



Review

# Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies

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## Abstract

**Objective:** To provide insight into patients' and doctors' experiences with CFS.

**Methods:** We compiled available qualitative studies and applied meta-ethnography to identify and translate across the studies. Analysis provided second-order interpretation of the original findings and developed third-order constructs from a line of arguments.

**Results:** Twenty qualitative studies on CFS experiences were identified. Symptom experiences and the responses from significant others could jeopardise the patients' senses of identity. They felt severely ill, yet blamed and dismissed. Patients' beliefs and causal attributions oppose the doctor's understanding of the condition. For the patient, getting a diagnosis and knowing more was necessary for recovery. Doctors were reluctant towards the diagnosis, and struggle to maintain professional authority. For patients, experience of discreditation could lead to withdrawal and behavioural disengagement.

**Conclusion:** The identities of CFS patients are challenged when the legitimacy of their illness is questioned. This significant burden adds to a loss of previously established identity and makes the patient more vulnerable than just suffering from the symptoms. CFS patients work hard to cope with their condition by knowing more, keeping a distance to protect themselves and learning more about their limits.

**Practice implications:** Doctors can support patients' coping by supporting the strong sides of the patients instead of casting doubt upon them.

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**Keywords:** Fatigue syndrome; Chronic; Qualitative research; Meta-analysis; Adaptation; Psychological; Identity crisis; Physician–patient relations; Chronic disease

## 1. Introduction

Chronic Fatigue Syndrome (CFS) is characterized by severe, disabling fatigue and other symptoms, including musculoskeletal pain, sleep disturbance, headaches and impaired concentration and short-term memory [1,2]. The diagnosis can be made only after all relevant differential diagnoses have been excluded [3]. CFS prevalence among US adults is 0.23–0.42% [4].

The CFS concept, including diagnosis and etiology, is debated among professionals and patients, especially since consistent biomedical markers are missing. Patients are often annoyed by the lack of understanding from others, including medical

professionals. Doctors seem to find CFS challenging too [5,6]. The burden of suffering for this group of patients is extensive and justifies development of knowledge which can be used to increase the quality of care. Patient experiences may provide access to understanding of significant issues beyond the biomedical level. An increasing number of studies report experiences with CFS, mainly in patients but also in relatives and doctors.

The aim of this article is to explore how patients experience CFS and how doctors relate to the condition. By synthesizing the qualitative research, we want to organize the existing body of knowledge about CFS experiences and create access to processes possibly influencing the progress and impact of CFS.

## 2. Design, methods, and material

Systematic reviews aim to gather, critically appraise and synthesize primary studies in a transparent way. For synthesis

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**Box 1. Noblit and Hare's seven steps for meta-ethnography (Noblit & Hare [8])**

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into each other
6. Synthesizing translations
7. Expressing the synthesis

of qualitative studies, different methodologies have been presented [7]. In this article, we chose *meta-ethnography*, a strategy presented by Noblit and Hare [8] for synthesizing findings across a number of qualitative studies (Box 1).

### 2.1. Search and selection of studies

Getting started (step 1), we aimed to identify qualitative studies about CFS experiences in English or any of the Nordic languages. We searched MEDLINE, EMBASE, CINAHL, PsycINFO, and AMED up to February 2006. The databases were searched using topic specific subject headings (in MEDLINE MeSH headings Fatigue Syndrome, chronic and fatigue, asthenia, muscle weakness and neurasthenia) and text words (in MEDLINE a total of 31 e.g., myalgic encephalomyelitis, lassitude and CFIDS) in combination with search filters identifying different kinds of qualitative studies. Abstracts and titles were screened and potentially relevant articles were retrieved in full text and independently read (KM and LL) and screened according to

- Study design: Empirical qualitative studies
- Population: Patients with Chronic Fatigue Syndrome (CFS, ME, PVFS, CFIDS), their relatives, or doctors treating patient with this disorder

Quality assessment was done independently (KM and LL) according to a checklist for qualitative studies covering aim of the study, reflexivity, methods and design, data collection and sampling, theoretical framework, methods of analysis, results, discussion as well as presentation [9]. We excluded studies rated with low quality when several of the checklist chapters were not fulfilled to satisfaction.

### 2.2. Analysis

The authors proceeded through the analysis process together with subsequent negotiations towards agreement. We identified details of each study setting and participants, including number of par, illness duration, and data collection method (Table 1).

We then organized the themes of the primary studies (step 2) into three groups; (a) symptom experiences and consequences

for everyday life, (b) illness beliefs and causal attributions, and (c) doctor–patient interaction. A study might fit in more than one groups e.g., Denz-Penhey [10] represented both symptom experiences and doctor/patient interaction.

For each of the groups, we created a grid with studies along the *x*-axis and the *content issues* (essential findings and interpretations) along the *y*-axis (Table 2).

We chose an *index study* [5,11,12], as a starting point for each of three groups, characterized by high methodological quality, rich data and systematic presentation. Reading the studies closely (step 3), we identified content issues, as expressed by the original authors, for example ‘too tired to talk’. We determined how the studies in the same thematic group were related (step 4), and processed each of them into the grid, maintaining the terminology from the original papers. In this way, we were able to compare the content issues from each study (step 5). Examples of related issues were ‘too tired to talk’, ‘affected lifestyles’, and ‘devastated social relationships’. After having organized the core content issues of each paper, relating them to each other horizontally, we looked across the grid. We put them together in an overarching translation, synthesizing them into a new term, – a *second-order analysis* (step 6). These new concepts, such as “no longer capacity for social involvement”, “weak character” and “negotiating the nature of the disorder”, represented the outcome of the second-order analysis (Table 3). This reconceptualisation was mainly achieved by *reciprocal translation* [8], meaning that a higher order interpretation is grounded in the related and convergent findings of the primary studies. Concepts were also explored for divergent findings across the studies, which is *refutational translation*. Reading the findings from the second-order analysis, we developed a “*line of argument synthesis*” [13], where another level of understanding – a *third-order analysis* – was worked out [14].

## 3. Results

The initial search identified 806 titles. After screening titles and abstracts we were left with 48 articles retrieved in full text. Twenty two of these papers did not primarily deal with CFS. The remaining 26 were critically appraised. Six were excluded due to low methodological quality, such as limitations concerning design, poorly described analysis, insufficiently stated theoretical framework or missing discussion of implications [15–20]. Twenty papers were included in the synthesis of findings (Table 1). Below, we first express the synthesis from the second-order analysis for each of the thematic groups (step 7). Translations of noteworthy core contents are marked in italics.

### 3.1. Second-order analysis

#### 3.1.1. Symptom experiences and consequences for everyday life

Studies presented a broad range of accounts about how the condition affected daily life. The fatigue was described as

Table 1  
Features of the 20 primary studies included in the analysis

Source paper ( <i>n</i> = 20)	Country	Data collection	Sample origins	Participants (Illness duration)
Anderson and Ferrans [22]	USA	Personal semi-structured interview	Self recruited, convenience sample	22 (1.5–18 years)
Asbring [34]	Sweden	Personal semi-structured interview	Hospital outpatient clinic, strategic sample	12 (1–23 years)
Asbring and Narvanen [31]	Sweden	Personal semi-structured interview	Hospital outpatient clinic, strategic sample	12 (1–23 years)
Asbring and Narvanen [30]	Sweden	Personal semi-structured interview	26 doctors from general practice, rheumatology, internal medicine, rehabilitation, neurology or infectious medicine	26 (Not relevant)
Asbring and Narvanen [25]	Sweden	Personal semi-structured interview	Hospital outpatient clinic, strategic sample	12 (1–23 years)
Clarke [17]	Canada	Personal semi-structured interview	Recruited CFS-support groups	59 (12.5% over 10 years)
Clements et al.[28]	UK	Personal semi-structured interview	Medical infectious disease department, 66 consecutive patients	66 (6 months to 7 years)
Denz-Penhey and Mardoch [10]	Australia	Personal semi-structured interview, group-agreed meeting statements, field notes, journal entries, questionnaires, handbook Pilot action model	General practice, first 10 patients	10 (Mean 9.4 years)
Gray and Fossey [21]	Australia	Personal semi-structured interview Narrative approach	Recruited form by patient organizations newsletter, purposeful selection CFS diagnosed by doctor	5 (2–10 years)
Hart and Grace [11]	New Zealand	Personal semi-structured interview  Discourse analyses	Recruited from general practice and ME support group  Not stated	11 (Not stated)
Horton-Salway [26]	UK	Personal semi-structured interview  Discourse analysis	Single case study  Not stated	One women and her husband (Not stated)
Horton-Salway [5]	UK	Personal semi-structured interview	Recommendation from patient organization Strategic sample	10 GPs (Not relevant)
Horton-Salway [29]	UK	Observation  Personal semi-structured interview	Meeting in a British patient organization with a psychologist as speaker  Strategic sample from the members	14 (Not stated)  1
Lovell [23]	UK	Personal semi-structured interview	Recruited through a travel health clinic for overseas aid workers	12 (24 months)
Raine et al. [6]	UK	Group interview	Random selection of general practitioners	46 (Not relevant)
Soderlund et al. [2]	Norway	Group interview Questionnaire	Members of local self-help patient organization, purposeful sample	12 (1–20 years)
Soderlund and Malterud [27]	Norway	Personal semi-structured interview	Members of local self-help patient organization purposeful sample	8 (2–11 years)
Taylor [33]	USA	Group interview Questionnaire	Local self helping organizations, physicians specializing in treatment of CFS, and advertisement	47 (Not stated)
Ware [1]	USA	Personal semi-structured interview	Not stated	66 (2.5–36 years)
Woodward et al.[32]	Australia	Personal semi-structured interview	GPs recruited from RACGP Patients diagnosed by doctors as having CFS	20 GPs 50 (Not stated)

physical, mental, and fatigue within one's self [21]. An overwhelming and specific lack of energy, comparable to the impression of *an empty battery or a blown fuse*, was portrayed as an 'extreme' and abnormal depletion of energy compared to life before illness onset [2,22]. A Norwegian member of a support group, said:

“If I managed to prepare dinner, I could not manage to sit at the table and eat it. I could not lift my arm holding the fork before having rested.” [2]

Across the studies patients told about the losses experienced when they felt *controlled and betrayed by their*

Table 2  
Content issues from the primary articles about symptom experience and consequences for daily life

Hart (2000)	Søderlund (2000)	Gray (2003)	Åsbring (2001)	Clarke (1999)	Lovell (1999)	Anderson (1997)	Taylor (2005)	Ware (1998)	Our translations:
Communication— too tired to talk	Social life	Affected lifestyles - school	Reflection upon life and priorities	Busy active lives before illness	Very healthy premorbid health	Devastated social relationships and activities		Communication skills essential to effectiveness at work.	The body cannot bear social interaction
The whole body— their bodies talk	Sound	Physical fatigue			Symptoms of CFS	Variability		Mobility to work	The body controls and betrays me Reduced mobility No bright spots
Mobility—getting about Relation to illness— knocking the stuffing out.		Walking					No positive gain		
Energy—lack of	Exhaustion	Fatigue. Physical and mental				Depletion of energy			The fuse is blown the battery is empty Pain
	Pain Concentration – learning and short term memory	Mental fatigue		Sudden onset		It changed absolutely everything Application process social security disability benefit.		Cognitive impairment inhibits job-related learning	Problems with memory and learning It changed absolutely everything Standing up for one's rights

Table 3  
Synthesis, including second- and third-order analyses

Groups	Second-order analyses	Third-order analyses
Symptom experience and consequences for everyday life	An empty battery or a blown fuse Controlled and betrayed by their bodies Bodies which no longer held the capacity for social involvement	Identity Legitimacy of their illness being questioned Previous sense of identity became more or less invalid Strategies for coping Knowing more about the condition Keeping a distance to protect oneself Learning to know more about their limits
Illness belief and causal attributions	A classical infection striking a fragile immune system Bodily collapse due to stress and overload Definitely not a psychosomatic disorder Weak character	
Doctor-patient interaction- "are you really sick?"	Negotiated the nature of the disorder Confrontations with their doctors when biomedical markers were absent Guilt, blame, shame game Challenges when a professional authority should be managed under considerable scientific uncertainty The significance of getting a diagnosis	

*bodies*. Several informants described struggles in completing what for healthy persons are relatively effortless routines [1]. Range of activities and environments had become severely restricted [21]. Constrained movements expressed through references to walking and driving, entail a considerable limitation of mobility [11]. Patients complained of pain, sleep difficulties, headache, nausea, dizziness, muscle weakness—like having the flu every morning [2,21]. Auditive perceptions occurred, such as a high-pitched sound, noise in general or an excessive sensitivity [2]. The mental fatigue affected memory and concentration. Conversations might be hard to follow, and several felt that their learning abilities had deteriorated [2]. An Australian man diagnosed with CFS declared:

“I worked out that if I do an activity for a couple of hours, my brain sort-of goes over-active. . . so if I lie down for it, it could be even 10 min, or in the complete darkness with no noise or anything . . . it settles my brain down, and that seems to help all of my symptoms.” [21]

Symptoms could have an extensive impact on social life, including school or work [1,2,21]. Analysis revealed stories about *bodies which no longer held the capacity for social involvement*. Some patients had managed to remain in the labour force by prioritizing work, eliminating other activities to conserve energy [1]. However, communication skills essential at work, such as listening, speaking or writing, might become compromised by the illness [1]. Most patients told about a good premorbid health, with busy and active lives [23,24]. The illness had devastated their social relationships and activities [22]. Especially hard for those who had previously been regarded as social and outgoing was the experience that significant others did not understand the impact of their disease [2]. A Swedish woman, said:

“Our lives have become like that of a pensioner. You just can’t cope with having guests at the house, at least very rarely. And you can’t plan for it as you may feel so awful that you can’t face seeing anyone.” [25]

### 3.1.2. Illness beliefs and causal attributions

CFS was described by patients as a physical illness with symptoms reflecting immune system dysfunction [10]. An underlying assumption is that there is a biomedical explanation, such as *a classical infection striking a fragile immune system* [5,10,23,26,25] A Norwegian woman states:

“The AIDS virus wasn’t discovered for quite a long time, so only God must know how long it will take before they find this one.” [27]

Several studies describe patient perceptions of *bodily collapse due to stress and overload*. Participants suggest that they have become susceptible to a virus infection which triggered CFS [10,23,25,27,28] Perpetuating factors are described as stress at work, being put pressure upon, stressful life, living conditions, work burden and social relations [5,23,27,28] an English woman puts it this way:

“...this is the last thing you must do is to push yourself when you first go down with ME and I was doing all the wrong things and I think that’s why I’ve never ever recovered” [26]

While patients and doctors attribute symptom fluctuations to mental as well as physical factors [5,23,27,28] patients uniformly attribute the origin of the illness to physical factors. Although patients consider physical-, disease-, stress-, activity- and lifestyle factors as possible causes, they emphasize that their condition is *definitely not a psychosomatic disorder* [23,26,28]. Ten out of twelve overseas workers reported that they had been consistently healthy before CFS started [23] and an English patient stated that:

“It (the illness) hit me at a time of life when I couldn’t have been more fulfilled. So at no time must anyone dare tell me that it is all in the mind.” [23]

Still, patients as well as doctors find it difficult that there are no objective medical markers [25]. Doctors apply psychodynamic or psychosomatic models when objective measurable values do not verify the patient’s symptoms [5,25]. They

interpret symptoms as psychological vulnerability in patients with certain personality traits, such as a *weak character* [5,6,23].

### 3.1.3. Doctor–patient interaction

Analysis including refutational translation demonstrated tensions when doctor and patient *negotiated the nature of the disorder* in question. Experiences and viewpoints covering both sides of the interaction were demonstrated in several studies. An action research study explored patients’ needs and wishes regarding culturally suitable service delivery for people with CFS [10]. A British woman, member of an ME support group, concluded:

“I think a lot of the depression side of ME in sufferers comes from the fact that we become depressed trying to convince the doctors, the medical profession, that there is something wrong with us.” [29]

Patients reported experiences of *confrontations with their doctors when biomedical markers were absent* and a precise bodily location of the illness could not be identified [10]. Patients remarked the insufficiency of doctor’s illness models [10], while doctors complained about contradictory views on the nature of the condition [30]. Negotiations took place about whether the disorder was a mental disease [5,29]. According to doctors, patients were reluctant to psychological referral [5]. The diagnostic label could make a difference for patients. An ME diagnosis was considered as ‘less psychological’ than a CFS diagnosis [29] by patients. Correspondingly, doctors could judge a patient as more or less psychologically vulnerable, thereby attributing a vote in the combat patients called the ‘*guilt, blame, shame game*’ arising when the doctor thought it was all in their minds [5]. A Swedish woman commented:

“I am not that stupid that I don’t get it, when it is like implied that it is probably due to nerves in some way.” [31]

Some of the studies revealed the challenges for the professionals when *a professional authority should be managed under considerable scientific uncertainty* [5,12,32]. They felt uneasy when the biomedical ideals did not fit with the clinical reality [12], and considered the diagnostic category dubious [5,6]. Some doctors characterized CFS patients by lacking stoicism and having certain personality traits described pejoratively [5,6]. Patients perceive such attitudes as dismissing their morality and credibility, asking whether they are really sick [10,31]. This could lead to lack of trust and power-strategies applied by patients in the consultation [25]. A British GP said about these patients that there was

“...a certain personality trait that is chronic fatigue syndrome waiting to happen.” [6]

*The significance of getting a diagnosis* was consistently reported by patients [10,24,31,32]. Getting a diagnosis was mentioned as the single most helpful event by patients [32]. Several patients had found it frustrating to wait for years before receiving a CFS diagnosis, and some had initially been misdiagnosed. Yet, doctors appeared reluctant

on this issue [32]. Some patients experience difficulty in accepting this diagnosis, which could also function as a burden for them [23,31]. An Australian patient presented this experience:

“..I’ve got something which no one believes in. Even the doctor who gave me the diagnosis told me he had always thought it was hysteria.” [31]

### 3.2. Third-order analysis

The findings from the second-order analysis provided the foundation for development of a *logical line of argument* (Fig. 1):

- CFS patients’ symptom experiences shape their illness beliefs.
- Doctors’ beliefs, shaped by biomedical presumptions, are very different.
- Tensions emerge in the doctor–patient interaction when these beliefs are conflicting.
- The antagonism has an impact on CFS patients’ identity and coping.

The way their bodies were affected, convinced patients that CFS was definitely not a psychosomatic condition, while doctors were reluctant even to regard this condition as a disease. Conflicting views lead to negotiations as to the nature of the disorder. These experiences became crucial for patients’ identity and coping experiences. Below, we elaborate the synthesis from the third-order analysis.

#### 3.2.1. Identity

The profound bodily and social consequences of the condition affected CFS patients’ feelings of self, when they gradually found themselves socially marginalized. Moving towards a more passive life, led to loss of relationships with significant others. Combined with a declining personal economy, transformation of identity could occur [25]. For some, the most distressing experiences were negative responses from family members and workplace, *questioning the legitimacy of their illness behaviour* due to the fluctuations of the impairment [33]. The biographical disruption and

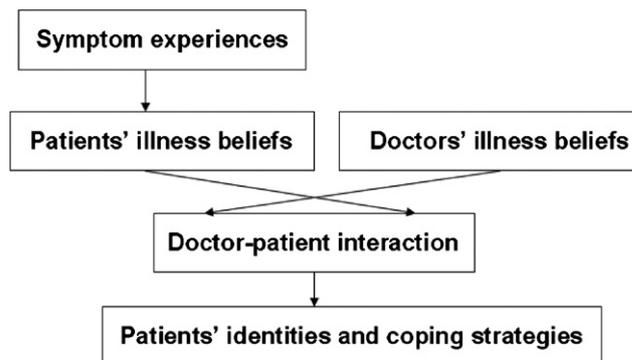


Fig. 1. Line of arguments—third-order analysis.

lifestyle changes experienced by patients could imply that their *previous sense of identity became more or less invalid* [21,34]. A Swedish woman said:

“This having lived a little over 2 years with a ‘me’ that is no longer the ‘real me’, because it is a completely new person. As time passes I can find certain things that I recognize from before but the rest is actually new and it’s not me and I don’t recognize myself. And still, I must socialize with this person.” [34]

Such considerations were sustained by being severely ill, and yet feeling blamed, mistrusted, dismissed, and morally judged by everybody [26,31–33] Since the disease was not recognizable, the ill person’s experience was denied, explained by doctors as a tricky case with a dubious diagnosis [5,10,12]

### 3.2.2. Strategies for coping

Managing the conflicting experiences, CFS patients employed cognitive, psychosocial and activity-based strategies to come to terms with the illness, without letting the illness taking over. To deal with the uncertainty related to the nature and prognosis of the condition, many of them sought understanding through acquisition of knowledge, hoping to find a possible diagnosis [25]. Diagnosis gave them something to hang on to, expecting to clarify the situation, make sense of the problems, and protect from being blamed by others [10,31,32]. *Knowing more about the condition* was mentioned as necessary for reconciliation and creating strategies for hope and recovery [21,28,34].

Yet, repeated incidents of being discredited could lead to patterns of withdrawal and disengagement [25,31,33,34]. *Keeping a distance to protect oneself* could be handled by concealing the illness as far as possible [1,12]. An American laboratory worker with CFS thought she had no choice but to ‘play dumb’ because her colleagues would never accept CFS as a ‘real illness’:

“No one else in the lab knows and there’s no way you can tell somebody, ‘Look, I’ve got CFS, I’ve got cognitive dysfunction deficit. Can you do my calculation for me?’ They’ll laugh at you. ... I make myself look stupid so people will help me.” [1]

Many ways of re-establishing their sense of self, bodily as well as mentally, were described. An appropriate balance of activity and rest was often mentioned, finding flexibility and *learning to know more about their limits* [1,21,34,26]. Compensating deficits could be mediated by changing expectations, making everyday priorities, and resisting role constriction [1,21]. The unpredictability of symptoms was disturbing, and worsening of symptoms would therefore sometimes be taken as self-inflicted [1,5]. Relapse prevention became important, listening to early warning signals, putting the body in the best possible situation, and regulating activity by pacing [10,28]. A British patient diagnosed with CFS reported intermittent attempts to overcome the restriction imposed by the illness:

“I don’t like giving in to it. . . . But then I’m always sorry because I can spend all day tomorrow in bed for fighting it today.” [28]

## 4. Discussion and conclusions

### 4.1. Discussion

#### 4.1.1. Methodological challenges

While *meta-analysis* with pooling of standardized quantitative randomized controlled trials allows for reanalysis of data, qualitative studies provide access to *meta-synthesis* of findings through systematic interpretation [35]. The purpose is to extend the level of interpretation, not to test prevailing conclusions [7]. A number of methods for synthesis of qualitative evidence exist. We chose an approach based on a detailed and transparent procedure – *meta-ethnography* as described by Noblit and Hare [8]. This strategy has previously been used by several authors [14,36,37] whose publications demonstrate some important methodological challenges.

First, the researcher need to consider whether the search strategy should be theoretical (saturated) or comprehensive (attempt to identify all). We chose the latter, but do not believe that any search strategy will guarantee full coverage of the potentially eligible primary studies, since key words and referencing of qualitative articles still are not always adequate.

The second question deals with quality assessment of the primary studies. We used Malterud’s [9] checklist and found it surprisingly easy to agree to which articles were of too low quality to be included in the analysis. However, although we found that the quality of the remaining articles varied much, the methodological traditions within such a cross-disciplinary academic field provide different format traditions and quality criteria. Comparing and assessing quality is simpler when study designs are more standardized. We included studies representing different designs such as interview studies, discourse analyses, narrative analyses, and grounded theory. The different approaches added to the variation of findings, but the consequences of such challenges need to be explored.

#### 4.1.2. Feeling severely ill, yet blamed and dismissed

Our analysis demonstrated that patients’ sense of identity becomes more or less invalid and that a change in identity is experienced. The foundations and severity of such shifts have been described in biographical accounts [38], but not previously documented by research describing the development through symptom experience, illness belief and doctor–patient interaction. Our findings align with knowledge about diseases such as arthritis, fibromyalgia and chronic depression, and extend the understanding of how chronic illness may invade the person’s sense of self [39]. The patients feel severely ill, yet they feel blamed and dismissed by the doctors who hold a different illness understanding than themselves. Worst of all is to be told without explanation that “it’s nothing; it’s all in your head”. Diagnosis not only names the malady but also implies that it has a recognizable cause. This is why people with

fibromyalgia or CFS struggle to have their maladies named [39].

Patients develop different coping strategies. Getting a diagnosis and knowing more was necessary for reconciliation and creating strategies for hope and recovery, independent of an immediate effect on treatment strategies. Experience of discreditation could lead to withdrawal, disengagement and keeping a distance to self and others.

Doctors describe a struggle to maintain their professional authority under considerable scientific uncertainty. Montgomery [40] states that the clinical encounter focuses on a pressing, practical question: what is causing this patient to feel ill? The patient want to know the cause and expect that science will supply the answer [40]. For the physician not to identify the malady – even when the physical suffering is relieved or cured is somehow puzzling, a source of unease in itself.

#### 4.2. Conclusion

The identities of CFS patients are challenged when the legitimacy of their illness is questioned. This significant burden adds to a loss of previously established identity and makes the patient more vulnerable than just suffering from the debilitating symptoms.

#### 4.3. Practice implications

CFS patients work hard to cope with their condition by knowing more, keeping a distance to protect themselves and learning more about their limits. Doctors can support patients' coping by recognising the pitfalls arising from these complexities and support the strong sides of the patients instead of casting doubt upon them. A challenge for further research is to explore the coping processes of CFS patients who meet health professionals that support and encourage their coping efforts and strong sides.

#### Conflict of interest statement

We are aware of no conflicts of interest.

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*Contributors:* LL and KM selected relevant articles and did quality assessment. LL and KM conducted the analyses and wrote the paper together. LL will act as guarantor for the paper. Both authors have made substantial contributions and comments on the paper.

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