, being careful not to exclude all biological factors from further conversations (Burton et al., 2015)
- 3. Address fatigue in a flexible and multifactorial manner as early as possible, highlighting interlinking physiological and psychological mechanisms relevant to the patient
- 4. Check patient understanding (Kirmayer et al., 2004)
- 5. Double or follow-up appointments may be necessary (Hannon et al., 2012)
- 6. Actively inviting patients back to discuss and monitor self-management could be considered
- 7. Pre-existing CFS management interventions could be valuable preventative tools

recommendations should be interpreted cautiously, due to the small nature of the current study.

In conclusion, fatigue is a complex and potentially re-occurring problem. Even as a symptom in the early stages or experienced in shorter episodes, patients experienced negative impact. GPs' understanding of fatigue and non-physiological management strategies did not seem to transfer to patients, which may contribute to unresolved and ongoing fatigue. Pre-emptive biopsychosocial explanations and encouraging re-presentation could help patients during this early stage.

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Ethical approval was obtained from NRES Committee South Central - Hampshire A.

## **Conflict of interest**

All authors declare no conflict of interest.

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# Appendix A: Patient interview schedule

# Section 1: Acceptability and feasibility

#### Recruitment

a. How did you first find out about this study?

Probes:

i Poster or leaflet

ii GP

iii Nurse

iv Word of mouth

v Other

b. Can you tell me what happened when you were first invited to take part in this study? Probes:

i Who/where/when/how

ii How long ago did fatigue start (time until help sought?)

c. How did you feel about being asked to take part?

Prompts:

i Initial reactions

ii Hopes

iii Concerns

- d. What made you decide to take part?
- e What did you think about the information you were given? Clear/unclear?
- f What did you think about the way you were invited to take part? Acceptable/ unacceptable?

## Sample collection

a. Did you give a blood sample for the study?i If so, how did you feel about doing thisii If not, what were the reason(s) for this

## Questionnaires

- a. Did you complete the study questionnaires?
  - Prompts:
  - i Baseline
  - ii Follow-up
  - iii Timing okay
- b. How did you feel about the questionnaires you completed?
  - i Understandability/ease of completion
  - ii Time taken to complete
- c. Is there any additional feedback you would like to give us about the questionnaires? Prompts:
  - i Relevance
  - ii Ease of completion
  - iii Clarity
  - iv Timing

## Patient welfare

- a. How sensitive do you feel this study was to your needs as a patient? (appropriate, sensitively handled?)
- b. Is there anything that you felt would have made the experience of taking part better for you as a patient?

## Participant questions

a. Is there anything else about taking part in this study that you think would be useful for us to know about?

# Section 2: Perspectives on and beliefs about fatigue

- 1. Clarify when fatigue started.
- 2. How does it manifest itself for you? (personal experience of symptoms).
- 3. How has your health been since we asked you to take part?
  - i. How have your fatigue symptoms been recently?
  - ii. Any other major health issues since you joined the study?
- 4. Can you describe a typical day for me? activity, sleep patterns.
- 5. If you are still having problems with fatigue, how is this affecting your life? (Can you tell me about how the fatigue is affecting your life example?)
  - Prompts:
  - i. Impact on employment, childcare, education, relationships
  - ii. How do you feel about this?
- 6. How do you feel about your fatigue symptoms at the moment?
- 7. To what extent have you spoken to your GP about your fatigue symptoms? Prompts:
  - i. Do you feel that fatigue is a symptom that it's 'OK' or legitimate to seek help for?
  - ii. How important is the fatigue to you relative to the other symptoms you may have had? (e.g., sore throat).
  - iii. How important do you feel the fatigue was to your GP relative to other symptoms?
- 8. What do you think might be causing your symptoms/what might have caused your symptoms? (Interviewer note: listen for how patient is making sense of their acute

*fatigue, that is, conceptualizing and perceiving acute fatigue)*Prompts:

- i. Emotional stress (e.g., anxiety, reaction to negative life events)
- ii. Physical stress (e.g., work pressure, shift work, disturbed nights)
- iii. Biomedical viral, immune, allergies
- iv. Environment or lifestyle
- 9. What are your thoughts on when your symptoms will get better/what are your thoughts on when your symptoms did get better?
- 10. Could you describe your thoughts on what might help your symptoms get better/ what are your thoughts on what helped your symptoms get better?
  - i. Prompt: factors that did/might impact on symptom improvement (Interviewer note: listen for illness beliefs and catastrophization)

# Anything else?

- 11. How do you tend to cope with your fatigue symptoms/did you cope with your fatigue symptoms?
  - i. Can you describe what you do when you are tired (to try and feel better)?
- 12. Have you sought help/support independently of your GP? Elaborate
  - i. Prompts: Friends/family/other private/NHS providers?
- 13. Can you tell me about the support you are being offered to help you with your fatigue/were offered at the time you had symptoms of fatigue?
  - i. Any support at all?
  - ii. Offered/requested?
  - iii. Adequate? Too much/not enough?
- 14. (What) Are there any other modes of support would you ideally have liked/like to have available to you now? Describe these.
  - i. None?
  - ii. Group-based support?
  - iii. Family/friends?
  - iv. GP?
  - v. Other?

#### Anything else?

- 15. Part of this research hopes to develop a resource for people with symptoms of fatigue. This is likely to be leaflet and/or web-based.
  - (interactive sessions, nurse support)
- 16. Can you tell me what you did when you first noticed your fatigue? (time between noticing and seeking help)
- 17. Could you describe any experiences of health care when you first noticed your fatigue?
  - i. Appointment?
  - ii. Info seeking?
  - iii. Management?
- 18. Thinking back to that time when you first sought advice about the fatigue, could you tell me about anything you found helpful/unhelpful?
- 19. Could you describe what you think would be the best way of providing help to people with symptoms of fatigue?
- 20. Could you tell me what your initial thoughts are about the resource?
  - i. What do you think would be useful to include? (helpful/unhelpful?)
  - ii. Is there anything you would have reservations about?

iii. Any ideas for how it would work best? Anything else?

# Appendix B: GP interview schedule

- 1. Just to start off with, can you give me an overview of what you think about the presentation of fatigue in primary care?
  - i. Acute versus chronic
  - ii. Causes
  - iii. Feel towards patients? (especially if no specific cause)
- 2. Can you describe the occurrence of patients presenting with fatigue from your point of view?
  - i. Frequency.
  - ii. Primary presentation or secondary complaint to another problem? (which is more common?)
  - iii. What are patients' main concerns?
- 3. How do you tend to deal with patients with symptoms of fatigue?
  - i. How do patients react?
- 4. Part of this research hopes to develop a resource for people with symptoms of fatigue to prevent it persisting and becoming chronic. This is likely to be leaflet and/or webbased. Could you tell me what your initial thoughts are about this?
  - i. What do you think would be useful to include?
  - ii. Is there anything you would have reservations about?
- 5. Is there anything from your side that you would find helpful when dealing with individuals presenting with fatigue symptoms?

  Anything else?

# **Appendix C: Additional quotes**

## 1. Change from normal – the impact of fatigue

**Patient** 

Cognitive impact.

I found I was very tired, I was having difficulty concentrating and that's a problem for me, I work for myself... (P0017)

...couldn't concentrate on things. The thought of having to - say - talk to someone or go and see someone, was like overwhelming [...] mentally tired, you know, I couldn't concentrate or I found listening quite difficult. (P0034)

# Physical impact.

I suppose just feeling exhausted, just-having no energy, everything, even getting out of bed is the most ridiculous effort. (P0071)

I think – in my mind – you've got tiredness where you generally just feel tired, but to me, the fatigue was the feeling that swept over me – that my arms and legs felt heavy and

that I just couldn't move, couldn't physically move – like I was completely, totally exhausted. (P0086)

## Emotional impact.

Low energy gives you low mood; you just feel... much more negative than positive. (P0034)

I find myself being very snappy with people, very sort of – short tempered... (P0071)

Not depressed, it's more irritated and fed up with it [...] I'd not gone out very much, I'd missed a lot of things...(P0083)

I shouldn't be falling asleep in the middle of the day  $[\ldots]$  I have timescales and deadlines to work to so I get a bit annoyed with myself. (P0017)

# Changed self.

 $\dots$ once it's got hold of me, I feel like a completely different person. (P0052)

My wife says I'm more irritable than normal – and that could be possibly because I'm tired or because I don't want to be tired'. 'I do feel a little bit inadequate that way, because I've always done that sort of thing, you know, I've always done my decorating. (P0008)

...short tempered and all these sorts of things and I don't want to be that person, because that's not normally what I'm like'. 'My stress levels and my ability to deal with things normally, in a rational way – totally out of the window which, again, is not like me at all. (P0071)

Never did consider myself as that type of person, they sort of have what they call power naps in the afternoon, but I've never done that. And I've found myself, you know, just nodding off. (P0124)

#### Shared

#### Sphere of impact.

I might look at it for September next year – look at reducing my working hours. . . So I think try and get some time back to fit in other things, which then might allow you to have more rest time. (P0100)

And my class teacher saw a change in me as well and, you know, people were always asking – are you alright? (P0052)

...because they're fed up of feeling tired or – particularly if it's affecting their day-to-day effectiveness. (GP5)

# 2. The challenges of fatigue

## **Patient**

## Patients' understanding.

It turns out I've got two family members have had post-viral fatigue and my daughter has got PoTS [postural orthostatic tachycardia syndrome]; I think it's a hereditary something that has triggered this. (P0065)

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...thyroid, you know that's one thing your body but there's other things that could be affecting it. I don't know, maybe kidneys or liver... I don't want to sound like I'm a hypochondriac but there could be something in my head, in my brain. (P0052)

And obviously our food and everything's changed, we put more preservatives in food – you don't know if that's part of it... Years ago you didn't work weekends, whereas now everything's open 24/7... And there's no answer for that – it's how life evolved isn't it. (P0100)

## Patients' management strategies.

I think when you've actually got symptoms of something wrong it's easier to deal with but it is just being tired, and light-headed and a bit off – so it doesn't feel like there's a definite wrong with you, you're just not up to scratch. (P0083)

There's no pattern, not one that I can determine anyway. (P0001)

I just kind of want facts, you know, I want to know what's going on and I want to know what I can do and I want to change it and I want to do that as quickly as possible. (P0071)

when I'm like that I do things in short bouts... I pace myself I suppose is the best way to do it. (P0083)

I do try and rest and – but, as I say – and make sure that I do get up and walk around... (P0106)

I had physio for something else and the activity has helped me in all manner of ways... I get it less often now and I just put it down to the fact that I'm more active than I was, but I don't really know, we make things up ourselves [laughing]. (P0001)

I have been exercising more and I have found that does help with my energy levels – I'm not quite as slumpy as I have been. (P0061)

#### GP

#### Exploring fatigue in limited time.

It can be anything from having a low blood count to an underactive thyroid, being diabetic to having problems with your kidney, problems with your liver, too much salt, not enough salt. So physically there's quite a lot of things that it can be. (GP8)

Well if you look at the main group, sort of people of working age, 95% of the time it is – social, psychological, occupational related, so there isn't a physical disease, it's a physical reaction to the social, psychological environment they're in. . And then there are this small group of people that have a physical illness and usually they're have other symptoms associated, which gives you a clue. . . (GP10)

#### Shared

## No quick fix.

So you're just permanently looking for solutions and as quickly as possible really'. 'Maybe I'm looking for a miracle which doesn't exist. (P0071)

...but quite often I guess the majority of patients don't necessarily have anything you can find from the blood test and you can fix very quickly. (GP3)

Well, you're not going to just give them a prescription, some easy - you know - answer  $\dots$  it's complex basically... you need to see them at least twice, possibly three times or longer. (GP4)

# 3. The consultation – the good, the bad, and the misunderstood

#### The Good

One thing you want to avoid is a total line between – there's something wrong with you and there's something that's not – and if not, here's this [alternative resource]. You know, it has to link in, there might still be something wrong with you, it might still be investigated. . . these are the tools that might actually help you feel better, regardless of whether there's anything diagnosed or not. Because otherwise, you have to really work at people to utilise things like the psychological pain therapies, because they won't do it unless everything else is excluded. (GP1)

Patients aren't fools. I mean they might not understand the terms we use but the concepts aren't alien and I think, you know, if you present it I think you're more likely to get a buy-in as well. (GP4)

#### The Bad

And I did and they did some blood tests and they said – oh – there's nothing wrong with your blood tests, it just must be depression – and said, you know, we'll put you on antidepressants. And I said no, I didn't think it was and I didn't want to take antidepressants – because I think that's kind of – I don't know, it's only my opinion I just think that it's just an [easy win] to say – you're depressed, take these, you'll feel better, whereas I don't think that's always true. I think – my dad has depression – and he really does have depression, it's very obvious; he's got all the tell-tale signs and he takes antidepressants and he's absolutely fine, I don't think he would cope without them. I don't think I'm depressed, I'm just god damn tired. (P0052)

So I didn't see the same doctor and the second doctor, when he looked at the information, he was the one that said—I had a deficiency, whereas the first doctor made it sound like I was kind of like dangerously low on Vitamin D. So it's a matter of interpretation, I suppose. (P0086)

I mean [doctor] said sometimes people with fatigue and that – they sometimes benefit with antidepressants but I've got to be honest, I don't really want to go down that road. I've just got a thing about antidepressants... it's not in my mind, I'm not depressed, because I haven't got any reason to feel depressed. (P0106)

...but with online resources, they'll often list the minutiae of the possible causes, you know—which are vanishingly rare and sometimes patients get really hooked on that. And so it can be—it just makes the consultation even harder in terms of trying to persuade them that there's nothing wrong. (GP6)

## Shared

#### Presentation.

Well they are often worried about what's causing it . . . But it's also just the effect it has on their day-to-day life that they are often worried about. (GP6)

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Yes, because you do – you know – you do think the worst, I know it sounds awful, but you do sort of think – Christ, you know, this is something more serious? (P0071)

Feel like I've been a bit of a fraud 'cos just going [to the GP] you know, saying you're tired – 'cos everyone feels tired don't they'. 'I'm prepared to – to leave things for a little while longer, but if it gets worse, obviously I have no choice, but I need to go through this period to see if things balance themselves out a bit. (P0017)

So I just thought I was fighting a virus and everyone was – you know – the posters say – your GP can't do anything, sort of thing, and then I got told off. I left it a bit too long. (P0065)

If they're feeling fatigued, it can come quite slowly, if it is not always there, so sometimes they are feeling ok, sometimes they're not – they don't see it to be a big problem, they get on with things. (GP7)

I guess because tiredness is part of our normal human experience for everybody, whereas chest pain isn't. So acute tiredness is not abnormal for the vast majority of people, whereas chronic tiredness is. (GP10)

#### Resources.

I think, to me, it would be worth trying anything, you know. I can't see why anyone would say no, to be honest. (P0106)

It does [give something to signpost patients], especially since the wait for CBT locally is just – you know – ridiculous: 3 months-ish. (GP1)

I think increasingly we are becoming over and over worked and if there is a resource that we can potentially have around the surgery – before they even present or something that we can highlight and reiterate these points post presentation would be excellent. . . educational tool for patients and pre-empt presentation, and enable self-management, which has to be the way forward for a lot of the things we potentially see. (GP2)

I think that there are a lot of basics that could be discussed with these people and we don't have time to do it, like sleep hygiene and the diet and giving them sort of empathy...(GP7)

to have some advice about what would be the most likely causes and what would be an appropriate screen to instigate on the basis of that... would be a useful tool to have, to enable us to more confidently deal with things conservatively rather than reaching for investigations and medicalising patients. (GP2)

# The misunderstood.

Assume there is something physical going on and maybe we don't see them again, so we assume that they got better. (GP7)

Like I said, you feel almost silly going to the GP because you know deep down there's not a lot they can do unless they find something that's causing it. (P0061)

So I always say that it's likely to be a bit of stress, maybe a bit of mild depression, but – I'd rather just check everything else is normal first, before giving them that as the diagnosis. (GP13)