

What are the Attitudes, Beliefs and Knowledge of Health Care Professionals about Chronic Fatigue Syndrome: A Systematic Review to guide curriculum development

By Garth Reypert

RYPGAR001

Mini Dissertation for Masters of Public Health

(General Track)



Supervised by:

Assoc Prof Romy Parker

And

Dr Maylene Shung King

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Part 0: Preamble

Abstract

Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME) is a relatively unknown disease and is often referred to as a diagnosis of exclusion. Diagnostic tests are not available for this disease because a single empirical cause or marker has yet to be discovered. This means that diagnosis and management is almost solely based on the skill of the health care professional to notice the signs and symptoms of the disease, the subtleties of which often only come with experience. While some studies have assessed the knowledge, attitudes and beliefs of health care professionals (HCP) towards CFS/ME, none have reviewed all the studies focused on health care professionals to aide students and inexperienced professionals to avoid negative behaviours that might lead to a CFS/ME patient not being diagnosed as having CFS/ME.

This review contains three parts.

Part A is the protocol for the review. This will highlight the background of CFS/ME knowledge and outline the review's methodology. The review will take the form of a qualitative systematic review. Six databases will be searched with the relevant keywords and search terms outlined in the protocol. Appropriate articles will be selected based on the inclusion and exclusion criteria defined in the protocol.

Part B is the literature review of the existing research available in the field of CFS/ME, the knowledge of the disease and the attitudes and beliefs of health care professionals about CFS/ME. It will provide a background for the full systematic review in Part C. This review will detail what is known about CFS/ME as a disease, report on potential causal mechanisms for CFS/ME as a disease and report on the scope of the disease in epidemiological terms.

Part C is the full systematic review. It follows the previous section in the description of the background as well as outlining the methodology followed. The results of the search are then reviewed and discussed in detail.

The results show that HCPs rely heavily on a Biomedical model of understanding CFS/ME. This reflected in their treatment options they chose as well as their attitude towards their patients. Even recently, student HCPs felt that CFS/ME patients were “time wasters” and “malingerers”. Less importance was placed on CFS/ME when it was self-studied by students. However, HCPs when education incorporated an interactive session as well as having personal interaction with a CFS/ME patient resulted in better treatment options used by HCPs and their attitudes about the disease and patient improved.

This dissertation is adding to the knowledge base of CFS/ME. It will highlight specific areas where health care professionals will need further training, and what type of training is needed, to address any negative beliefs or attitudes they might have towards CFS/ME. This dissertation also provides a nuanced understanding of CFS/ME from the perspective of the professionals that are required to diagnose and manage this complex disease.

Acknowledgements

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To Dr. Maylene Shung King, without her timely intervention and willingness to help, this dissertation would not be the completed project that it is now. Her attention to detail and technical advice has been greatly appreciated.

To Joanna, the constant support and sacrifice she has freely given has astounded me and no words can express my full appreciation and love.

Plagiarism Declaration

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Part A: Protocol

Part B: Literature Review

Part C: Journal Manuscript

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Abbreviations and Acronyms

HCP	Health Care Professionals
CFS	Chronic Fatigue Syndrome
ME	Myalgic Encephalomyelitis
KAB	Knowledge, Attitudes and Beliefs
ICC	International Consensus Criteria
CDC	Center for Disease Control
RCT	Randomized Control Trial
RP	Romy Parker
MSK	Maylene Shung King
GR	Garth Reypert

Part A: Protocol

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INTRODUCTION

Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME) is a disease characterized by a persistent debilitating fatigue with a definite onset (Carruthers, 2011, Brurberg, 2014), and in combination with other symptoms that include, but are not limited to, musculoskeletal pain, decreased concentration and poor sleep patterns or disturbances (Brurberg, 2014). In most studies, the case definition proposed by the Center for Disease Control (CDC) in 1994 (Fukuda, 1994) has been used (Brurberg, 2014). The case definition has gone through some changes and modifications since then with the most recent definition proposed in the International Consensus Criteria meant to simplify the transition between clinical diagnosis and research evaluations (Carruthers, 2011, Brurberg, 2014). Owing to the multiple changes in case definition over a short period of time, health professionals might be apprehensive about the requirements for a diagnosis of CFS/ME (Revelas, 2013). Adding to this confusing list of definitions that clinicians have to remember is that there is a proposal for the reclassification of CFS/ME to systemic exertion intolerance disease or SEID (Medicine, 2015), however this is intended to assist in the correct diagnosis.

This apprehension might affect the reported prevalence of CFS/ME as it is dependent on the clinical application of the definition, hence the prevalence rates ranging from 0.2% to 2.4% in different studies (Flo and Chalder, 2014). The most commonly used case definition is the 1994 CDC case definition (Flo and Chalder, 2014). The case definitions have been standardized since 2011 with the International Consensus Criteria (ICC) for ME (Carruthers, 2011), which should lead to more consistent prevalence rates, but few of these studies have been conducted since 2011.

The prevalence rate in children is considered similar to adults (Crawley, 2014, Lievesley, 2014, Inger Johanne Bakken, 2014), depending on which case definition is used (Crawley, 2014, Inger Johanne Bakken, 2014) but actual figures show that they have a lower reported rate. However, these rates are thought to be higher than actually reported and two problems were highlighted for the lower prevalence rates in children. One problem is the inability of children to access the correct medical care because they are not diagnosed correctly and the other is that those with disabling fatigue tended to not consult a doctor regarding their fatigue (Revelas, 2013, Crawley, 2014). Furthermore, one study has

reported two age peaks for the incidence of CFS/ME, one in adolescents between 10-20 years of age and another peak between 30-40 years (Inger Johanne Bakken, 2014).

Epidemiologically, females account for more than 70% of CFS/ME cases (Crawley, 2014, Johnston, 2013, Flo and Chalder, 2014) and are therefore the most at risk group of developing CFS/ME. However, contrary to the conventional belief that most patients are in a higher socioeconomic group, CFS/ME affects people in all socioeconomic levels, equally (Revelas, 2013). It is actually suggested that, with women being mostly affected, those in lower socioeconomic groups and from minority groups within society are equally affected (Revelas, 2013).

Many health professionals strive to manage patients according to the best available evidence. While there are easily accessible evidence-based guidelines for the diagnosis and management of CFS/ME, the availability of such are not the only requirements for changing patient care (McCullough, 2015). What is also needed is a 'contextual element', such as leadership by Health Care Professionals (HCP) with experience of the CFS/ME disease, and a belief in the quality of the evidence by HCPs to overcome the current mismanagement of CFS/ME (McCullough, 2015). This highlights a potential problem that CFS/ME patients may have. The perceived quality of evidence is not seen by HCPs as sufficient to overcome the current management, which results in misdiagnosis and stigmatization of the patient (Anderson, 2012, Revelas, 2013).

This study highlights the knowledge gaps that clinicians may have, as well as potential negative attitudes and beliefs, about ME/CFS. The application of the results of this study would enable health promotion programs among current health professionals and training curriculums for students to be better placed to bridge the knowledge gaps efficiently and reduce the stigma associated with ME/CFS among health professionals. The specific areas raised in the analysis could then be targeted in educational activities for improvement of the overall treatment and service that is provided by HCPs. The aim of this review is to identify the knowledge, attitudes and beliefs of health care professionals about ME/CFS in order to identify educational targets for the improvement of patient care.

Current evidence does not suitably answer the study question as, although individual studies have been undertaken to assess the knowledge, attitudes and beliefs of different health professionals regarding ME/CFS, a systematic review of these studies is necessary to highlight common areas of misunderstanding and gaps in clinician's knowledge base to better plan and implement health promotion and health education interventions with regards to ME/CFS. A Systematic review has been conducted that combined patient and physician perspectives of ME/CFS (Anderson, 2012) in 2010. However, this review does not cover the full scope of the study question, and focused more intently on the patients' perceptions and attitudes with less of an emphasis on clinician attitudes and beliefs about ME/CFS (Anderson, 2012). Further, there have been some individual studies since the previous systematic review that have not been quantified in a review (Erueti et al., 2012, Brimmer et al., 2010)

The case definitions and current treatment for ME/CFS have been known for many years but there is still reluctance on behalf of health practitioners to diagnose ME/CFS (Anderson, 2012, Revelas, 2013). With a more accurate understanding of the knowledge gaps of HCPs about CFS/ME, the efficiency of health promotion programs and student training can be enhanced. Once the knowledge gaps are found, a review that highlights important and relevant methods to change HCPs perceptions would be important in altering the way CFS/ME patients are treated within the health care system.

Review question

What is the knowledge of, attitude towards and beliefs about CFS/ME held by HCPs and how do they affect the management of the CFS/ME patient?

Objectives

1. To identify knowledge gaps about CFS/ME by HCPs
2. To identify HCPs attitudes and beliefs about CFS/ME and how it affects their practice as HCPs
3. To consider research and HCP training implications raised by the systematic review

METHODS

Approach to the review

A qualitative systematic review is the review of choice for this study as it enables the user to identify, assess and synthesize the available research (Evans and Pearson, 2001). A systematic review is a review conducted retrospectively in a methodologically sound way. It attempts to identify all the available literature appropriate to answer a particular research question. It summarizes individual articles within a specific research question using clearly defined search strategies and eligibility criteria (Higgins, 2008). This is then followed by a critical appraisal of the literature and synthesis of the appropriate literature found in those searches in a systematic manner (Higgins, 2008).

The Cochrane Collaboration has a set of guidelines for conducting a review, that is suitable for any type of review, including a qualitative systematic review (Higgins, 2008). The rationale for the format guidelines is to ensure that the readers can locate the results quickly and helping authors to describe their work in a coherent and succinct manner to allow the reader to quickly assess and read the reviewers results (Higgins, 2008). With this rationale, they recommend three stages to completing a review: the planning stage, the actual conducting of the review and lastly, the reporting and dissemination of the results (Higgins, 2008).

The Protocol is developed in the planning stage. This will outline what the problem is that needs to be solved by a review and will stipulate how the review will be prepared and the limits of the review, for example what is included and excluded from the review, is set (Higgins, 2008). The second stage of the review follows the comprehensive guidelines set out in the review. The process includes a detailed and thorough literature search using key words associated with the review question. Data will then be extracted from the articles selected for the review and will be analyzed and presented in the review (Higgins, 2008, Evans and Pearson, 2001, Pearson, 2004). Finally, the last stage of the review is the dissemination of the results, which should be done in a clear and presentable

When systematic reviews were initially conducted in literature, they have mostly been conducted to evaluate Randomised Control Trials (RCT) (Evans and Pearson, 2001). However, health care professionals

often need to know the beliefs, understandings and expectations of a system by its users and for this a qualitative review is necessary (Evans and Pearson, 2001, Carnwell and Daly, 2001). The systematic nature of this review will aid in decreasing the researcher bias through the methodological and transparent process to be able to analyse and synthesise the findings reported. Therefore, a qualitative systematic review is the correct type of review to be used to analyse the beliefs and attitudes of health care professionals.

The process of reviewing qualitative data is difficult as RCTs are critically appraised for their quality before their inclusion to reduce the risk of bias or error (Evans and Pearson, 2001). This same process is difficult for qualitative articles as the process is less clear than for RCT articles and, because there is still debate about how to adequately appraise qualitative articles, it has been argued for and against the use of critical appraisal in qualitative reviews (Evans and Pearson, 2001). Without the use of critical appraisal, it was recommended that stringent inclusion and exclusion criteria be used to account for any potential bias and to maintain transparency (Carnwell and Daly, 2001).

Narrative analysis is often conducted in qualitative studies (Riessman, 2005, Carnwell and Daly, 2001). Narrative analysis contains many different types or methods to obtain data, in this review we are using Thematic Analysis. Thematic analysis is a form of content analysis that focusses on “what” is being said, rather than in other methods such as “how” it is being said or the interaction between the interviewee and the interviewer (Riessman, 2005). Thematic analysis is the preferred choice in this case as we are wanting to determine the dominant themes that are currently in the literature. These dominant themes will guide our discussion about the most important issues.

Thematic analysis refers to the process of capturing all the key ideas or ‘themes’ from the collected articles (Bearman, 2013). This type of analysis will enable the researcher to synthesise qualitative data from different descriptions (Bearman, 2013, Riessman, 2005). A limitation of this type of analysis can be that the context of the interview or dialogue is not studied or referenced, and this could have a bearing on the meaning of the words that the interviewees use (Riessman, 2005). To account for this potential confounder, articles selected in the review should be of a similar context.

Search Strategy:

A thorough literature search, of six separate electronic databases, was conducted to identify as many relevant articles as possible. Articles specific to the Knowledge, Attitudes and Beliefs of HCPs was selected using pre-defined inclusion and exclusion criteria. Each database had a slightly different method of searching within the database and how they categorized their various search filters.

The electronic databases that were searched are Pubmed, Scopus (which includes the EMBASE database), Web of Science, Cumulative Index of Nursing and Allied Health (CINAHL), Africa-Wide International and PsycINFO. The last three databases of CINAHL, Africa-Wide International and PsycINFO were searched via EBSCOhost. Full search terms can be found in Appendix 1.

The search terms that were used included the keywords: “Chronic Fatigue Syndrome”, “Myalgic Encephalomyelitis”, “Health Professionals”, as well as any subcategories of health professionals, such as Doctors, Physicians, Nurses, Physiotherapists and Occupational Therapists and students of these professions. Combinations of Knowledge, Attitudes or Beliefs were also added to these search terms. An example of the Pubmed search terms are as follows:

```
((Chronic Fatigue Syndrome[Title] OR Myalgic Encephalomyelitis[Title] OR Systemic Exertion Intolerance Disease[Title])) AND Health Professionals[MeSH Terms] OR Doctor OR Physician OR Allied Health Workers OR Physiotherapist OR ‘Occupational Therapist’ OR Nurse OR Health personnel OR Medical Student OR Student) AND (Knowledge OR Attitudes OR Beliefs)
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Once the searches had been completed, the titles and abstracts were screened independently by both GR and RP. Full journal articles were then selected for the review from the articles found in the search. Other potential sources of articles were: the reference lists of the articles selected; any previous systematic review that may have been on a similar topic; any unpublished articles known to the supervisors.

Selection criteria

Inclusion and exclusion criteria was vital to ensuring that the correct articles were collected from those results that were included in the initial search (Evans and Pearson, 2001). Inclusion criteria should focus on the population of interest and have a focus on articles with a similar research approach (Evans and Pearson, 2001). The inclusion and exclusion criteria provided a framework for researchers to transparently describe their decision making process when selecting articles (Carnwell and Daly, 2001).

This review included:

- I. Articles that pertain to Knowledge, Attitudes and Beliefs about CFS/ME which will include both qualitative and quantitative methods.
- II. The articles' main focus should regard HCPs attitudes primarily. HCPs would include any HCP regardless of qualification, from student to specialist, primary to tertiary health care and allied health care.
- III. Articles from High Income Countries as well as Lower and Middle Income Countries. This is important as there is a relatively small pool of articles on CFS/ME.
- IV. Original or review articles with titles and abstracts relevant to the research question.
- V. Full text available from the University of Cape Town's medical Library subscription
- VI. Any Article from 1990 until present. This will allow the researchers to evaluate the changing levels of attitudes and beliefs over time as knowledge of CFS/ME has increased.
- VII. Studies published in English. This may lead to a language bias.

Articles were excluded with the criteria that follows:

- I. Articles or citations without abstracts
- II. Articles Prior to 1990
- III. Opinion Articles or Letters to the Editor
- IV. Articles with a Primary focus on Patient's Attitudes, Beliefs and Knowledge of CFS/ME
- V. Articles that do not discuss HCP's Knowledge, Attitude or Beliefs of CFS/ME in the results or discussion of the full text
- VI. Duplicate articles of an article selected already

Once the searches were concluded, the researcher and the supervisor independently reviewed the titles and abstracts of all the results of the searches to assess eligibility. Any studies that may have been contentious for inclusion were evaluated in a discussion between the researcher and the supervisor until consensus was reached. If consensus could not be reached, a third evaluator was asked to review the study for inclusion. After duplications were removed, the remaining full length articles were assessed for their eligibility in the review, and the same discussion process as for the abstracts ensued.

Quality Review / Critical Appraisal

The appraisal of the quality of the articles selected for this review was done concurrently with the data extraction. The process of critical appraisal is conducted of the selected articles to eliminate bias or error within quantitative data (Evans and Pearson, 2001). This is a difficult process for qualitative reviews to complete and has been the source of much debate regarding an appropriate method for the appraisal of qualitative articles (Evans and Pearson, 2001, Pearson, 2004). In the absence of clear and uniform guidelines, it is recommended for the appraisal process to be transparent as many of the previous methods used have been for quantitative studies (Evans and Pearson, 2001, Pearson, 2004).

For this review, a quality assessment tool was used to evaluate the quality of the articles selected. The Occupational Therapy department at McMaster University has created a Critical Review Form which is currently in its second generation (Version 2 is attached in the Appendix 2) and has a clear set of guidelines for the use in qualitative reviews (Letts, 2007). The assessment tool contains nine specific review components, and they include: The Citation, the Study Purpose, the Literature included, the Study Design, the Sampling Methods, the Data Collection process, the Data Analysis used, the overall rigor and the Conclusions and Implications (Letts, 2007).

Included in the critical appraisal, these nine topics were assessed and as the guidelines suggested, particular attention was paid to the study design and the design types that were used and the appropriateness of the design used. Sampling and participants involved in the study were scrutinized. The overall rigor was assessed, with particular attention placed on data collection and data analysis. Lastly, the study findings and conclusions of the authors, as this is done with the data extraction, was

assessed for their suitability to the research question and field of research (Letts, 2007). A template of the table this is presented in the appendix. The primary concern was whether the article could answer the research question rather than needing to fulfil specific design questions, such as in an RCT (Evans and Pearson, 2001, Pearson, 2004). An independent reviewer, RP (the supervisor), assisted in the quality assessment of the studies selected for review.

Data Extraction

The aim of the data extraction was to minimize any potential bias, ensuring reliable and valid results (Evans and Pearson, 2001). In order for data extraction to be consistent with the primary data, the reviewer read all the relevant articles before the extraction process began. A data extraction form was then made with all potential and expected themes, with space available for unexpected themes should they have arisen. There has been no clear and consistently used data extraction form for qualitative data (Evans and Pearson, 2001), hence one was needed to be made for this review.

To ensure that the extraction form was accurate, one article from the sample was extracted by the reviewer and the extraction was then assessed by the supervisors for interrater reliability. Where necessary, adjustments were then made to the extraction form.

Key data was then extracted using qualitative thematic analysis of all the articles that had met the inclusion criteria and could not be excluded. From the initial reading of the articles mentioned above, the reviewer created themes within the expected topics. The main topics were: Knowledge, Attitudes, Beliefs, Recommendations and Implications. These were then broken into separate themes within each topic. See Appendix 4 for template.

Data analysis and synthesis

Thematic analysis drove the analysis and synthesis of the data presented in the articles in the review. Qualitative synthesis differs from the usual synthesis expected in systematic reviews of RCT's as qualitative synthesis relates more closely to a meta-synthesis (Evans and Pearson, 2001). The challenge

of a meta-synthesis is for the researcher to “capture the essence” of the data presented in their interpretation of the data (Evans and Pearson, 2001). Deductive themes were used in this dissertation and were obtained from the initial reading of the search results and discussion with independent reviewers, RP and MSK.

Initially, the reviewer read and re-read the selected articles. Detailed reading included the findings and discussion sections of the articles. The initial coding and theme formation of recurrent levels of Knowledge, Attitudes and Beliefs which HCPs harbor about CFS/ME was simultaneously completed during the detailed reading phase.

Once all the articles had been coded into themes, the coded data was then tabulated according to their codes as well as chronologically for ease of reference. Similar themes and common ideas that were present in the data was identified in this process and grouped according to the main themes mentioned earlier. This enabled the reviewer to identify the most common themes and topics.

Analysis of the tabulated data occurred in the final part of the process of data synthesis. This process included a detailed review of the tabulated data. During this review the data was analyzed for recurrent themes present throughout all the main topics to provide for possible links, or hidden themes, between the Knowledge and Attitudes or Beliefs HCPs have towards CFS/ME.

Ethical Considerations

Systematic reviews require no formal ethical or confidential considerations as the data presented in this review is from articles available publically and have already undergone ethical clearance. For this reason, no ethical procedures have been completed for this review.

Study Limitations

Selection bias is a potential limitation as there is no gold standard for collecting qualitative articles, therefore the articles selected for this review might be subject to a selection bias on behalf of the

reviewer, due to their own understanding and insights. To limit this bias, articles were discussed between reviewers and were subject to critical appraisal to ensure the quality of the review was maintained. Language bias is another potential limitation as no articles in languages other than English were selected. This limitation is due to time constraints that interpretation of these studies would exceed.

Dissemination

Dissemination of the results of this review will include a summary of the analysis and synthesis of the data presented herein. This will be presented to health educators and managers associated with the training of HCPs and management of CFS/ME clinically. The review intends to highlight the discrepancies in the care of CFS/ME and how educators can improve training methods to cover for those discrepancies. Further dissemination occurs with the intention to publish in the journal entitled *Health Education* (ISSN: 0965-4283) to enable HCPs in other settings to benefit from this review. See Part D for Journal Author Guidelines

Timetable

<u>Timetable</u>			
Task	Date	Lead reviewer	Supervision / Support
Draft protocol for internal review	06/04/15	Garth Reypert	
Protocol for external review	03/05/15	Garth Reypert	Romy Parker
Searching and study selection	21/05/15	Garth Reypert	Romy Parker
Data extraction	13/08/15	Garth Reypert	
Quality assessment of extraction	24/08/15	Romy Parker	Maylene Shung King
Thematic Analysis	23/09/15	Garth Reypert	

First Draft of Full Document	29/11/15	Garth Reypert	Maylene Shung King & Romy Parker
Second Draft of Full Document	14/01/16	Garth Reypert	Romy Parker & Maylene Shung King
Final Draft report for peer review	10/02/16	Garth Reypert	
Submit for publication	30/06/16	Garth Reypert	

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APPENDICES

Appendix 1: Search Strategy

PubMed

((Chronic Fatigue Syndrome[Title] OR Myalgic Encephalomyelitis[Title] OR Systemic Exertion Intolerance Disease[Title]))

AND

(Health Professionals[MeSH Terms] OR Doctor OR Physician OR Allied Health Workers OR Physiotherapist OR 'Occupational Therapist' OR Nurse OR Health personnel OR Medical Student OR Student)

AND

(Knowledge OR Attitudes OR Beliefs)

EMBASE via Scopus

(TITLE-ABS-KEY ("Chronic Fatigue Syndrome" OR "myalgic encephalomyelitis" OR "Systemic exertion intolerance disease"))

AND

(TITLE-ABS-KEY ("Doctor" OR "Physician" OR "Nurse" OR "Physiotherapist" OR "Physical therapist" OR "Occupational Therapist" OR "Student"))

AND

(TITLE-ABS-KEY ("Attitude" OR "Knowledge" OR "Belief" OR "Understanding"))

Cumulative Index of Nursing and Allied Health (CINAHL) via EBSCOhost

((TX Chronic fatigue syndrome) OR (TX myalgic encephalomyelitis) OR (TX systemic exertion intolerance disease))

AND

((TX (physical therapy OR physiotherapy OR Occupational Therapy)) OR (TX (Physician OR Doctor OR Nurse OR Health Professional OR Medical Practitioner)) OR (TX Students))

AND

((TX (Knowledge OR Attitude OR Belief)) OR (TX Culture) OR (TX Knowledge transfer))

[PsycINFO via EBSCOhost](#)

TX Knowledge OR Understanding OR Attitude OR Belief

AND

TX doctor OR physician OR nurse OR Physiotherapist OR Physical Therapist OR Occupational Therapist OR Student

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TX chronic fatigue syndrome OR TX myalgic encephalomyelitis OR TX systemic exertion intolerance disease

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TX Knowledge OR Understanding OR Attitude OR Belief

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TS= (Physician OR Doctor OR Health Professional OR Nurse OR Physiotherap* OR Physical Therap* OR Occupational Therap* OR Health Student OR Medical Student OR Allied Health Profession* OR Therapy Student)

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TS= (Chronic Fatigue Syndrome OR Myalgic Encephalomyelitis OR Systemic exertion intolerance disease)

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	Comments
STUDY PURPOSE: Was the purpose and/or research question stated clearly? ☐ yes ☐ no	Outline the purpose of the study and/or research question.
LITERATURE: Was relevant background literature reviewed? ☐ yes ☐ no	Describe the justification of the need for this study. Was it clear and compelling?
	How does the study apply to your practice and/or to your research question? Is it worth continuing this review? ¹

¹ When doing critical reviews, there are strategic points in the process at which you may decide the research is not applicable to your practice and question. You may decide then that it is not worthwhile to continue with the review.

STUDY DESIGN: What was the design? ☐ phenomenology ☐ ethnography ☐ grounded theory ☐ participatory action research ☐ other _____	Was the design appropriate for the study question? (i.e., rationale) Explain.
Was a theoretical perspective identified? ☐ yes ☐ no	Describe the theoretical or philosophical perspective for this study e.g., researcher's perspective.
Method(s) used: ☐ participant observation ☐ interviews ☐ document review ☐ focus groups ☐ other _____	Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?
SAMPLING: Was the process of purposeful selection described? ☐ yes ☐ no	Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question?
Was sampling done until redundancy in data was reached?² ☐ yes ☐ no ☐ not addressed	Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing?

² Throughout the form, “no” means the authors explicitly state reasons for not doing it; “not addressed” should be ticked if there is no mention of the issue.

Was informed consent obtained? ☐ yes ☐ no ☐ not addressed	
DATA COLLECTION: Descriptive Clarity Clear & complete description of site: ☐ yes ☐ no participants: ☐ yes ☐ no Role of researcher & relationship with participants: { ☐ yes ☐ no Identification of assumptions and biases of researcher: { ☐ yes ☐ no	Describe the context of the study. Was it sufficient for understanding of the “whole” picture? What was missing and how does that influence your understanding of the research?
Procedural Rigour Procedural rigor was used in data collection strategies? ☐ yes ☐ no ☐ not addressed	Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design & data collection methods.
DATA ANALYSES: Analytical Rigour Data analyses were inductive? ☐ yes ☐ no ☐ not addressed Findings were consistent with & reflective of data? ☐ yes ☐ no	Describe method(s) of data analysis. Were the methods appropriate? What were the findings?

CONCLUSIONS & IMPLICATIONS Conclusions were appropriate given the study findings? ☐ yes ☐ no The findings contributed to theory development & future OT practice/ research? ☐ yes ☐ no	What did the study conclude? What were the implications of the findings for occupational therapy (practice & research)? What were the main limitations in the study?
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Appendix 3: Article Summary Template

Article	Year	HCPs	Country	Setting	Methods	Sample Size

Appendix 4: Data Extraction Template

Author	Year	Knowledge			
		Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Attitude					
		Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS
					to relevance of CFS
Beliefs					
		Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty
					Management of Disease
Recommendations					
		Dissemination	Awareness	Further study	Improved KAB
Implications					
		Service provision	Health system components	HR costs	Training

Part B: Literature review

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Introduction

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) is a disease characterised by a persistent debilitating fatigue with a definite onset (Carruthers, 2011, Brurberg, 2014), and in combination with other symptoms that include, but are not limited to, musculoskeletal pain, decreased concentration and poor sleep patterns or disturbances (Brurberg, 2014). In most studies, the case definition proposed by the Centre for Disease Control (CDC) in 1994 (Fukuda, 1994) has been used (Brurberg, 2014). Briefly, it requires a patient to have chronic debilitating fatigue accompanied with four of the following symptoms: post exertional malaise, unrefreshing sleep, short-term memory and concentration problems, muscle pain, joint pain, tender lymph nodes and a sore throat.

Definitions of CFS

The Case Definition of CFS/ME has had a varied history. Two definitions were put forward in 1988 one by Ramsay (Ramsay, 1988) and another by Holmes (Holmes et al., 1988). The former has become known as the London definition and the latter is known as the CDC – 1988. The British definition was enhanced in 1991 (Sharpe, 1991), and became known as the Oxford Definition for CFS/ME. Clinicians were still not satisfied that the definition of CFS was appropriate and the CDC created more refined version of their 1988 definition in 1994 (Fukuda, 1994). This definition has become the base definition from which other groups have used as a point of reference when considering changes or alterations to the definition of CFS/ME (Brurberg et al., 2014). After the CDC version, the Royal College of Physicians and Surgeons of Canada in 2003 created another definition, which was the basis for the International Consensus Criteria (ICC) (Brurberg et al., 2014, Carruthers, 2011). Before the ICC was released in 2011, the National Institute for Health and Clinical Excellence in the UK release a separate set of guidelines in 2007 (Brurberg et al., 2014).

The most recent definition proposed in the ICC is meant to simplify the transition between clinical diagnosis and research evaluations (Carruthers, 2011, Brurberg, 2014). Owing to the multiple changes in case definition over a short period of time, health professionals might be apprehensive about the requirements for a diagnosis of ME/CFS (Revelas, 2013). Adding to this confusing list of definitions that clinicians have to remember is that there is a proposal for the reclassification of ME/CFS to systemic

exertion intolerance disease or SEID (Medicine, 2015). This might lead to even more confusion for diagnosing health care professionals (HCPs).

Factors in Diagnosis

The cause of CFS/ME is currently unknown. Initially, it was thought to be a post-viral fatigue (Holmes et al., 1988), specifically the Epstein-Barr virus. Later studies have highlighted this and added the importance of the impact of the immunological dysfunction (Brurberg et al., 2014). They also referred to the interplay between the genetic and psychosocial factors (Brurberg et al., 2014). However, some studies have tried to understand how the physiology of the body has changed in CFS/ME patients compared to controls with a view of finding a potential diagnostic test (Brenu et al., 2014). Genetic causes have also been investigated and one study was able to distinguish genetic differences between CFS/ME patients when compared to depressed or normal control groups (Shimosako and Kerr, 2014), however, they did mention that their sample size was too small to make broad generalizations (Shimosako and Kerr, 2014). Hypocortisolism has been noted in adolescents with CFS/ME, but this was not considered a cause of CFS/ME. The change in cortisol levels was instead considered to be a marker for successful treatment (Nijhof et al., 2014).

Not all HCPs have the same roles in the diagnosis and management of CFS/ME. The two main groupings of HCPs, with relation to CFS/ME, operate in the primary care setting (Chew-Graham et al., 2010) and a more tertiary or specialist setting (Moosajee, 1998). Another article has described specialist services to include Physiotherapists, Occupational Therapists and Doctors and non-specialist care to include Doctors, Occupational health professionals and what was described as a “Holistic Practice” professional (Horton et al., 2010). A profession that was mostly related the primary care setting was Nurse professionals (Chew-Graham et al., 2010). They did have some role in the more tertiary setting as they could often be involved in the rehabilitation of the CFS/ME patient (Peters et al., 2011). Doctors who form part of the primary care of CFS/ME patients need to feel comfortable making the diagnosis of CFS/ME as they are required to facilitate the initial management of CFS/ME patients (Chew-Graham et al., 2010). There is very little empirical evidence to state which HCPs should be involved in diagnosis and management, this seems largely left to the individual system that manages the patient. This is evident, for example, where some articles refer to CFS/ME only in a primary care setting for diagnosis (Chew-

Graham et al., 2009) and others refer to primary care, hospital based and specialist HCPs are all involved with diagnosis (Moosajee, 1998).

Epidemiology

It is probably this lack of comfort with diagnosing and treating CFS/ME that has led to such a varied prevalence rate ranging from 0.2% to 2.6% in different studies (Flo and Chalder, 2014, Saez-Francas et al., 2014). It might also be due to the introduction of new definitions mentioned earlier but that seems to be a superficial observation because the most commonly used case definition, in the form of the 1994 CDC case definition (Flo and Chalder, 2014, Christley et al., 2012), also has a variance of between 0.19% and 2.1% when used as the only definition in prevalence studies (Johnston, 2013a). The case definitions seem to have been standardized since 2011 with ICC for ME (Carruthers, 2011, Johnston, 2013a), which should lead to more consistent prevalence rates, but few of these studies have been conducted since 2011 (Johnston, 2013a). More of these studies are necessary as HCPs begin to use one definition of CFS/ME because there would likely be a more consistent diagnosis, no matter the context, due to one set of diagnostic criteria being used.

The prevalence rate in children is considered similar to adults (Crawley, 2014, Lievesley, 2014, Inger Johanne Bakken, 2014), depending on which case definition is used (Crawley, 2014, Inger Johanne Bakken, 2014) but actual figures show that they have a lower reported rate. However, these rates are thought to be higher than actually reported and two problems were highlighted for the lower prevalence rates in children. They were that children might not be able to access medical care because they are not diagnosed correctly and the other is that those with disabling fatigue tended to not consult a doctor regarding their fatigue (Revelas, 2013, Crawley, 2014). Furthermore, one study has reported two age peaks for the incidence of CFS/ME, one in adolescents between 10-20 years of age and another peak between 30-40 years (Inger Johanne Bakken, 2014).

Conventionally, HCPs have believed that CFS/ME is a disease that almost solely affects middle class Caucasian females. Prevalence studies have found that females account for more than 70% of ME/CFS cases (Crawley, 2014, Johnston, 2013b, Flo and Chalder, 2014) and are therefore the most at risk group

of developing CFS/ME. However, contrary to the conventional belief that most patients are in a higher socioeconomic group, ME/CFS affects people in all socioeconomic levels, equally (Revelas, 2013). It is actually suggested that, with women being mostly affected, those in lower socioeconomic groups and from minority groups within society are equally affected (Revelas, 2013).

CFS Management

Many health professionals strive to manage patients according to the best available evidence. The sections above show that there is reasonable evidence for HCPs to have sufficient knowledge of CFS/ME to make a diagnosis and manage the disease using evidence-based approaches. However, a recent study has shown that the availability of knowledge is not the only determinant for knowledge to affect change (McCullough, 2015). What is also needed is a 'contextual element', such as leadership, and a belief in the quality of the evidence to overcome current management (McCullough, 2015). This highlights a potential problem that ME/CFS patients may encounter, as the perceived quality of evidence does not seem to be sufficient to overcome the current inadequate management, resulting in misdiagnosis and stigmatization of the patient (Anderson, 2012, Revelas, 2013).

The treatment offered to CFS/ME patients is often symptom related (Burns, 2012). HCPs are encouraged to treat the symptoms while addressing other potential causes in the meantime (Burns, 2012). Two of the most used and accepted methods for treating CFS/ME are more psychological than pharmaceutical, in that they address predisposing factors that may have led up to the initial onset of symptoms, these treatments are pacing schedules and cognitive behavioral therapy (Burns, 2012). In practice, pharmaceutical usage is the most commonly used treatment by HCPs because fatigued patients commonly present with symptoms of depression and are prescribed anti-depressive medication (Thomas and Smith, 2005).

Knowledge, Attitude and Belief Studies

Individual studies have been undertaken to assess the knowledge, attitudes and beliefs of different health professionals regarding CFS/ME (Anderson, 2012). A systematic review of these studies is necessary to highlight common areas of misunderstanding and gaps in clinician's knowledge base to

better plan and implement health promotion programs with regards to CFS/ME. However, a previous review does not cover the full scope of the attitudes and beliefs of HCPs towards CFS/ME, and focused more intently on the patients' perceptions and attitudes with less of an emphasis on the HCPs knowledge, attitudes and beliefs (KAB) about CFS/ME (Anderson, 2012). Despite the focus not remaining on clinicians, individual studies have since been published that have added to the body of evidence related to attitudes of HCPs (Erueti et al., 2012, Brimmer et al., 2010).

The Study of the transition of knowledge and the effect that attitude and beliefs (KAB) of an HCP have on their decisions is an area of study that has grown in recent years. HCPs have sought to improve their clinical skills by attempting to understand the behaviours of their patients (Saleem et al., 2012). This field of study is viewed as helpful to gain greater insight into behaviours and experiences that quantitative research cannot describe (Saleem et al., 2012). These studies are useful because the data they produce can help towards answering why individuals choose a course of action. Such as articulating patients reasoning for non-adherence (Saleem et al., 2012), which can allow for more nuanced and specific interventions, as well as raise questions that might not have seemed obvious to a researcher initially.

KAB Studies are also helpful for gathering many separate ideas within a community and drawing out the commonalities between the individuals', within that community, ideas, even if they are articulated differently (Teferi and Shewangizaw, 2015). They can show what barriers a community (or individual) might face when using the health system and approaching HCP, such as the different difficulties faced by urban and rural communities (Teferi and Shewangizaw, 2015). This type of study will enable the researcher to uncover subtle differences between different types of HCPs and at different stages of their development (Bientzle, 2014). It is evident that this form of study is good at identifying intangible differences in the populations of study (Bientzle, 2014, Saleem et al., 2012, Teferi and Shewangizaw, 2015).

Conclusion

The case definitions and current treatment for ME/CFS have been known for many years but there is still reluctance on behalf of health practitioners to diagnose ME/CFS (Anderson, 2012, Revelas, 2013). With a

more accurate understanding of where the knowledge gaps HCPs have about ME/CFS lies, the content and targeting of health promotion programs and student training can be enhanced. Once the knowledge gap is found, a review that highlights important and relevant methods to change HCPs perceptions would be important in altering the way CFS/ME patients are treated within the system.

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Part C: Journal Manuscript

Title Page

Working Title: The CFS/ME Conundrum

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Abstract

Background

Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME) is a disease characterised by debilitating fatigue with a definite onset. However, the definition of CFS/ME has changed multiple times over the last twenty to thirty years. Despite this constant change in definition, the prevalence of CFS/ME is consistent in adults and children with a rate of between 0.2% and 2.4% depending on the definition used. These definition changes can pose a problem for Health Care Professionals (HCPs) who diagnose and manage CFS/ME patients because the regular change in definition can engender negative attitudes towards the CFS/ME patient and beliefs about the disease.

Methods

Six separate databases were searched to find articles related to the Knowledge, Attitudes and Beliefs of HCPs towards CFS/ME with either qualitative or quantitative results. A thematic template was created to extract data from the articles found. The template highlighted and grouped the expected themes from both qualitative and quantitative studies

Results

Thirty studies met the selection criteria after duplications were removed. Three main sections were highlighted in the data collected, the knowledge HCPs have about CFS/ME, the attitude and beliefs those HCPs have towards CFS/ME and lastly, how their knowledge, attitudes and beliefs affected their practice. HCPs relied heavily on a Biomedical model of understanding CFS/ME and expressed a need for guidelines of diagnosis and management for CFS/ME. A lack of this often lead to the labelling of CFS/ME patients as “time wasters” and “malingerers”. Empathy was shown by some HCPs to be a useful tool in overcoming the current problems in the management of CFS/ME.

Discussion

The reliance on a Biomedical model was reflected in the treatment options HCPs chose, and their attitude towards their patients. Less importance was placed on CFS/ME when it was self-studied by students. This highlighted the need for including CFS/ME patients in their training to improve HCP understanding of CFS/ME and to have empathy towards the difficulties CFS/ME patients endure. Education of HCPs needed to incorporate interactive sessions as these resulted in better knowledge and understanding of the treatment options used by HCPs. Their attitudes about the disease and patient also improved. The use of media to access HCPs should be used to increase awareness and interest in CFS/ME.

Conclusion

HCPs Knowledge, Attitude and Beliefs about CFS/ME significantly improved when training was interactive with CFS/ME patients. This resulted in the correct use of the treatment options and improved knowledge of CFS/ME guidelines available to HCPs.

Introduction

Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME) is a disease characterized by a persistent debilitating fatigue with a definite onset (Carruthers, 2011, Brurberg, 2014), in combination with other symptoms that include, but are not limited to, musculoskeletal pain, decreased concentration and poor sleep patterns or disturbances (Brurberg, 2014). In most studies, this case definition proposed by the Centre for Disease Control (CDC) in 1994 (Fukuda, 1994) has been used (Brurberg, 2014). Briefly, it requires a patient to have chronic debilitating fatigue accompanied with four of the following symptoms: post exertional malaise, unrefreshing sleep, short-term memory and concentration problems, muscle pain, joint pain, tender lymph nodes and a sore throat.

The case definition has gone through some changes and modifications since then with the most recent definition proposed in the International Consensus Criteria meant to simplify the transition between clinical diagnosis and research evaluations (Carruthers, 2011, Brurberg, 2014). Owing to the multiple changes in case definition over a short period of time, health professionals might be apprehensive about the requirements for a diagnosis of ME/CFS (Revelas, 2013). Adding to this confusing list of definitions that clinicians have to remember is that there is a proposal for the reclassification of ME/CFS to systemic exertion intolerance disease or SEID (Medicine, 2015), however this is intended to assist in the correct diagnosis.

It is probably this lack of comfort health care professionals (HCPs) have with the CFS/ME diagnosis that has led to such a varied prevalence rate ranging from 0.2% to 2.6% in different studies (Flo and Chalder, 2014, Saez-Francas et al., 2014). It might also be due to the introduction of new definitions mentioned earlier but that seems to be a superficial observation because the most commonly used case definition, in the form of the 1994 CDC case definition (Flo and Chalder, 2014, Christley et al., 2012), also has a variance of between 0.19% and 2.1% when used as the only definition in prevalence studies (Johnston, 2013a). The case definitions seem to have been standardized since 2011 with the International Consensus Criteria (ICC) for ME (Carruthers, 2011, Johnston, 2013a), which should lead to more consistent prevalence rates, but few of these studies have been conducted since 2011 (Johnston, 2013a).

The prevalence rate in children is similar to adults (Crawley, 2014, Lievesley, 2014), and corresponds with the case definition used (Crawley, 2014). Females account for more than 70% of ME/CFS cases

(Crawley, 2014, Johnston, 2013b, Flo and Chalder, 2014). Contrary to the misconception that most patients are in a higher socioeconomic group, ME/CFS affects people in all socioeconomic levels (Revelas, 2013).

Many health professionals strive to manage patients according to the best available evidence. The sections above show that there is reasonable evidence for HCPs to have sufficient knowledge of CFS/ME to make a diagnosis and manage the disease in an evidence-based manner. However, a recent study has shown that the availability of knowledge is not the only determinant for knowledge to effect change (McCullough, 2015). What is also needed is a 'contextual element', such as leadership by experienced HCPs, and a belief in the quality of the evidence to appropriately alter current management (McCullough, 2015). This highlights a potential problem that CFS/ME patients may encounter, as the perceived quality of evidence does not seem to be sufficient to overcome the current inadequate management, which results in misdiagnosis and stigmatization of the patient (Anderson, 2012, Revelas, 2013).

Not all HCPs have the same roles in the diagnosis and management of CFS/ME. The two main groupings of HCPs, with relation to CFS/ME, are those in the primary care setting (Chew-Graham et al., 2010) and a more tertiary or specialist setting (Moosajee, 1998). Specialist services have been described as including Physiotherapists, Occupational Therapists and Doctors and non-specialist care to include Doctors, Occupational health professional and what was described as a "Holistic Practice" professional (Horton et al., 2010). A profession that was mostly related to the primary care setting was Nurse professionals (Chew-Graham et al., 2010). They did have some role in the more tertiary setting as they could often be involved in the rehabilitation of the CFS/ME patient (Peters et al., 2011). Doctors who form part of the primary care of CFS/ME patients need to feel comfortable making the diagnosis of CFS/ME as they are required to facilitate the initial management of CFS/ME patients (Chew-Graham et al., 2010). There is very little empirical evidence to state which HCPs should be involved in diagnosis and management, this seems largely left to the individual system that manages the patient. This is evident, for example, where some articles refer to CFS/ME only in a primary care setting for diagnosis (Chew-Graham et al., 2009) and others refer to primary care, hospital based and specialist HCPs all involved with diagnosis (Moosajee, 1998).

The case definitions and current treatment for ME/CFS have been known for many years but there is still reluctance on behalf of health practitioners to diagnose ME/CFS (Anderson, 2012, Revelas, 2013). With a more accurate understanding of the knowledge gaps clinicians have about ME/CFS, the content and targeting of health promotion programs and student training can be enhanced. Once the knowledge gap is found, a review that highlights important and relevant methods to change HCPs perceptions would be imperative in altering the way CFS/ME patients are treated within the system.

The aim of this review is to identify the knowledge, attitudes and beliefs of health care professionals about ME/CFS in order to identify educational targets for the improvement of patient care. Therefore, the knowledge gaps that clinicians may have, as well as potential negative attitudes and beliefs, about ME/CFS will be highlighted. The application of the results of this study would enable health promotion programs among current health professionals and training curriculums for students to be better placed to bridge the knowledge gaps efficiently and reduce the stigma associated with ME/CFS among health professionals. This would enable current HCPs to become more equipped to manage CFS/ME patients and to improve the care these patients receive. The specific areas raised in the analysis would then be targeted in educational activities for improvement of the overall treatment and service that is received by ME/CFS patients.

Methods

This review has undertaken a systematic process that identified and consolidated current literature on the Knowledge, Attitudes and Beliefs of HCPs. A qualitative systematic review was selected to assist in the reduction of researcher bias and enabled a synthesis of different methodologies used in the articles selected for this review (Evans and Pearson, 2001, Pearson, 2004, Higgins, 2008). Ethical and confidential considerations were not required for this review as the data used within this review was collected from articles available publically and had been published.

Search Strategy

The electronic databases that were searched were Pubmed, Scopus (which included the EMBASE database) and Web of Science as well as CINAHL, Africa-Wide and PsycINFO. The latter three were independently searched through EBSCOhost.

The search terms that were used included the keywords: “Chronic Fatigue Syndrome”, “Myalgic Encephalomyelitis”, “Health Professionals”, as well as any subcategories of health professionals, such as Doctors, Physicians, Nurses, Physiotherapists and Occupational Therapists. Combination of Knowledge, Attitudes or Beliefs were also included. Other sources of articles included reference lists of the articles selected and any previous systematic review that may have been on a similar topic, as well as any unpublished articles known to the supervisor.

Selection criteria

This review included all English articles that report the Knowledge, Attitude or Beliefs that health professionals, since 1990, have about or towards patients with ME/CFS, the diagnosis of ME/CFS or the treatment of ME/CFS. A Health Professional in this study was considered any profession that might be involved in the diagnosis and/or treatment of CFS/ME. An HCP included a Doctor, Physician, Nurse, Physiotherapist, Occupational Therapist or Allied Health Worker and those studying to become one of those professions. Articles from locations in High Income Countries as well as Low to Middle Income Countries were considered for inclusion.

We excluded an article or data if it pertained to a patient’s Knowledge, Attitude or Beliefs about CFS/ME, or if the data did not specifically pertain to Knowledge, Attitudes or Beliefs about CFS/ME in the full text. If the articles were prior to 1990, or opinion articles, such as Letters to the Editor, they were excluded.

Once the searches were concluded, the researcher (GR) and supervisors (RP and MSK) independently reviewed the titles and abstracts of all the results of the searches to assess eligibility. Any studies that were contentious were evaluated in a discussion between GR, RP and MSK, until a consensus was reached. After duplications were removed, the remaining full length articles were assessed for their eligibility in the review, and the same discussion process as for the abstracts ensued. See Figure 1 for a breakdown of articles included.

Quality review and data extraction and analysis

The quality appraisal of the articles selected for this review was done concurrently with the data extraction. The process of assessing article quality for qualitative reviews is a difficult process to

complete and has been the source of much debate regarding an appropriate method for the appraisal of qualitative articles (Evans and Pearson, 2001, Pearson, 2004). For this review, a Critical Review Form, which is currently in its second generation and has a clear set of guidelines for the use in qualitative reviews from McMaster University, was used (Letts, 2007).

Key data was extracted using Qualitative Thematic Analysis of all the articles that had met the inclusion criteria and could not be excluded. Primary thematic analysis was conducted by GR. The data was coded on full reading of the articles selected. The coded data was then tabulated according to their codes as well as chronologically for ease of reference. Similar themes and common ideas that were present in the data were identified in this process and grouped according to the main themes. After which further discussion with RP and MSK to consolidate data according to themes and sub-themes occurred. Analysis of the tabulated data took place in the final part of the process of data synthesis.

Results

Search Results

The search resulted in 903 articles for title and abstract evaluation. After separate evaluation by RP and GR, 38 articles were selected for full article evaluation for inclusion. Of those 38 articles, 30 have been selected for review in this article, see Figure 1 for further detail of the article selection process. The eight articles that were not selected for the review did not fulfill the inclusion criteria. Table 1 gives a summary of the articles excluded from the review. Table 2 describes the articles selected for review in this study

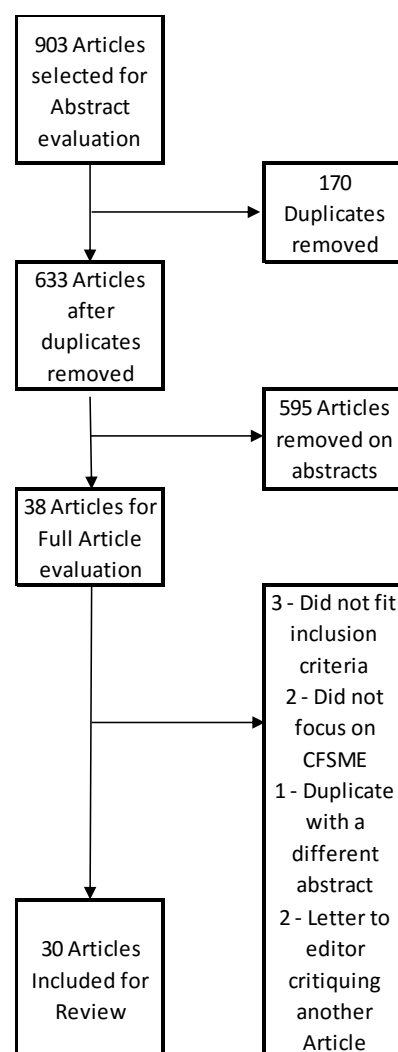


Figure 1: Summary of Article Selection

Article	Reason for Exclusion
Arber 1995	Opinion piece about Scott et al 1995
Banks and Prior 2001	Did not meet the Inclusion criteria. The article focussed on the politics of running a CFS/ME clinic.
Bayliss et al 2014	A review article synthesising patient and practitioner data. Did not fit the inclusion criteria
Jason et al 2010	This author of this article was contacted for the provision of the paper. After receipt of the article it was found to not fit the inclusion criteria.
Lu et al 2008	Duplicate of Lu et al 2007, from a different publication - article already included
Shattock et al 2013	The focus was on medically unexplained symptoms and not CFS/ME as a specific disease and therefore did not meet the inclusion criteria
Shepherd 1995	Opinion Piece about Scott et al 1995
Wainright et al 2006	The focus was on medically unexplained symptoms and not CFS/ME as a specific disease and therefore did not meet the inclusion criteria

Table 1: Articles Excluded

Articles	Year	HCP's	Country	Setting	Methods	Sample Size
Ho-Yen and McNamara	1991	General Practitioners	UK		questionnaire, mailed	178 replies
Scott et al	1995	General Practitioners	UK	Scotland	Case scenario Questionnaire	132/200 responders
Woodward et al	1995	Doctors and Patients	Australia	Canberra	Semi-Structured interviews	20 GP's
Fitzgibbon et al	1997	General Practitioners	Ireland		Questionnaire	118 participants
Moosajee	1998	Doctors and Patients	USA		questionnaire	115 doctors
Moore et al	2000	Occupational Therapists	UK		structured interview	20 participants
Prins et al	2000	Doctors and Patients	Netherlands		questionnaire	121 GP's
Jason et al (2)	2001	Clinical care and research professionals	USA		questionnaire	85 professionals
Jason et al (1)	2001	Trainees, medical	USA	Chicago	questionnaire	105 trainees
Taylor et al	2001	Social Workers and Psychologists	USA	Chicago	pre- and post lec questions	100% of attendees
Jason et al	2002	Trainees, medical	USA	Chicago	questionnaire	105 trainees
Asbring et al	2003	Physicians	Sweden		Semi-Structured interviews	26 participants
Raine et al	2004	General Practitioners and mental health	UK		Semi-Structured interviews	177 Professionals
Bowen et al	2005	General Practitioners	UK		questionnaire, mailed	811 participants
Thomas and Smith	2005	Primary care Workers	UK	Cardiff, Wales	Questionnaire booklets	45(43)/120 GP's
Wainright et al	2006	GP's and Patients	UK	Southwest England	Semi-Structured interviews	14 GP's
Daly and Hartz	2007	Family Physicians and Acupuncturists	USA	Iowa	questionnaire, mailed	35% response
Lu et al	2007	Medical Students	USA		Survey	55 students
Scheeres et al	2007	General Practitioners	Netherlands		Questionnaire	301 responders/452
Chew-Graham et al	2008	Family Physicians and Patients	UK		Semi-Structured interviews	12 Fam Phys
Cho et al	2008	Specialists	Brazil		questionnaire, survey	120 specialists
Friedberg et al	2008	Medical Students	USA		pre- and post lec questions	45 students
Swoboda	2008	Physicians	USA	New York	12 point questionnaire	59% response (of 800)
Chew-Graham et al	2009	Nurses	UK		Semi-Structured interviews	29 nurses
Brimmer et al	2010	Health Professionals	USA		Survey	1225 and 1250
Chew-Graham et al	2010	General Practitioners	UK	Northwest England	Semi-Structured interviews	46 GP's
Horton et al	2010	Health Professionals	UK		Semi-Structured interviews	6 HCP's
Erzeti et al	2012	Medical Students	Australia		Questionnaire	190 in 3 cohorts
Shattock et al	2013	3rd and 4th year Medical Students	UK	Northwest England	Participant led Interviews	43 Students
Ali et al	2014	Occupational Health Professionals	UK		pre- and post lec questions	106 participants
Knight et al	2014	paediatricians	Australia		online questionnaire	178 respondents
Stenhoff et al	2015	Students	UK	Manchester	Semi-Structured interviews	21 participants

Table 2: Summary of Selected Articles

Articles selected have been published at regular intervals chronologically with an increase in more recent years after the definition of CFS/ME has been refined over the years. This can be seen in Figure 2. The “0” represents the years that an important definition change occurred.

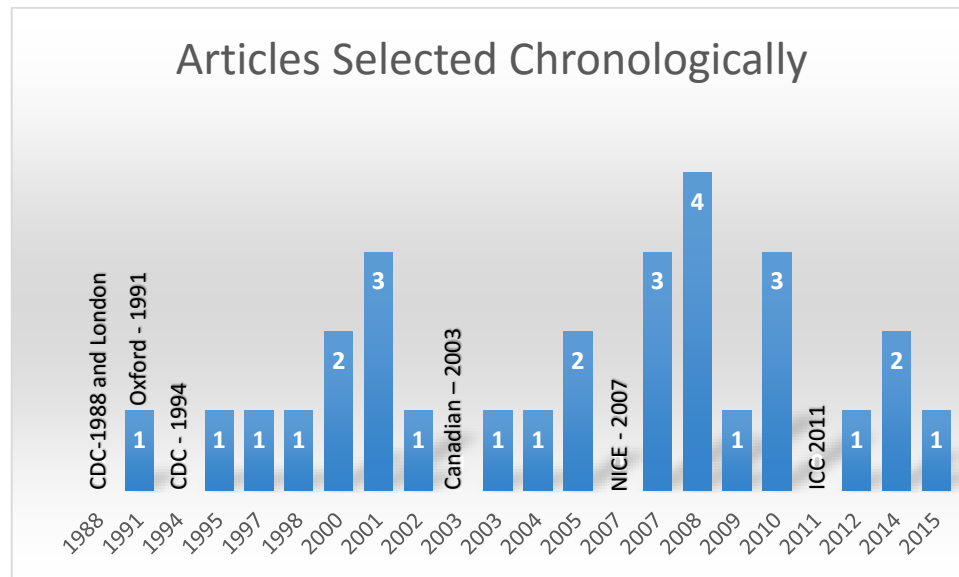


Figure 2: No. of Publications on CFS/ME KABs chronologically

Data Captured

The following Tables show the data collected from the reviewed articles. The data is presented for each theme in a table, which will include all articles for each theme. If an article does not present any data for a theme, the associated data entry point is left empty. Each theme will have different sub-theme headers. The five main themes are: Knowledge, Attitudes, Beliefs, Recommendations and Implications.

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Ho-Yen and McNamara	1991	71% of HCP's accept that CFS is an existing disease (pg324, results, para2) CFS prevalence of CFS is 1,3 per 1000 (pg324, results, para2)	Practices with only one diagnostic HCP reported significantly less CFS pts than those with more than one diagnostic HCP (pg324, results, para3)		
Scott et al	1995		Self-diagnosis by the pt. led to difficulties in communication with the pt. about the management and differential diagnoses for this 'misunderstood disease' (pg508, comment, para3)		HCP's were more likely to refer a personnel officer than an office cleaner to counselling was the only significant result that occupation played (pg508, results, para7)

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Woodward et al	1995	Only 1/20 HCP's was not aware of a disease called CFS (pg326, results, sec1, para1)	14/20 HCP's were reluctant to diagnose CFS due to the 'scientific uncertainty' about the condition (pg326, results, sec1, para2) They were concerned that their diagnosis of CFS would become a self-fulfilling prophecy (pg326, results, sec1, para5) "with CFS as a label, HCP's were able to help pts work out their own ways of coping" (pg327, results, sec1, para7)	HCP's did not speculate on the consequences for pts' lives of not having a diagnosis (pg326, results, sec1, para2) Some HCP's reported increased tensions when the pt. had already seen many other HCP's - they then described complicated stories with great emotion (pg326, results, sec1, para4b)	HCP's thought that appropriate care comprised of either advice and "pushing along" or Psychotherapy (pg326, results, sec1, para3b) Several HCP's questioned what they care they could actually offer (pg326, results, sec1, para4) Some HCP's adopted a 'collaborative approach' to providing care (pg326, results, sec1, para6) Some HCP's viewed themselves as 'case managers' that allowed them to refer to specialists, and other HCP's for alternative management that they might not have been too knowledgeable on (pg327, results, sec1, para7) Some HCP's had not learnt these approaches in medical training, but rather through exposure to CFS pt., or social knowledge of CFS (pg327, results, sec1, para8)
Fitzgibbon et al	1997	Estimated incidence of 1 per 1000 (pg619, results, sec3, para1) 58% of responding HCP's consider CFS a disease (pg619, results, sec4, para3)	Nearly half (45%) use incorrect terms to refer CFS pts for further management (pg619, results, sec4, para2) However, 82% of responding HCP's felt that if given a CFS pt., they would consider to diagnose them as such (pg619, results, sec4, para3b)		A variety of treatment options has been suggested, but no guidelines have been presented for their treatment options (pg619, results, sec4 para2)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Moosajee	1998	Hospital doctors were negative towards CFS, despite being new graduates and having CFS in their syllabus (pg57, results, sec1.2, para4) 73% of this sample believed CFS to be a legitimate disease (pg59, results, sec1.3.3, para1) knowledge of CFS was obtained from the media (pg60, results, sec1.3.3, para5)	Hospital Doctors were sceptical of CFS and they worked less frequently with CFS pts (pg57, results, sec1.3.1, para2) only 19/72 doctors had ever diagnosed a CFS pt. (pg58, results, tab10) HCP's have reservations about committing to a diagnosis in the absence of clearly defined patho-physiology (pg59, results, sec1.3.2, para2)	64% of HCP's in this sample had reported never working with CFS pts (pg59, results, sec1.3.3, para2) HCP's did not consider the psychological and social aspects of CFS (pg60, results, sec 1.3.3, para4)	

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Moore et al	2000	ALL 20 HCP's interviewed recognised CFS as a condition (p166, results, sec1, para1)		only 20% (4 participants) had never met an individual with CFS (pg166, results, sec1, para1b) 100% of the HCP's in this study, concluded that CFS affects every aspect of daily life (pg167, results, sec3, para1)	9/10 mental health OT's thought that CFS was resolved within 5 years, but 4/10 physical OT's thought CFS was resolved between 6 to >10 years (pg. 166, results, sec2, fig2) All participants thought that there was at least partial recovery, with 3 mental health OT's expecting full recovery (pg167, results, sec2, para5) only 2 OT's (10%) thought that a better prognosis was expected when "early effective management" is implemented (pg167, results, sec2, para6) All HCP's reported their role as an "enabling them to function and supporting them against the world (pg167, results, sec2, para2) 25% of OT's were unsure of any management framework for CFS (pg167, results, sec3, para3) only 25% of OT's had had managed patients with CFS (pg167, results, sec3, fig4)

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Prins et al	2000	52% of GP's had diagnosed CFS (pg9, results, tab1) 20% of those who did not diagnose CFS, did not acknowledge CFS as a diagnosis (pg9, results, para1)	reasons for not diagnosing CFS was ignorance of diagnostic criteria in 69% of those who did not diagnose CFS (pg9, results, para1) HCP's who had increased diagnosis from 45% to 62% between 1995 and 1997 (pg9, results, para1b)	HCP's were significantly less likely to agree with a self-diagnosis of CFS if they had not diagnosed CFS (pg9, results, para2)	only 10% of HCP's were felt capable to provide pts with information of CFS to pts (pg9, results, para3) those that had not diagnosed CFS were significantly less likely to be able to provide information about CFS to pts (p9, results, para3)
Jason et al (2)	2001	HCP's identified CFS pts as CFS rather than ME and FND (pg66, results, sec1, para1) medical trainees were more likely to have heard of CFS than undergraduates (pg68, results, sec3, para2)	When a case study was given the name ME, HCP's responded in a predominantly biomedical framework rather than psychiatric explanations (pg11, results, sec1 para1b) Medical trainees were significantly more likely to attribute the symptoms to primary depression (pg66, results, sec2, para1) medical trainees were significantly more likely to classify CFS as a psychiatric condition on post hoc analysis (pg67, results, sec2, para2b)	Suicide attempts were more likely to be predicted by medical trainees - this was correlated with the depression diagnosis (pg66, results, sec2, para2) Medical trainee's rated pts quality of life significantly poorer than undergraduates (pg67, results, sec2, para2b) In post hoc analysis, medical trainees were more likely to have known someone with CFS than undergraduates (pg68, results, sec3, para2)	

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Jason et al 2001(1)	2001	74% of clinical HCP felt that CFS should change its name (pg429, results, Tab1) 54% of research orientated HCP's felt that CFS needed to change its name (pg429, results, Tab1)	If HCP's had to choose a name, ME was chosen by 47.6% of researcher HCP's and 44.1% of clinical care HCP's (pg431, results, Tab3) 31.0% of researchers and 41.2% of clinicians chose Neuro-endocrine Immune Disorder (pg431, results, Tab3)		
Taylor et al	2001	There were no significantly different views across the three groups about the aetiology, treatment and their familiarity of CFS (pg173, results, para2)			

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Jason et al	2002	When given a case study, 54% of those in the CFS group correctly diagnosed it as CFS, compared to 28% and 19% for ME and FND respectively (pg140, results, sec1, para1) 100% of family practice and psychiatry residents had heard of CFS but 87% of med students had heard of it (pg142, results, sec2, para1) 75% of med students, 80% of family practice residents and 76% of psychiatry residents considered CFS a legitimate organic disease (pg143, results, sec2, para1c)	21% of med students had read an article on CFS compared to 40% of family practice and 90% of psychiatry residents (pg143, results, sec2, para1b)	82% of the entire sample felt that the pt. described had a moderately poor or poor QOL (pg141, results, sec1, para4c) 43% felt it may be stress related, 37% felt it was primary depression (pg141, results, sec1, para4c) Psychiatry residents rated the QOL significantly worse compared to med students (pg143, results, sec2, para2b) Psychiatry residents were also more likely to think that CFS pts would commit suicide in the next two years (pg143, results, sec2 para2c)	In the CFS and FND groups, 42% and 41% respectively thought that it was likely that the pt. would recover in the next 2 years; however only 16% thought likewise in the ME group (pg140, results, sec1, para1b) however, 11% of the entire sample felt it likely or very likely that the pt. would recover in the next 2 yrs. (pg142, results, sec1, para6)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Asbring et al	2003	many HCP's expressed scepticism of conditions that did not have an objective measureable values that would make it possible to establish cause (pg714, results, sec1, para1) CFS has not been accepted as a disease as there is no biological causal mechanism found on research (pg714, results, sec1, para2)		CFS symptoms were regarded as not too severe as to be able to live with them (pg714, results, sec2, para1)	Management options used by HCP's included: Adjusting the ideal to reality, doing something concrete for the pt., keeping a distance or getting closer, pursue causes other than biomedical, giving responsibility to the pt., trying to get acceptance from the pt. (pg716, results, sec5, para1) A professional distance was imperative as HCP's felt they were becoming too involved with the pts and were unable to act professionally (pg716, results, sec5.3, para3)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Raine et al	2004				HCP's often had "conflicts" with pts about their management options (pg2, results, sec1, para1e) HCP's reported not knowing who to refer to (pg2, results, sec2, para1b) Even with a biopsychosocial awareness, mental health interventions were often overlooked (pg2, results, sec2, para2a) 5 main reasons for lack of referral were: lack of familiarity with mental health management, believed that CFS could be managed in a primary care setting, perceived resistance of the pts to psychological management, lack of knowledge about local resources available and doubts about the quality of evidence for alternate interventions (pg2, results, sec2, para2b)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Bowen et al	2005	72% of HCP's recognised CFS as a clinical entity (pg. 391, results, para3) 28% did not accept CFS as a clinical entity despite a local authority publically recognising it as a real disease (pg392, discuss, para2)	49% of HCP's knew the three key features of CFS (pg391, results, para 4) Knowledge of clinical features had no correlation to feelings of confidence (pg391, results, para4b) Biomedical exclusion diseases most commonly excluded were thyroid diseases, anaemia and mood disorders (pg391, results, para 5)	36% of HCP's knew someone with CFS, and this had a favourable impact on their attitudes towards CFS (pg. 391, results, para3)	

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Thomas and Smith	2005	55.8% of HCP's that responded believed that a condition called CFS existed (pg4, results, sec2, para1)	67.4% of those that believed the disease existed had diagnosed a pt. as having CFS (pg4, results, sec2, para1) None of the HCP's used the CDC or Oxford criteria to diagnose CFS, 68.8% preferred to exclude other conditions first (pg4, results, para1c)	on average 6.2 appointments were needed to diagnose CFS (pg4, results, sec2, para1) only 14.8% of surgeries surveyed carried information leaflets on CFS (pg4, results, sec2, para3)	65.9% of HCP's referred the patient to tertiary care for further management (pg4, results, sec2, para1d) Of those who had diagnosed CFS, 89.3% had offered treatment strategies to the patient (pg4, results, sec2, para2) the most common treatment offered was antidepressant therapy, 84% used SSRI AD's, 28% used SNRI AD's and 24% used Tricyclic AD's (pg4, results, sec2, para2b) 56.7% of GP's were aware of consultants in their area that specialised in CFS (pg4, results, sec2, para4) places of referral were General medical outpatients clinics (16.7%), Rheumatology clinics (6.7%), Neurology clinics and Psychology clinics (6.7% ea.) (pg4, results, sec2, para4b)
Daly and Hartz	2007				GP's used supportive counselling (74.1%), AD meds (96.3%), and analgesics (55.6%) most commonly with just over half recommending dietary changes (pg200, results, tab3) Licenced Acupuncturists regularly used herbal remedies (76.2%) and dietary recommendation (71.4%) most commonly (pg200, results, Tab3)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Lu et al	2007	Pre-education session, 72.1% of students thought that CFS was a legitimate disorder, afterward, 81.4% thought that it was legitimate. This change was not statistically significant (pg28, results, para2)	Prior to an education session, 48.8% of students felt uncomfortable diagnosing and managing CFS and 0 students felt very confident (pg28, results, para1) After education, only 23.3% of students felt uncomfortable diagnosing and managing CFS (pg28, results, para1b)		pre education, 37.2% of students were willing to treat a pt. with CFS, after intervention, 53.5% of students were willing which was a statistically significant change (pg28, results, para3)
Scheeres et al	2007		99 of 452 GPs had diagnosed CFS in the last 16 months (pg3, results, para1) Informed HCP's had fewer objections than uninformed HCP's towards the diagnosis of CFS (pg3, results, para1b)		70% of respondents have been informed about CFS and the new management options available (pg3, results, para1)

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Chew-Graham et al	2008	Doubt over the genuineness of the disease was due to pts symptoms being out of proportion to the signs presented (pg343, results, sec1, para1) HCP's questioned the existence of the disease after admitting limited understanding of CFS (pg343, results, sec1, para10) After seeing pts with CFS in social contexts, Some HCP's concluded that the disease existed (pg344, results, sec2.2, para3)	HCP's did not follow any diagnostic guidelines, but rather ran many tests which invariably come back negative (pg343, results, sec1, para7)	Social knowledge of pts with CFS created greater understanding of CFS for the HCP (pg344, results, sec2.2, para1) and again in (pg345, results, sec2.3, para3)	Due to a lack of medical and scientific training on CFS, HCP's turned to alternate sources of evidence (pg344, results, sec2, para1)
Cho et al	2008		30.8% of specialists mentioned CFS as a differential diagnosis and 23.0% used it as their final diagnosis of a case study given to them (pg352, results, sec1, para2)		

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Friedberg et al	2008			After an education session, students felt that employers would be more likely to offer flexible work hours for CFS pts (pg619, results, para2b)	
Swoboda	2008	HCP's who had diagnosed CFS were on average twice as likely to say that there was sufficient evidence for the legitimacy of the disease (pg465, results, sec2, para2)	51% of HCP's had diagnosed one or more individuals with CFS (pg463, results, sec1, para1) CFS Expert HCP's were 3.0 times more likely than non-expert HCPs to have diagnosed a case of CFS (pg463, results, sec1, Tab2) A Combination of a belief of sufficient evidence, use of conference proceedings as a source of information and CFS expertise lead to a "propensity to diagnose CFS (pg467, results, sec2, para4) Priorities for all HCP's were, firstly, 'treatment efficiency' and secondly, 'psychological evaluation' (pg467, results, sec3, para2)		

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Chew-Graham et al	2009	Nurses admissions that they have a knowledge gap about CFS (pg4, results, sec1, para5) Nurses don't know 'what's all that about' with regards to CFS and therefore don't know what CFS is (pg5, results, sec3, para4) CFS is viewed as a new disease and therefore not a real disease (pg5, results, sec3, para4) the diagnosis is viewed with scepticism as it is still considered a contentious disease despite it being a recognised disease (pg6, results, sec4, para8)	Many Nurses were uncertain as to how the disease presented (pg. 4, results sec1, para3) Nurses had more knowledge of CFS when they knew a pt. socially (pg4, results, sec1, para 11) Nurses did not trust their clinical judgement and found it difficult to diagnose due to a lack of guidelines (pg5, results, sec 4, para4) Nurses consider CFS pts not as Biomedical but only as somatic (pg7, results, sec6, para9) Nurses felt they needed more than a short catch-up course in order to effectively diagnose and manage CFS pts as they did not see enough CFS pts to keep their skills sharp (pg7, results, sec6, para13)	Nurses reported limited experience in working with CFS (how would they know if they had seen a patient with CFS?) (pg4, results sec1, para1)	There is an over-reliance on the biomedical model, that when all medical tests come back 'normal', they don't know how to treat or who to refer to. (pg5, results, sec3, para 10) Nurses did not know the treatment options available and how to implement those treatment options (pg7, results, sec5, para18) Nurses don't feel that they are adequately trained in management of CFS (pg7, results, sec5, para 20) Nurses do not know their role in the disease management and the power of an appropriate referral (pg7, results, sec6, para8) Nurses felt that knowledge of CFS and its management aids in active participation by the pt. and HCP and improves enjoyment of both HCP and pt. (pg8, results, sec23)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Brimmer et al	2010	41% of HCP's had diagnosed CFS, of conference attendees (pg3, results, sec1, para2); HCP's who had diagnosed a pt. with CFS were much more likely to know more about CFS p<0.0001 (pg6, results, sec 4, para1)	If an HCP had previously given a diagnosis of CFS, they were more likely to know the criteria for diagnosis p<0.001 (pg4, results, para 3), (And again in pg8, results, sec 5, mid para3); Physicians, PA's and nurse practitioners had better scores for knowledge than nurses and other HCP's or PhD's (pg. 4, results, sec2, para1) Between 25 - 30% of Doctors felt that there was enough available info to make a CFS Diagnosis (pg. 8, results, sec 5, para 2); Most Doctors were able to correctly identify four symptoms of CFS (pg. 8, results, sec 5, end para 4)		less than 50% of Doctors replying to a questionnaire agreed that there were several treatment options available to a CFS pt. (pg. 8, results, sec5, mid para 2)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Chew-Graham et al	2010	HCP's refer to it as a new diagnostic term (pg3, results, sec1, para5a) HCP's focussed on the biomedical model, and did not take other causes into account (pg3, results, sec2, para3) HCP's don't believe CFS to be a truthful diagnosis (pg3, results, sec3, para2)	HCPs struggle to make sense of difficult set of symptoms (pg2, results, sec1, para1) Symptoms associated with somatic presentations rather than and actual disease (pg3, results, sec para3)		Excluding the treatable - display lack of knowledge of treatment options for CFS (pg3, results sec2 para6) HCP's avoid CFS diagnosis as it sets the pt. "off on a track that will get them nowhere" (pg3, results, sec3 para6) HCP's don't feel like they can refer because the response is often "what can we do?" (pg4, results, sec4, para3)

Horton et al	2010	Diagnosis of CFS can be challenging for HCPs to make, especially if they don't have the experience of the condition (pg4, results, sec1, para1) HCP's thought the NICE guidelines helpful (pg7, results, sec1, para1b) Exposure to different/new presentations of CFS is NB for improving primary care and confidence in diagnosis (pg7, results, sec1, para2a) CFS was commonly misdiagnosed as depression (pg7, results, sec1, para3b)	HCP's thought that not having a conclusive diagnostic test was negatively impacting HCP's and patients (pg7, results, sec1, para1c) HCP's recognised that CFS pts had received "a rough time" from the medical profession (pg7, results, sec1, para 2c) Different pts respond differently to the knowledge of a CFS diagnosis and HCP's need to be aware of the long term nature of CFS and the slow progress that occurs in the recovery (pg7, results, sec2, para1b) HCP's were aware of the difficulties that CFS posed for their social lives with respect to leisure activities that required concentration and memory (pg7, results, sec2, para3) HCP's found financial pressures to be a significant barrier to access to the health system and their support system (pg8, results, sec2 para5)	HCP's a subjected to patient demands for more investigations (pg7, results, sec1, para1d) HCP's thought that referral to specialist services was occurring quicker and were more accurate than before (pg7, results, sec1, para1e) Specialist practitioners are regarded as having better awareness of the symptoms physical/psychological through their increased exposure to the disease (pg7, results, sec1, para2d) HCP's need to provide holistic and flexible support to CFS pts (pg7, results, sec2, para2) HCP's recognise the importance of support structures for pts to cope with CFS appropriately (pg8, results, sec2, para4) Successful management of CFS is dependent on the willingness of the pt. to accept the diagnosis and implement lifestyle changes (pg8, results, sec3, para1) some of the management options chosen by pts cannot be recommended by HCP's due to the poor evidence base for those alternative treatments (pg8, results, sec3, para5) CBT is the main treatment, and the timing of the implementation is seen as key to the successful management of CFS (pg. 9, results, sec3, para6)
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Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Erueti et al	2012	75% of student thought that CFS was a disease, but 96% of students thought that ME was a disease (pg3, results, tab1) when compared to a previous article by Campbell 1979, ME results were consistent and CFS results had improved from 40% of students (pg2, results, fig1)			
Ali et al	2014	Attending the workshops seemed to reinforce the confidence and knowledge of the disease, diagnosis and management of CFS (pg195, results, sec2.2 para2)	A significant increase in confidence of diagnosis was noted after the workshop (pg194, results, sec1.3, para1) The workshops were helpful for the HCP's in their identification of symptoms (pg194, results, sec2.3, para2)		After the workshops, HCP's reported having better knowledge of when to manage in their practice and when to refer onward (pg194, results, sec2.1, para3) HCP's highlighted that the workshops increased their knowledge of available management options (pg195, results, sec2.4, para2) Some HCP's reported that there was no potential referral as there were no fatigue clinics in their area (pg195, results, sec2.5, para15)

Knowledge

Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Knight et al	2014		88% of paediatricians had diagnosed at least one patient with CFS (pg1003, results, tab2) 56% had not used criteria to make the diagnosis and 24% had used the International ME Criteria (pg1003, results, tab2)	53% of paediatricians needed 3 or more months to make the diagnosis and a further 43% needed more than 6 months to make the diagnosis (pg1003, results, tab2)	Paediatricians commonly referred to teachers, physios and psychologists in the diagnosis and management of CFS (pg1003, results, para2)

Knowledge					
Author	Year	Is CFS a disease?	Criteria for Diagnosis	Patient difficulties	Treatment options and referral
Stenhoff et al	2015	Students thought that CFS was a diagnosis of exclusion, and reported many different views about its aetiology (pg201, results, sec1, para3)	Students found it "difficult to describe symptoms beyond tiredness and fatigue" (pg200, results, sec1, para1) views ranged between viral, biomedical and psychiatric explanations for the disease (pg201, results, sec1, para5-7) some students thought that CFS was caused by either personality type, hypersensitivity of the brain or medically unexplained (pg201, results sec1, para8) Still other students thought the causes were a combination of factors, and used a biopsychosocial approach (pg201, results, sec1, para10) Students felt that course convenors prioritised diseases that were more prevalent and for this reason, CFS was not considered important (pg204, results, sec3, para4)	Students who had personal knowledge of CFS pts reported that this had changed their attitudes towards CFS pts positively (pg203, results, sec2, para22)	Students were reliant on the Biomedical model for management (pg202, results, sec1, para3) the student who had some psychology training highlighted the evidence base for CBT and GET, whereas those who do not have the training did not mention those treatment options in the management of CFS (pg202, results, sec2, para7)

Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Ho-Yen and McNamara	1991					
Scott et al	1995	When a pt. had a self-diagnosis of CFS, the HCP was less likely to think that the pt. would comply with treatment (pg508, comment, para2)				
Woodward et al	1995	HCP's thought that appropriate care comprised of either advice and "pushing along" or Psychotherapy (pg326, results, sec1, para3b) One HCP thought that the pts "needed their symptoms" (pg326, results sec1, para3c) When and HCP and pt. had a difference of opinion, the HCP would always take their view would prevail (pg326, results, sec1, para3d)	Scepticism towards 'fashionable epidemics' from some HCP's about CFS (pg326, results, sec1, para1)		Several HCP's questioned what they care they could actually offer (pg326, results, sec1, para4)	
Fitzgibbon et al	1997					
Moosajee	1998	Hospital and specialist doctors were more varied with their attitudes towards CFS pts than GP's (pg53, results, sec1.1, para4) Attitudes differed greatly depending on place of work (pg. 53, results, sec1.2, para2)	Doctors shied away from diagnosing CFS as it might become a self-fulfilling prophecy (pg60, results, sec1.3.3, para6)	GP's were more likely to believe myths and specialists and hospital doctors were more likely to uphold stereotypes of pts (pg50, results, sec1.1, para2) the range of scores HCP's obtained on the attitude scale was "very diverse" (pg50, results, sec1.1, para3)		

Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Moore et al	2000			Generally, a positive attitude was shown toward the prognosis of individuals (pg166, results, sec2, para5) the OT's reported that other professional's attitudes are "quite scathing of CFS" (pg168, results, sec4, para2)		
Prins et al	2000	HCP's that empathised with CFS pts had significantly less problems from them than non-empathising HCP's (pg10, results, sec2, para1) The most problematic tendencies highlighted by HCPs were vague complaints, somatisation and the compelling attitude of the CFS pt. (pg10, results, sec2, para2)				
Jason et al (2) Importance of Name	2001					
Jason et al 2001(1)	2001					

Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Taylor et al	2001			HCP's in the Ampligen group were more likely to think the pt. was significantly more disabled than in the CBT group (pg173, results, para1b)	HCP's assigned to the medication group (Ampligen) were significantly more likely to think that the pt. was correctly diagnosed as having CFS (pg171, results, para1)	
Jason et al	2002		39% of those in the ME group felt that the condition was caused by medical causes compared to 22% in the CFS group (pg141, results, sec1, para3)	67% of the entire sample felt that the condition described was severe or very severe (pg141, results, sec1, para4b)		
Asbring et al	2003	CFS pts represented themselves differently to other sick people are expected to look and behave, you must look sick to treated as such (pg714, results, sec2, para 3)	Feelings of frustration, helplessness and failure are felt by HCP's when a discrepancy between their ideal and reality occur (pg715, results, sec4, para3)			
Raine et al	2004	Pts were viewed as having being malingers and made no effort to get well (pg2, results, sec1, para1d) the HCP's stereotyping of CFS had "ceased to be seen as a discrete disorder and became a feature of the patient" (pg2, results, sec2, para1a)	Delegitimised disease because it has no consistent disease history (pg2, results, sec1, para1c)	HCP's viewed caring for CFS pts as a 'burden' (pg2, results, sec2, para1c)	Both pts and HCP's violated the "sick roles" that they usually would play for other diseases (pg2, results, sec1, para2)	

Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Bowen et al	2005	36% of HCP's knew someone with CFS, and this had a favourable impact on their attitudes towards CFS (pg. 391, results, para3) Having seen more CFS patients had no bearing on feelings of insecurity, frustration and despair felt by the HCP (pg. 391, results para 3b)	48% of HCP's did not feel confident in making a diagnosis of CFS (pg391, results, para 2)	57% of HCP's scored positively in an attitude test about CFS (pg. 391, results, para 2) Those who have seen more CFS patients in the last year have better attitudes towards CFS patients (pg. 391, results, para3b) This study cannot distinguish how attitudes towards other chronic diseases and CFS differ (pg392, discuss, para 6)	41 % of HCP's did not feel confident in treating CFS (pg. 391, results, para 2)	
Thomas and Smith	2005					
Daly and Hartz	2007					
Lu et al	2007					
Scheeres et al	2007					
Chew-Graham et al	2008	HCP's reported that pts sought out scientific evidence and would confront HCP's in the session with the evidence they have used (pg345, results, sec3, para4)		HCP's wanted to maintain their position as an expert and would do this by using "biomedical discourse" (pg345, results, sec3, para8)		
Cho et al	2008					

Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Friedberg et al	2008	HCP's have a positive attitude to the veracity of CFS and how it affects the pt. (pg619, results, para 1b)		Generally, attitude towards CFS, when asked specifically CFS related questions, was neutral or slightly favourable (pg619, results, para1a) after and education session, attitudes towards CFS significantly improved (pg619, results, para2a)		
Swoboda	2008		CFS experts were between 1.7 and 2.6 times as likely to have diagnosed another contested illness than non-expert HCP's (pg464, results, tab2)			

Chew-Graham et al	2009	Attitudes towards CFS patients are better when nurses know a CFS pt. socially (pg4, results, sec1, para 11) Some nurses attitudes showed empathy towards CFS pts (pg4, results, sec2, para2) Negative attitudes are evident when labelling patients non-copers (pg5, results, sec2, para 9) some nurses have shown some understanding towards CFS pts of the difficulty of the disease they live with (pg. 5, results, sec3, para2) However, some nurses have negative connotations when label them "those people" (pg. 5, results, sec3, para4) because of the belief that the genuineness of CFS is debatable, some nurses have a negative attitude toward the CFS pt. (pg5, results, sec3, para7) Some nurses felt that the money spent on CFS management could be better spent, and that other diseases are being neglected because these pts are taking up time and money (pg7, results, sec6, para6)	Not willing to check the evidence against what they "don't think" as it is easier to have a negative attitude towards CFS pts (pg5, results, sec2, para 4) Nurses don't like to work with CFS as they don't anticipate the enjoyment of seeing the patient progress (pg8, results, sec6, para21)	Nurses felt that they were more empathetic than other HCP with respect to CFS pts (pg6, results, sec5, para6)	Nurses opinions are shaped by negative attitudes of senior staff towards CFS patients (pg4, results, sec1, para7) Nurses reported not having an interest in CFS as it is a chronic long term problem (pg7, results, sec6, para8)
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Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Brimmer et al	2010	Most HCP's at the conference held generally positive attitudes towards CFS (Pg. 4, results, para 2)	HCP's in a community setting were more likely to have negative attitudes towards CFS [this would be concerning as in SA this is the patients first point of access to healthcare] (pg. 6, results, sec3, para1)	those HCP's who had diagnosed CFS were strongly linked ($p<0.05$) to the attitude that "people with CFS are just depressed" (pg. 4, results, para3) Generally Nurses and physicians had the worst Attitude scores towards CFS of all the HCP's at the convention (pg4, results, section 2, para1)		All HCP's in the sample showed negative attitudes towards pts with CFS (pg. 9, discuss, para 6)
Chew-Graham et al	2010	Negative attitude towards the CFS pt. in that they believe what they want to believe, regardless of the truth of that label (pg3, results, sec3, para2) HCP's attitude needs to remain supportive towards the pt. (pg4, results, sec 5, para4)		Negative attitude associated with ability to cure CFS once it is classified as a medical condition (pg3, results, sec1, para6)	HCP's needed to accept that they cannot cure, but can help to alleviate the symptoms (pg4, results, sec5, para2)	

Attitudes						
Author	Year	Patient related	Diagnosis related (Making a Diagnosis)	Disease related (CFS as a disease)	Treatment of CFS	To relevance of CFS
Horton et al	2010	HCP's thought that some pts "find it hard to accept" the diagnosis even when they have experienced mistrust of HCP's, self-doubt and living with the disease (pg7, results, sec2, para1a) HCP's felt that CFS was stigmatised in their patient's workplace (pg7, results, sec2, para2b) employers don't understand the meaning of 'low grade ME' but respond better to 'post viral fatigue' (pg9, results, sec4, para3b)	Consequences for delayed diagnosis were considered significant (pg7, results, sec1, para3)	Specialist HCP's felt that their referrals came from a small group of GP's and they found that "whole practices" of GP's did not think that CFS did not exist (pg9, results, sec4, para1)		HCP's were frustrated at the lack of recognition or acknowledgement of CFS by society and its institutions (pg10, results, sec5, para4)
Erueti et al	2012					
Ali et al	2014					
Knight et al	2014					
Stenhoff et al	2015	Negative attitudes were held towards CFS pts both implicitly and explicitly, such as "everyone get knackered no-one really cares" (pg202, results, sec2, para9-10)		The disease is "invisible" in nature and is a complex disease that is "frustrating, difficult and intimidating" (pg202, results, sec2, para3)		Some students felt that there shouldn't be any extra emphasis on CFS as it would be "a wasted week" of training (pg204, results, sec3, para11)

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Ho-Yen and McNamara	1991					
Scott et al	1995					
Woodward et al	1995		Pts were expected to accept the HCP's assessments, and comply with interventions (pg326, results, sec1, para3)			Some HCP's believed their role to be Authoritative and directive (pg326, results sec1, para3a)
Fitzgibbon et al	1997	45% of HCP's used terms that they felt would be accepted by the recipient (pg619, results, sec4, para2)				
Moosajee	1998	Doctors preferred not to label due to uncertainty of the existence of CFS (pg60, results, sec1.3.3, para3) HCP's are still defensive of their opinions on CFS (pg60, results, sec1.3.3, para9)	Hospital doctors believed stereotypes of CFS pt. more than GP's and specialists (pg53, results, sec1.2, para3)		Doctors mostly used the biomedical model for diagnosing (pg59, results, sec1.3.3, para3)	

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Moore et al	2000	90% of the HCP's interviewed thought that the nature of the disease was a combination of psychological and physical in origin (pg166, results, sec2, para1) some pts use the illness as a coping strategy (pg166, results, sec2, para2)	HCP's believed that a person's personality affected how the recovered from any disease (pg166, results, sec2, para2)			CFS was seen as a long term disease by 70% of participants (pg166, results, sec2, para4)
Prins et al	2000		HCP's felt that CFS pts took more time (89%), had more problems (73%) and had poor co-operation from the them (31%) (pg10, results, sec2, para1)		HCP's considered that most of their pts complaints as psychological in origin and not physical (pg11, results, sec4, para2) 91% of those not diagnosing CFS consider the pts symptom as psychological, compared to 76% of those who had diagnosed (pg11, results, sec4, para2)	

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Jason et al (2)	2001		Medical trainees were less likely to consider CFS pts as malingerers (pg67, results, sec2, para3)			Medical trainees were less likely to believe CFS pts would recover in the next two years than undergraduates (pg67, results, sec2, para4)
Jason et al 2001(1)	2001					
Taylor et al	2001					
Jason et al	2002	Medical trainees believe that the ME label indicates a more severe chronic, debilitating disease than CFS (pg140, results, sec1, para1c) 57% of all trainees felt that the patient was severely or very severely disabled (pg141, results, sec1, para 4b)	Only 3% in the whole trainee sample felt that the patient was malingering (pg141, results, sec1, para4) psychiatry residents were significantly less likely to believe that the pt. was malingering than med students (pg143, results, sec2, para2)		when given the same case study, trainees were significantly more likely to think that those with the CFS diagnosis was correctly given, than the FND (pg140, results, sec1, para2a)	those in the ME group were more likely to believe the pt. would not qualify for organ donation compared to the CFS group (pg141, results, sec1, para2b) 67% of trainees in the CFS group would use psychiatric interventions compared to 43%in the ME group (pg141, results, sec1, para3b)

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Asbring et al	2003	HCP's believe pts don't behave like they are sick or in pain (pg714, results, sec2, para4)	Patients exaggerate the severity of their problems (714, results, sec2, para2b) HCP's called the pts morality into question and their work ethic as they only had the pts version of events (pg714, results, sec2, para5) the HCP's in characterised 5 different types of pt. characters - not all mutually exclusive - the ambitious, the active, the illness fixated, the demanding, the medicalising (pg715, results, sec3, para1) HCP's thought that these pt. had a pessimistic view on life and that this was difficult to break (pg715, results, sec3, para3)		Some HCP's doubted whether the scientific ordeal for having a causal mechanism which made the diagnosis of CFS more difficult (pg714, results, sec1, para3)	HCP's are unable to provide a causal explanation of CFS and this makes it difficult to treat and answer pts questions (pg715, results, sec3, para1) HCP's who made a diagnosis had the satisfaction of doing something and the gratitude of the pt. as they have done something for them (pg715, results, sec4, para2)
Raine et al	2004	CFS was difficult to conceptualise and without a precise location, "it's not like a broken a leg" (pg2, results, sec1, para1b)	GP's who saw CFS pts expected them to have "a certain personality trait that is CFS waiting to happen" (pg2, results, sec1, para1) the trait was described as introspective and a low symptom threshold (pg2, results, sec1, para1)			HCP's felt that their impartiality and authority had been challenged when pts had preconceived ideas about the disease and its causes (pg2, results, sec2, para2b)
Bowen et al	2005					
Thomas and Smith	2005					
Daly and Hartz	2007					
Lu et al	2007					

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Scheeres et al	2007					
Chew-Graham et al	2008	CFS had more credibility with some HCP's if they knew of a celebrity, whom they respected, had it (pg344, results, sec2.1, para6)				
Cho et al	2008					
Friedberg et al	2008	After an education session, students viewed CFS not primarily as a psychological disease (pg619, results, para2c)	Even after the education session students still felt that CFS pt. were lazy and depressed (pg620, results, para2d)			
Swoboda	2008	51% of HCP's who diagnosed CFS identified 'organic factors' more than any other factors when diagnosing CFS (pg469, results, sec4, para2)			Non-expert were 7.7 times more likely than CFS experts to believe that CFS aetiology is unclear (pg469, results, sec4, para2)	

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Chew-Graham et al	2009	Nurses don't believe that it is a real disease and therefore don't put in the same effort that they would do when they are convinced of the veracity of the disease (pg5, results, sec2, para11) Nurses don't believe it is a real disease and therefore have less sympathy towards CFS pts (pg5, results, sec 3, para6)	Negative beliefs and stereotypes of CFS pts colours the knowledge of the disease (pg. 5, results, sec 2, para 4) Lazy bastards, waste of space, lazy fags (pg5, results, sec3, para10) belief in stereotypes about patients being "skivers" and match their symptoms to what they find on the internet (pg6, results, sec4, para9) Not all nurses have bad beliefs, some believe that they need to be treated as individuals and not labelled as a nuisance (pg. 6, results, sec4, para11)	Lack of training opportunities highlight lack of importance placed on CFS (pg4, results, sec1, para1) Nurses don't believe CFS is important enough to be added to the responsibilities of primary level care (pg7, results, sec6, para12)	Diagnosis brings relief for the CFS pt. (pg5, results, sec4, para2) CFS diagnosis is susceptible to the lead clinician's sympathies/belief in CFS (pg5, results, sec4, para5)	Management of CFS is time consuming and frustrating - essentially it's not worth it. (pg6, results, sec5, para2) Nurses role was functional, follow the instructions the GP gives (pg6, results, sec5, para3) Nurses believe that they cannot make a difference for CFS pts (pg. 8, results, sec6, para21)
Brimmer et al	2010	All other HCP's have better beliefs about CFS when compared to nurses (pg. 9, discuss, para 6)	the vast majority of doctors believed that CFS impairs the QOL of the pt. and their caregivers (pg8, results, sec 5, end para 2); Doctors who had previously diagnosed CFS were less likely to believe that the symptoms were in the pts head (pg8, results, sec 5, end para 3)	HCP's agreed that CFS is a big problem and that it affects all socio economic groups equally (pg4, results, para 2)	HCP's agreed that CFS is more difficult to diagnose (pg. 4, results, end para 2) This link is more likely (p<0.05) to occur when and HCP has previously diagnosed CFS (pg4, results, para 3)	HCP's agreed that, compared to other illnesses, CFS is more difficult to treat and manage (pg4, results, end para 2) This link is more likely (p<0.05) to occur when and HCP has previously diagnosed CFS (pg4, results, para 3)

Beliefs

Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Chew-Graham et al	2010	Because it is a new diagnostic term, HCP's do not recognise it as an illness (pg3, results, sec1, para5b)	HCP's believed that CFS pts were people who gave up/gave in to their symptoms (pg3, results, sec1, para3b) HCP's felt that some pts liked having a label (pg3, results, sec3, para2) HCP's felt that once the label is given that pts disengage with the causes of their illness and that this was harmful in the long term management of the pt. (pg3, results, sec3, para4) Labels can create a self-fulfilling prophecy (pg3, results, sec3, para7)	Some HCP's believe that classifying CFS as a medical condition gives the incorrect implication that it can be cured (pg3, results, sec1, para6) Because CFS "has no cure" the long term management that goes into a CFS pt. is "undervalued" by the health system as it is not important enough to support the management of the disease financially (pg4, results, sec5, para8b)	HCP's don't think that they can do the "extra testing" that others can do (pg4, results, sec4, para5)	HCP's felt that if they sent a pt. for tests, that would provide some psychological relief for the pt. as the HCP is seen as 'taking the pt. seriously' (pg3, results, sec2, para4) Excluding the treatable highlights the belief that CFS is not treatable (pg3, results, sec2, para6) HCP's felt that once the label is given that pts disengage with the causes of their illness and that this was harmful in the long term management of the pt. (pg3, results, sec3, para4) HCP's felt that CFS is a difficult disease to manage because there is no cure (pg. 4, results, sec5, para 5) Because of the no cure belief, there are "no rewards" in further management or referral (pg4, results, sec5, para8)

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Horton et al	2010	HCP's reported that most of their pts were white females, despite a diverse catchment area (pg10, results, sec5, para3) HCP's believed that men would struggle to come to terms with a diagnosis of CFS and the associated ability to perform work (pg10, results, sec5, para3b)	Confirmation of diagnosis represents the end of a long period of uncertainty for the pt. and this brings them relief (pg7, results, sec1 para3c) For some pts who have had comparatively short periods until the confirmation of diagnosis, the confirmation is not as "welcome" (pg7, results, sec1, para3d) Pts will present differently, as they will have symptoms other than fatigue, and their reporting of that does not mean that they are unreliable pts (pg8, results, sec3, para2a) "Most people do come out in the end and do start to move forwards" (pg8, results, sec3, para3b) Trust between a pt. and HCP is considered as an NB issue (pg9, results, sec4, para3a) HCP's found that pts who were not in work because of CFS mostly wanted to return to work, but required support to maintain consistent activity (pg9, results, sec4, para3c)		HCP's thought that not having a conclusive diagnostic test was negatively impacting HCP's and patients (pg7, results, sec1, para1c) HCP's believed that some patients still struggled with uncertain diagnoses because of conflicting evidence and beliefs by HCP's (pg7, results, sec1, para3c)	HCP's felt management was made more difficult when the pt. did not agree/ were ambivalent towards the diagnosis of CFS (pg7, results, sec2, para1) HCP's felt they needed to maintain contact with the patient by visiting them at home or telephonically contacting them to assist the pt. and caregivers in their management (pg8, results, sec3, para2b) Because pts often do not see their progress, the HCP-pt. relationship can be put under pressure (pg8, results, sec3, para4) some of the management options chosen by pts cannot be recommended by HCP's due to the poor evidence base for those alternative treatments (pg8, results, sec3, para5) HCP's focused on engaging patients to enable them to manage their disease (pg9, results, sec5, para1a)
Erueti et al	2012					
Ali et al	2014					

Beliefs						
Author	Year	Validity of CFS	About patient's character	Importance of CFS	Diagnosis difficulty	Management of Disease
Knight et al	2014					
Stenhoff et al	2015	Students reported that they often questioned the "legitimacy" of the CFS pts symptoms (pg202, results, sec2, para1) However, based on QOL, Students reported that CFS was a severe condition (pg202, results, sec2, para3b) Negative and dismissive attitudes were "passed down" to students through throwaway comments and gestures (pg203, results, sec2, para17) Students thought it was a western disease and people in Africa did not get CFS and couldn't afford to get CFS as they need to work and feed their families (pg203, results, sec2, para21)	Students who had studied psychology felt that they had "more sympathetic" towards CFS pts (pg202, results, sec2, para5) CFS pts were viewed as being malingerers and time-wasters who have a second agenda (pg202, results, sec2, para11) students associated CFS with poor coping skills and laziness (pg203, results, sec2, para13)	Students took their opinions and beliefs from their tutors and clinical educators as they had more experience (pg203, results, sec2, para15) Students reported that CFS was "brushed under the rug" or "skimmed over" in their medical curriculum (pg204, results, sec3, para2) Student often had to self-study in undergraduate courses and viewed CFS as a psychosomatic or psychosocial disease and therefore a lower priority to other diseases (pg204, results, sec3, para12)	Students were hesitant with their own beliefs, and showed that their knowledge was limited (pg201, results, sec1, para17)	Students believed that the disease was a "lifelong condition" and that outcomes varied depending on the severity of the condition (pg201, results, sec1, para13)

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Ho-Yen and McNamara	1991				
Scott et al	1995				
Woodward et al	1995		Having a diagnosis may ease the distress and contribute towards beneficial changes for the pts (pg328, discuss, para2)		
Fitzgibbon et al	1997				
Moosajee	1998	Education programs aimed at HCP's attitudes (pg68, discuss, sec2, para1)	Awareness through education programs and the media is important (pg68, discuss, sec2, para2)	Further study into the knowledge base of HCP's (pg67, discuss, sec2, para1)	Philosophically HCP's are agreed that CFS is a disease but their practice does not bear this out (pg67, discuss, sec1, para2)

Recommendations

Author	Year	Dissemination	Awareness	Further study	Improved KAB
Moore et al	2000	14 of 20 HCP's felt the media contributed significantly towards their knowledge and beliefs (pg167, results, sec4, para1) Only 4 of 20 felt their knowledge was gained from professional and university training (pg167, results, sec4, para1)	50% of HCP's were influenced by other professionals' approaches and attitudes towards CFS (pg167, results, sec4, para2)	re-evaluation of the criteria for diagnosis, especially the wait for 6months of fatigue, as early management was considered the most appropriate and this criteria, prohibits such management (pg168, discuss, sec1, para5)	Some HCP's reported that they would like more formal training on CFS as they are coming across CFS pts (pg168, results, sec4, para2)
Prins et al	2000		this paper highlighted that HCP's were not aware of the diagnosis guidelines (pg12, discuss, para1)		
Jason et al (2)	2001	Medical trainees were more likely, on post hoc analysis, to have read articles on CFS than undergraduates (pg68, results, sec3, para2)	Changing the name of CFS to ME disease could increase the ridicule experienced by the pts (pg69, discuss, para8)		

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Jason et al (1)	2001		They propose to instate more than one name, with slightly different criteria so that all the different stakeholders might be willing to accept the compromise (pg433, discuss, para7)		
Taylor et al	2001	Psychotherapy was recommended in the absence of other medical recommendations (pg174, discuss, para3)	Mental health practitioners need to work in closer collaboration with physicians (pg174, discuss, para3b)		
Jason et al	2002	Name changes and inaccurate recommendations have led to invalidation and stigmatisation of CFS pts by HCPs, dissemination needs to be clear and accurate (pg145, discuss, para5)		Future study was recommended to replicate this study in other population groups, such as patients, carers and lay personnel (pg145, discuss, para4)	Name changes for AIDS and MS occurred with less evidence available to suggest name changes, also MS was not subject to near as much stigma as CFS despite similar levels and amounts of evidence available (pg146, discuss, para6)

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Asbring et al	2003				
Raine et al	2004		Good clinical management is partly due to an effective HCP-Patient relationship (pg3, discuss, sec3, para1) HCP's need to understand their beliefs about CFS in order to overcome barriers to effective management (pg3, discuss, sec3, para1b)		
Bowen et al	2005	Dissemination needs to be readable (not long or verbose) otherwise HCP's will not have the time/space to apply the information (pg392, discuss, para 7)	Educational awareness needs to emphasise the patient's involvement in their management (pg. 392, discuss, para8)		

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Thomas and Smith	2005	Scepticism HCP in recognising CFS was considered a problem before this study and it found that it was still a problem, this highlights that previous efforts to educate might not have been that effective (pg5, discuss, para3)	43% of HCP were aware of specialist services available to them for managing CFS (pg5, discuss, para4)		The results of this study are very similar to previous studies and the responses of the GP's are familiar to the researchers, this highlights an issue with dissemination (pg5, discuss, para8)
Daly and Hartz	2007			Future study needs to address poor response to questionnaire by GP's and give treatment outcomes for the management suggested (pg201, discuss, para5)	

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Lu et al	2007	four keys areas education focussed on - accurate facts, dispelling myths, presenting a CFS pt. as a live case study and increasing awareness of treatment options (pg. 29, discuss, para1)		To determine if this early education is effective with a group of HCP's with a higher initial scepticism (pg29, discuss, para3)	
Scheeres et al	2007	their informational intervention would be an efficient method to inform HCP's and let them refer pts (pg4, discuss, sec3, para1)			
Chew-Graham et al	2008	HCP's report that the primary alternate source of evidence was from the media (pg344, results, sec2.1, para1) Working with CFS pts lead to greater understanding of the condition (pg344, results, sec2.2, para6) HCP's reported that personal experience was an extremely convincing form of evidence for CFS (pg345, results, sec2.3, para9)	Diagnosis is not the end point for the HCP (pg346, discuss, sec2, para2)		

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Cho et al	2008	Dissemination should be relevant to the sociocultural differences (pg345, discuss, sec3, para1) Biased media coverage often led to aggravated misunderstandings of CFS, attempts must be made to ensure that all dissemination is planned carefully to disseminate evidentially accurate information (pg354, discuss, sec3, para2b)	This study was conducted in the two most internationally collaborative hospitals in Brazil, the awareness would be expected to be less in other, less exposed to current evidence centres (pg353, discuss, sec1, para2)	Locally produced evidence for CFS needs to be done to assess the knowledge of CFS and appropriate management (pg354, discuss, sec1, para2a)	
Friedberg et al	2008	Students had a strong preference towards an interactive education session (pg620, discuss, para1)	Education sessions need to include a biopsychosocial approach (pg620, discuss, para4) during education sessions, different management options should be emphasised (pg620, discuss, para4)	After an education session, student was more likely to favour more funding for CFS research (pg619, results, para2b)	

Recommendations

Author	Year	Dissemination	Awareness	Further study	Improved KAB
Swoboda	2008	HCP's reported obtaining information from "articles in medical journals, conference proceedings, patient provided information, media reports, the internet and physician consultation" (pg465, results, sec2, para3a) HCP's diagnosing CFS were much more likely to use 'conference proceedings' as a source of illness information than non-diagnosing HCP's, $p<0.001$ (pg465, results, sec2, para3b)	Those that diagnosed CFS valued the clinical approach that requires the tolerance of uncertainty while pathogenic and etiological evidence, as well as diagnostic tools, are being developed in the interim (pg472, discuss, para2b)		When diagnosing, especially illness experts, rated empirical tests and patient collaboration as important for evaluating CFS (pg467, results, sec3, para2b)

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Chew-Graham et al	2009	Nurses reported that they needed more education on CFS in order to manage it effectively and reported the need for management guidelines (pg8, results, sec6, para25) This included other management options apart from the biomedical sphere (pg8, results, sec6, para29) Once off education days was not considered sufficient in order to manage CFS pts adequately (pg8, results, sec6, para30) Post education support and supervision when seeing CFS patients was recommended by nurses (pg8, results, sec6, para32) Dissemination of Evidence based guidelines needs to occur to HCP's is very NB (pg9, discuss, sec4, para1b)	Nurses suggested that CFS management should occur in a primary care setting (pg7, results, sec6, para1) If Nurses are to be the primary caregivers for CFS then their education needs must be met (pg9, results, discuss, sec4, para1a) Training strategies needed to overcome stereotypes and stigmas by HCPs (pg10, discuss, sec4, para2a) nurses needed protocols to follow to support CFS pts appropriately (pg10. discuss, sec4, para3)		Nurses Highlighted that much of their knowledge of CFS came from the media (pg4, results, sec1, para 9) Nurses suggested that treatment for CFS should commence as early as possible, even while other diseases are still being excluded (pg7, results, sec6, para3)

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Brimmer et al	2010	CFS education programmes need to be targeted at nurses and those that have not diagnosed CFS (pg. 10, discuss, end para 7); improve health seeking behaviour in those with CFS and educate them to "not concentrate on negative KAB's of providers" (pg. 12, discuss, para8); tailor the info for the audience use the appropriate channels and targeted info (pg. 13, discuss, para 11)	HCP's should alter their assessment and demeanour towards the difficult pt. because it's the CFS that is making them difficult (pg. 8, discuss, para 3); Education programmes should focus on assessment and management options, not awareness (pg. 13, discuss, para10)	Further research into why some Doctors have diagnosed CFS but still think the pt.'s symptoms are in their head (pg. 8, discuss, para 3)	The more informed physicians are of CFS the better their KAB's (pg. 8, discuss, end para 2)
Chew-Graham et al	2010	Training and Education of HCPs needs to be improved to assist with better diagnosis and management of CFS (pg5, discuss, sec4, para1a) Education needs to be interactive as passive learning has been found to be ineffective (pg5, discuss, sec4, para1c)	HCP's need clear and concise guidelines to implement (pg5, discuss, sec4, para1b)		

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Horton et al	2010	All HCP's in this study advocated for a self-management approach to empower the pt. (pg11, discuss, para5a)	Specialist HCP's highlighted a need for specialist services to be more visible to primary care services (pg10, results, sec5, para2) HCP's need to be flexible in their management and referral of CFS pts (pg11, discuss, para4)	HCP's felt that further study was needed with respect to CBT's contribution towards physical improvements (pg11, discuss, para5b)	
Erueti et al	2012				

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Ali et al	2014	Some felt it helpful to have information booklets to give to pts and others felt "examples of best practice and guidelines" were most helpful during the workshops (pg195, results, sec2.5, para7) Grouping the evidence of effective treatment would be helpful when advising managers (pg195, results, sec2.6, para2) HCP's enjoyed the interactive nature of the workshops (pg195, results, sec2.7, para1)	Some felt that it was difficult to implement their knowledge at their place of work as their managers were not as understanding of the disease and therefore timescales became an issue (pg195, results, sec2.5, para14)		General knowledge of CFS was significantly improved in pre-/ post workshop analysis (pg193, results, sec1.1, para1) 52% of HCP's recorded scores that showed implementation of knowledge gained from a workshop (pg194, results, sec1.2, para1)
Knight et al	2014	Clear use of comprehensive guidelines is needed for good clinical practice and needs regular appraisal (pg1004, discuss, sec2, para1b)		Best practice needs to be clarified as there is a variety of different management options that have been used (pg1005, discuss, sec4, para2)	

Recommendations					
Author	Year	Dissemination	Awareness	Further study	Improved KAB
Stenhoff et al	2015	Students gained some of their understanding from media (pg203, results, sec2, para 20) Students felt that CFS was more suited to a seminar or lecture rather than self-study (pg204, results, sec3, para14) Students recommended meeting CFS pt. to promote more positive attitudes towards them (pg204, results, sec3, para19) Students reported that they preferred interactive training taught by specialists on topics such as CFS (pg. 204, results, sec3, para21) Pts with CFS need to be involved with training of HCP's to improve their understanding (pg207, discuss, para4)	Students who had studied 1 year of psychology showed a better understanding of CFS and management with CBT (pg201, results, sec1, para12) Awareness programmes should not only focus on students but also to their senior HCP's and clinical staff (pg207, discuss, sec3, para3) Training needs to include the biopsychosocial approach, as CFS is "only" understood in this context (pg207, discuss, sec3, para5)		The theoretical model depicting the cycle of learning about CFS (pg206, discuss, fig1)

Implications						
Author	Year	Service provision	Health system components	HR costs	Training	
Ho-Yen and McNamara	1991					
Scott et al	1995					
Woodward et al	1995					
Fitzgibbon et al	1997					
Moosajee	1998	A lack of or delay in diagnosis impact on the CFS pts recovery negatively (pg67, discuss, sec1, para3)				
Moore et al	2000	The HCP's suggested that more clinics should be and allied HCP's should be included in CFS management, as 40% of CFS pts only have access to a GP, and not the appropriate support services required (pg168, discuss, sec1, para 6)			OT's seem to have a significant role in the management of CFS pts, however, they need greater knowledge of the disease and its management (pg168, discuss, sec1, para6b) Training is needed at both undergraduate and postgraduate level for CFS management (pg169, discuss, sec2, para1)	

Implications					
Author	Year	Service provision	Health system components	HR costs	Training
Prins et al	2000	provision of care needs to be in the primary level and seems to be of importance to the future course of the disease (pg13, discuss, para7)	spending more time with the pt. the first time would be beneficial for HCP/pt. relations and to decrease the need for many repeat visits (pg14, discuss, para10)		
Jason et al (2)	2001				
Jason et al 2001(1)	2001				
Taylor et al	2001				
Jason et al	2002				
Asbring et al	2003				
Raine et al	2004				
Bowen et al	2005				
Thomas and Smith	2005	Anti-depressive medication is the treatment of choice for GP's, despite more effective and varied treatments being available, that are also less of a burden financially (pg5, discuss, para6)			
Daly and Hartz	2007				
Lu et al	2007				
Scheeres et al	2007				

Implications						
Author	Year	Service provision	Health system components	HR costs	Training	
Chew-Graham et al	2008		CPD sessions directed at HCP's in the primary care setting on CFS guidelines as well as the use of pts with CFS in training (pg347, discuss, sec3, para1)		Current training does not prepare HCP's for primary care management of CFS pts (pg347, discuss, sec3, para1)	
Cho et al	2008		In third world countries, the primary care focus is geared towards infectious diseases and HCP's are less concerned about "newly emerging disorders" such as CFS (pg345, discuss, sec3, para1b)			
Friedberg et al	2008					
Swoboda	2008	HCP's who diagnose CFS 'appear to be based in rational decision making, not rush to judgement decisions in the absence of proof' (pg472, discuss, para2)				

Implications					
Author	Year	Service provision	Health system components	HR costs	Training
Chew-Graham et al	2009	Ability of staff to cope with an increased patient load considering their current difficulties at Primary level (pg7, results, sec6, para11) Supervision is required for newly taught guidelines and diseases (pg., results, sec6, para36) Nurses suggested that there is not the case load required to have pts in normal and suggested a once a week clinic for CFS pts, this would also allow nurses to gain clinical practice of CFS pts (pg10, discuss, sec4, para1c)	Primary level care has to cope with the demand of the entire health population, HCP's need to have adequate envisioning/teaching to cope with CFS (pg7, results, sec6, para11) Nurses feel that they do not have the capacity to increase their patient load as they feel that they are stretched to the limit already (pg. 7, results, sec6, para12)	Nurses felt that developing a specific role for CFS was too costly and that employers would not financially support any CFS role development (pg7, results, sec6, para16) Some nurses felt that reprioritising/referring to a less expensive HCP could be a way to support CFS pts in a financially appropriate way (pg8, results, sec6, para19)	Training and education needs to be on beliefs and stereotypes as well as diagnosis and management guidelines (pg10, discuss, sec4, para2a+b)
Brimmer et al	2010				
Chew-Graham et al	2010				

Implications					
Author	Year	Service provision	Health system components	HR costs	Training
Horton et al	2010	HCP's need to respond flexibly to accommodate the differing needs of pts to enable a trusting relationship with the pts (pg9, results, sec4, para2b) HCPs, such as OT's, often had more involvement in supporting GP's in making a diagnosis, prescribing medication and management options allowing them to be more flexible to the needs of the CFS pts (pg10, results, sec5, para2b) Making knowledge and Info of specialist services available at the primary care level, to enable and sustain management of CFS pts (pg11, discuss, para6)	Until a diagnostic test is found, CFS will remain a doubt in some HCP's and policy maker's minds (pg7, results, sec1, para1d) Time limits at primary level care are seen as hindrances to being able to diagnose and manage CFS appropriately (pg9, results, sec4, para2)		A careful history taking and listening skills associated with the presentation of symptoms needs to be taught (pg7. results, sec1, para2b)
Erueti et al	2012				
Ali et al	2014				
Knight et al	2014	Inconsistent application of guidelines was considered concerning (pg1004, discuss, sec2, para1)	MDT is needed for optimal management of CFS (pg1005, discuss, sec3, para1)		

Implications					
Author	Year	Service provision	Health system components	HR costs	Training
Stenhoff et al	2015				Students reported having had no formal training on CFS (pg203, results, sec3, para1) Students highlighted that any information would be desirable as that was how little they were taught about CFS (pg204, results, sec3, para8)

The following section is a description of the data collected and is divided into the differing sections of data collected and the most frequently occurring themes highlighted. If a theme was only mentioned once or twice within a segment, it will not be mentioned in this section.

Knowledge

Veracity of CFS/ME.

Throughout the scope of this study, 10 articles reported on qualitative data of HCPs opinions on whether or not CFS/ME is a disease. 71% of HCP's thought that CFS/ME was a disease (Ho-Yen and McNamara, 1991) while this figure fluctuated between 55.8% (Thomas and Smith, 2005) and 81% (Lu et al., 2007). In the latest study to measure these opinions, 75% of medical students surveyed thought that CFS/ME was a disease (Erueti et al., 2012). When HCPs were given a case study of a CFS/ME patient, just over half (54%) correctly identified CFS/ME as the condition described (Jason et al., 2002). This was highlighted in an alternative way in three separate papers between 2008 and 2010 (Brimmer et al., 2010), where it was commented that HCP's *"who had diagnosed CFS/ME were much more likely to know about CFS/ME"* (Brimmer et al., 2010).

Difficulty with Diagnosis.

Clinical knowledge is a theme that was present in the earlier papers and resurfaces in some of the later papers in 2009/10. In 1997, Fitzgibbon et al (Fitzgibbon et al., 1997) reported that 82% of HCP's felt that if given a CFS/ME patient then they would consider a CFS/ME diagnosis. Those who had spent more time in a clinical environment were more likely to have read an article on CFS/ME, and therefore know more about CFS/ME (Jason et al., 2002). This thought was confirmed in a later article that those HCP's that used conference proceedings and CFS/ME expertise had a "propensity to diagnose CFS/ME" (Swoboda, 2008). However, in a 2009 study, HCP's were found to not trust their clinical judgement as a consequence of a lack of guidelines for diagnosis (Chew-Graham et al., 2009).

Presentation of somatic symptoms regularly posed difficulty for HCPs (Chew-Graham et al., 2010) as they either did not have confidence in their own knowledge of the disease (Horton et al., 2010) or they did not know how the disease presented in a clinical setting (Chew-Graham et al., 2009). A few articles reported that

HCP's find it difficult to make the diagnosis of CFS without sufficient experience of the condition (Ho-Yen and McNamara, 1991, Swoboda, 2008, Horton et al., 2010).

In 8 separate papers HCP's expressed a desire for guidelines or the use of some form of classification (Prins et al., 2000, Jason et al., 2001, Thomas and Smith, 2005, Chew-Graham et al., 2008, Chew-Graham et al., 2009, Brimmer et al., 2010, Horton et al., 2010, Knight et al., 2014). The classification of CFS/ME was often referred to as a psychiatric or somatic condition by diagnosing HCPs (Jason et al., 2001) and guidelines for diagnosis of CFS/ME were not used by HCPs in three separate study groups, despite their availability. Only 25-30% of HCPs sampled in a 2010 study, thought that there was enough available information to make the diagnosis of CFS/ME (Brimmer et al., 2010). Finally, a recent article found that 56% of HCP's who had diagnosed CFS/ME had not used any criteria and only 24% had used the latest International ME Criteria (Knight et al., 2014).

The percentage of HCPs diagnosing CFS/ME has gradually increased over time. Although not all the study populations are comparable, the reported diagnostic percentages were low in the years leading up to 2000 with 26.39% reported in South Africa in 1998 (Moosajee, 1998), and in the Netherlands 45% reported in 1995 and 62% in 1997 (Prins et al., 2000). This figure fluctuated as 21.90% (Scheeres et al., 2007), again in the Netherlands, and 51% in the USA (Swoboda, 2008) until the last study to report diagnosis prevalence found that 88% of paediatricians having had diagnosed CFS/ME in Australia (Knight et al., 2014).

Part of the difficulty with diagnosing CFS/ME is a reliance on a biomedical model as students found "difficulty to describe symptoms of CFS/ME beyond tiredness and fatigue" (Stenhoff et al., 2015). This theme repeated a 2010 study which found that CFS/ME was commonly misdiagnosed as depression (Horton et al., 2010). Common diseases that were excluded before a CFS/ME diagnosis was given were thyroid diseases, anaemia and mood disorders (Bowen et al., 2005). Two papers published in 2001 noted that the name of the disease contributed towards the diagnostic framework that the HCP's used (Jason et al., 2001, Jason and Taylor, 2001).

Education sessions were shown to improve confidence in diagnosing CFS/ME. In one study 48.8% of students were uncomfortable in diagnosing CFS/ME compared to only 23.3% after education (Lu et al., 2007). Also,

those HCP's who were informed about CFS/ME were less likely to have objections towards the diagnosis of CFS/ME (Scheeres et al., 2007). A reason for this is a combination of the use of conference proceedings and seeking out CFS/ME expertise by HCPs which lead to "a propensity to diagnose CFS/ME" (Swoboda, 2008). However, confidence in making a CFS/ME diagnosis had no correlation to the knowledge of clinical features (Bowen et al., 2005). Some HCP's felt that they needed more than a short catch-up course in order to effectively diagnose CFS/ME but these sessions were "helpful" for HCP's and their identification of symptoms (Chew-Graham et al., 2009).

Patient Difficulties

HCPs do not intentionally uphold stereotypes, but often do not know the difficulties that CFS/ME patients go through from just their own clinical setting (Woodward et al., 1995). In every study that mentioned HCP's socially knowing someone with CFS/ME, without exception, reported that it favourably influenced the knowledge of CFS/ME and understanding of the patient with CFS/ME (Jason et al., 2001, Bowen et al., 2005, Chew-Graham et al., 2008, Horton et al., 2010, Stenhoff et al., 2015). Socially knowing a patient with CFS/ME gives the HCP greater insight to the daily struggle of the patient and how difficult their activities of daily living (ADL) have become as well as their leisure activities that required increased concentration and memory (Horton et al., 2010).

Articles that referred to difficulties of the disease and Quality of Life (QoL), referred to the time taken to make the diagnosis with one article reporting that 96% of HCP's in their study needed more than 3 months to make the diagnosis (Knight et al., 2014). HCP's also recognized that struggling with CFS/ME has a social impact on patient's ability to enjoy leisure activities that required concentration and memory (Horton et al., 2010). This correlated with another study that found that 82% of their sample had described CFS/ME patients as having a moderately poor or poor QoL (Jason et al., 2002). Those students with specialized postgraduate training rated CFS/ME patients as having a significantly poorer QoL than those with some medical training (Horton et al., 2010).

This knowledge gap about patient difficulties and poor perception of how the patient copes with daily activities and the overall QoL they have is not based on experience of the HCP. An earlier study reported 64% of HCP's having never worked with CFS patients (Moosajee, 1998). In a specifically selected sample in 2000

only 4 out of the 20 HCP's reported having worked with CFS patients (Moore, 2000). Another 2000 study found that HCP's were less likely to agree with a self-diagnosis of CFS/ME if they had not previously diagnosed CFS/ME (Prins et al., 2000). This is highlighted by CFS/ME patients needing, on average, 6.2 appointments to be diagnosed as having CFS/ME (Thomas and Smith, 2005).

Treatment options

Many HCP's initial response to management and treatment of CFS/ME was to question what they could actually offer the patient (Woodward et al., 1995, Raine et al., 2004). This uncertainty seemed to be linked, in an early article, to a lack of treatment guidelines available for CFS/ME (Fitzgibbon et al., 1997). However, only 25% of Occupational Therapists sampled were unsure of any management framework for CFS/ME patients (Moore, 2000). This was not the case with all HCPs as nurses reported that they did not know what treatment options were available and how to implement those options in a later study (Chew-Graham et al., 2009).

Interestingly, 70% of HCPs reported having been informed about CFS/ME and the management options available (Scheeres et al., 2007). However, less than 50% of HCP's agreed that there were several treatment options available for CFS/ME patients (Brimmer et al., 2010). When HCPs knew of available treatment options, they felt that some management options did not have sufficient evidence but did not mention what options those were (Horton et al., 2010). Positively, they did think that Cognitive Behavioral Therapy and the timing of interventions was the key to successful management of CFS/ME (Horton et al., 2010).

In 2000, only 25% of HCP's selected had treated patients with CFS/ME, despite all of the HCP's in this article reporting their role as "enabling (CFS/ME patients) to function and supporting them against the world" (Moore, 2000). Those who had not diagnosed CFS/ME were significantly less likely to provide information about CFS/ME to patients (Prins et al., 2000). Some HCP's used treatment options that centered on the patient and emphasized the patient's responsibility and gaining acceptance of their condition (Åsbring and Närvänen, 2003). This task becomes very difficult when, as a 2004 article found, HCP's have "conflicts" with their patients about their management options (Raine et al., 2004). These conflicts could be one explanation for only 89.3% of HCP's offering treatment strategies to those diagnosed with CFS/ME (Thomas and Smith, 2005).

Recognition as a disease

When writing a referral letter 45% of HCP's used terms that they felt would be accepted by the recipient of the referral in 1997, rather than using CFS/ME terms (Fitzgibbon et al., 1997). Only 51% of HCP's recognized "organic factors", more than any other factor when diagnosing CFS/ME (Swoboda, 2008). However, some HCP's still did not recognize CFS/ME as a disease because they believed it was still too new a diagnostic term in 2008 (Chew-Graham et al., 2010).

Knowledge of CFS/ME and the intricacies of the disease seem to be known by HCPs, however it is not only their knowledge that will inform their practice. In the next section the attitudes and beliefs of HCPs are analyzed.

Attitudes and Beliefs

This section deals with the functional knowledge of HCPs, how have they allowed the empirical evidence to inform their opinion of the patient in their practice. We will attempt to try to understand how knowledge has influenced the HCPs attitudes and beliefs about CFS/ME.

Empathy

Positive understanding and empathy was first reported by hospital based and specialist HCPs, who were more varied in their attitudes towards CFS/ME than primary care HCPs (Moosajee, 1998). Other HCPs referred to the CFS/ME patient's workplace as a place where they felt employers would not understand the meaning of "low grade CFS/ME" but would respond better to "post viral fatigue" (Horton et al., 2010).

HCPs who empathized with their CFS/ME patients had less problems with their patients than those who did not empathize with them (Prins et al., 2000). Student HCPs have a positive attitude towards CFS/ME veracity and how it affects the patient (Friedberg et al., 2008). Primary care orientated HCPs showed understanding towards CFS/ME patients and their difficulty living with the disease (Chew-Graham et al., 2009). This ideal of using empathy towards the CFS/ME patient was repeated by other HCPs when they emphasized that their attitude needed to remain supportive towards the CFS/ME patient (Chew-Graham et al., 2010).

Labelling and Stereotypes

Hospital based HCPs were found to believe stereotypes more than primary care and specialist HCPs, but all three tended to believe stereotypes of CFS/ME patients than not (Moosajee, 1998). HCPs also reported an attitude that was quite scathing of CFS/ME patients (Moore, 2000). HCP's reported that CFS/ME had "ceased to be seen as a discrete disorder and became a feature of the patient" (Raine et al., 2004). While other HCPs went a step further and labelled patients as "non-copers" and "those people" (Chew-Graham et al., 2009) as well as "malingerers" who made no effort to get well (Raine et al., 2004). Interestingly, a 2001 sample of student HCPs were found to be less likely than others to believe CFS/ME patients as malingerers (Jason et al., 2001). This was supported a year later in a separate sample of student HCPs, where only 3% believed a CFS/ME patient was malingering (Jason et al., 2002). When they separated the groups of students in this study, psychiatry residents were significantly less likely to believe a CFS/ME patient was a malingerer than a medical student (Stenhoff et al., 2015). HCP's felt that CFS/ME patients still suffered from stigmatism at their place of work as well, due to the term CFS/ME (Horton et al., 2010).

Experience with CFS/ME patients played an important role in the attitude the HCP had toward the patient because skepticism from some HCPs towards CFS/ME led to categorization of the disease as a "fashionable epidemics" (Woodward et al., 1995). Depending on the name given to different patients – ME or CFS – HCP's were more likely to assume medical causes in the ME labelled group (Jason et al., 2002). This continued difficulty with the label of CFS/ME has led some HCP's to delegitimize CFS/ME because the history of the disease is not considered consistent (Raine et al., 2004).

Labelling patients is used by HCPs to quantify a patient into specific categories, in order for an HCP to allocate what they deem the necessary resources to the patient in front of them. This becomes problematic because some labels that were used by HCP's were that CFS/ME patients are a "burden" (Raine et al., 2004), with the implication that it is a burden they should not have to bear. Some labels show HCPs to lack knowledge of the disease when they comment that CFS/ME patients are "just depressed" (Brimmer et al., 2010). Stigma related to the classification of CFS/ME as a disease because of the ability to "cure" CFS/ME was not present and therefore should not be considered a disease (Chew-Graham et al., 2010). The latest article reported that Student HCPs felt that CFS/ME was an invisible disease which cannot be treated and that receiving lectures on CFS/ME would be a "wasted week" of training (Stenhoff et al., 2015).

Some of the worst labels used for CFS/ME patients were upheld by HCPs regardless of the education received on the topic of CFS/ME. For example, student HCPs who attended an education session reported to still believe that CFS/ME patients were lazy and depressed, despite what they learned about CFS/ME in the session (Friedberg et al., 2008). These labels were shared by some primary care HCPs who felt that CFS/ME patients were “lazy bastards, (a) waste of space and lazy fags” (Chew-Graham et al., 2009). These HCPs perceived that their CFS/ME patients were “skivers” who looked up their symptoms on the internet (Chew-Graham et al., 2009).

Perception of CFS/ME

HCP's were found to be generally defensive of their opinions of CFS/ME (Moosajee, 1998). Student HCP's believed that the ME label indicated a more severe, chronic and debilitating disease than when the CFS label is used (Jason et al., 2002). Interestingly, some HCP's believed that CFS/ME had more credibility when they knew of a celebrity, who they respected, had the disease (Chew-Graham et al., 2008).

A biomedical perception was evident when HCPs reported that CFS/ME was difficult to conceptualize as “it's not like a broken leg” (Raine et al., 2004). However, 90% of HCP's interviewed believed the nature of the disease of CFS/ME to be psychological and physical in nature (Moore, 2000). This result was supported when HCP's who had attended an education session no longer viewed CFS/ME as a solely psychological disease (Friedberg et al., 2008).

The perception remains that CFS/ME is predominantly a female Caucasian disease as HCP's reported that they were the primary demographic treated for CFS/ME despite having a diverse catchment area and evidence to the contrary (Horton et al., 2010). From the same 2010 article, HCP's believed that men would struggle to come to terms with the diagnosis and subsequent decreased ability to perform at work (Horton et al., 2010). Student HCP's felt that CFS/ME was a western disease and that people in Africa did not get this disease and that they could not afford to get this disease because they needed to work and feed their families (Stenhoff et al., 2015).

HCPs felt that CFS/ME patients had a pessimistic view of life and that it was difficult to break that pessimism (Åsbring and Närvänen, 2003). This idea persisted, when negative beliefs and stereotypes of CFS/ME patients was reported to “colour” the knowledge of the disease (Chew-Graham et al., 2009). Another description of CFS/ME patients was that they were people who gave up or gave in to their symptoms (Chew-Graham et al., 2010). They mention that if the confirmation of CFS/ME happens in a comparatively short time frame, that confirmation is not seen as “welcome” (Horton et al., 2010). But the same HCPs felt that "Most people do come out in the end and do start to move forwards" in relation to the patients' prognosis (Horton et al., 2010). Student HCPs associated CFS with poor coping skills and laziness of the patient (Stenhoff et al., 2015).

Importance of CFS

Primary care HCPs don't believe CFS/ME is important enough to be added to the responsibilities of primary level care (Chew-Graham et al., 2009). Some HCPs believe that CFS should not be classified as a medical disease because they felt it implies that CFS/ME can be cured (Chew-Graham et al., 2010). Student HCPs reported that CFS/ME was “brushed under the rug” or “skimmed over” in their medical curriculum (Stenhoff et al., 2015). Student HCPs undervalued CFS/ME, as they were required to self-study and viewed CFS/ME as a psychosomatic/psychosocial disease, to which they placed a lower priority than other diseases (Stenhoff et al., 2015).

Patient Co-operation

A 1995 article reported that CFS/ME patients were expected to comply with the HCP's recommendations and accept their assessments (Woodward et al., 1995). This was followed by an article in 2000 reporting that HCPs believed a person's personality affected how they recovered from any disease (Moore, 2000). Also in 2000, 89% of HCPs believed that CFS/ME patients were more time consuming, 73% believed they had more problems than other patients and 31% believed that they received poor co-operation from them (Prins et al., 2000). HCPs questioned the morality of the CFS/ME patients and queried their work ethic because they only had the patient's version of events (Åsbring and Närvänen, 2003). Relief is the emotion felt by patients when they finally receive a diagnosis, as reported by HCPs (Horton et al., 2010, Chew-Graham et al., 2009, Chew-Graham et al., 2010).

Diagnosis difficulty

Some HCPs doubted whether the scientific ideal for having a causal mechanism for CFS/ME was met, which made the diagnosis of CFS/ME more difficult (Åsbring and Närvänen, 2003). This idea was so prevalent that one 2008 study reported that non-experts were 7.7 times as likely as CFS/ME experts to believe the aetiology of CFS/ME was unclear (Swoboda, 2008). Primary care HCPs are often unclear as to the scope of their role in diagnosis as a 2010 article reports that they felt that they cannot do the “extra testing” that other HCPs can (Chew-Graham et al., 2010). This belief continued later that same year, when HCPs thought that not having a conclusive diagnostic test was negatively impacting HCPs and patients (Horton et al., 2010). HCPs believed that some patients still struggled with uncertain diagnoses because of conflicting evidence and beliefs by their HCPs (Horton et al., 2010).

Despite the majority of HCPs philosophical acknowledgement that CFS/ME is a disease, many reported being skeptical of it. The reasons for this skepticism were queries around the naming of the disease (Jason and Taylor, 2001), the lack of objective measurable values (Åsbring and Närvänen, 2003), no biological cause found (Åsbring and Närvänen, 2003), the patients symptoms reported as being “out of proportion to the signs presented” (Chew-Graham et al., 2008), the contentious nature of the disease (Chew-Graham et al., 2009) and it being a new diagnostic term as well as CFS/ME not being a truthful diagnosis (Chew-Graham et al., 2010). This skepticism may link to the use of a biomedical model used by HCPs and students alike (Chew-Graham et al., 2010). A 2015 study highlighted that CFS was a disease of exclusion, that if all the tests were negative then they would diagnose CFS/ME (Stenhoff et al., 2015).

Management of the disease

CFS/ME was seen as a long term disease by 70% of the participants in one study (Moore, 2000). Student HCPs agreed that they were less likely to believe CFS/ME patients would recover in the next two years than other students (Jason et al., 2001). Because of the long term nature of CFS/ME and the time consuming nature of the management of the disease, HCPs were frustrated with it and felt that it was “essentially, not worth it” (Chew-Graham et al., 2009). This “not worth it” belief is compounded for primary care HCPs believed that they cannot make a difference for CFS/ME patients (Chew-Graham et al., 2009). Even in the most recent article, student HCPs believed that the disease was a “lifelong condition” and that outcomes varied depending on the severity of the condition (Stenhoff et al., 2015).

Attitudes towards treatment of CFS/ME patients

Several HCP's questioned what they could "actually" offer a CFS/ME patient in an early study (Woodward et al., 1995). Both CFS/ME patients and HCP's changed from their usual "sick roles" that they would play for other diseases (Raine et al., 2004). Some primary care HCP's felt that they were more empathetic than other HCP's with respect to CFS/ME patients (Chew-Graham et al., 2009). And in the later article, HCP's recognized that they needed to accept that they cannot cure CFS/ME but could rather help to alleviate the symptoms (Chew-Graham et al., 2010). HCP's reported a generally positive attitude towards the prognosis of CFS/ME patients (Moore, 2000). This was reiterated in a 2005 article where 57% of HCP's scored positively in an attitude test towards CFS/ME (Bowen et al., 2005). This followed through to a 2008 article where HCP's were asked specifically about CFS/ME and were found to have generally neutral or slightly favourable attitudes towards CFS/ME (Friedberg et al., 2008).

Practices

Attitudes and Beliefs have an effect on how HCPs behave, this next section attempts to report how it has affected HCPs when working with CFS/ME patients.

Negative Patient Interactions

The earlier papers highlighted a negative attitude with regards to patients when they try to self-diagnose themselves, with HCP viewing these patients as less likely to comply with their treatment (Scott et al., 1995). This was reiterated in another 1995 article, where HCP's would favour their own view over those of patients when there was a difference of opinions (Woodward et al., 1995). Also in this article, HCP's felt that appropriate care incorporated "pushing along" the patient to another HCP (Woodward et al., 1995). This attitude linked with the attitude of patients "needing their symptoms" (Woodward et al., 1995). HCP's still felt that patients would believe what they wanted to believe, regardless of the truth of their belief (Chew-Graham et al., 2010).

Primary care HCP's were more likely to believe myths about CFS/ME and specialist and hospital orientated HCP's were more likely to believe stereotypes of CFS/ME patients (Moosajee, 1998). When dealing with patients HCPs viewed their role to be authoritative and directive (Woodward et al., 1995). They often used "Biomedical Discourse" to maintain their position as the health expert with respect to the patient (Chew-

Graham et al., 2008). When a case study was given to HCP's in two groups, the medication group felt that the disability of the patient was significantly increased compared to the CBT group of HCP (Taylor et al., 2001). This was emphasized in a later article where HCPs would find it easier to have negative attitudes towards CFS patients than to evaluate the evidence (Chew-Graham et al., 2009). This is unsurprising because expert or specialist HCPs felt that many potential referring HCPs did not refer because they felt CFS/ME did not exist (Horton et al., 2010).

By not knowing a causal explanation for the patient's symptoms, HCP's felt that it was difficult to treat CFS/ME and answer any questions their patients might have (Åsbring and Närvänen, 2003). When the patients had preconceived ideas about the disease and its causes, HCPs reported that they felt their authority had been challenged (Raine et al., 2004). However, HCPs felt management was made more difficult when the patient did not agree with or were ambivalent towards their diagnosis of CFS/ME (Horton et al., 2010).

Diagnosis related attitudes

The experience of the CFS/ME by HCP's is felt as frustration, helplessness and failure when discrepancies between their ideal for patient management and the reality of what they can provide occur (Åsbring and Närvänen, 2003). CFS/ME experts were between 1.7 and 2.6 times more likely to diagnose another contested illness as other non-expert HCPs (Swoboda, 2008). This could result in a delayed diagnosis which HCPs considered would result in significant consequences for the patient (Horton et al., 2010).

Behaviour

HCP's preferred not to label CFS/ME patients as having CFS/ME due to the uncertainty of the existence of the disease (Moosajee, 1998). Some HCP's reported in a 2000 article that their patients used the illness as a coping strategy (Moore, 2000) but this was contradicted in 2003 when HCP's were reported to believe that CFS/ME patients do not behave as if they are sick or in pain (Åsbring and Närvänen, 2003). Beliefs clearly affect the management of a CFS/ME patient as one 2009 article reports primary care HCP's did not believe that CFS/ME existed and would not put the same effort into treating the patient as well as having less sympathy towards CFS/ME patients (Chew-Graham et al., 2009). The same group of primary care HCP's were found to have the worst beliefs about CFS/ME in one 2010 study (Chew-Graham et al., 2010). Student HCP's reported that negative and dismissive attitude were "passed down" to the students through throwaway comments and gestures by seniors (Stenhoff et al., 2015). HCPs also report that some CFS/ME patients seem

to be unreliable as they often complain of symptoms other than fatigue (Horton et al., 2010). Yet those same HCPs found that CFS/ME patients who were not in work because of the disease mostly wanted to return to work, but required support to maintain consistent (Horton et al., 2010).

In 2003, HCPs used various methods to manage CFS/ME patients but these were patient-specific with no formal guidelines followed (Åsbring and Närvänen, 2003). HCP's reported not knowing who to refer a CFS/ME patient to and overlooked less obvious treatment options which lay outside of their disease model (Raine et al., 2004). The most common form of management reflected this gap in knowledge of options, with a 2005 article finding that antidepressant therapy was the most common form of CFS/ME management by HCPs who could prescribe, with at least 84% of HCP's using at least one type of antidepressant (Thomas and Smith, 2005). A 2007 article supported this initial finding, reporting that 96.3% of HCP's used Antidepressants and 55.6% used analgesics (Daly and Hartz, 2007). However, they also found that nearly three quarters used supportive counselling as a genuine management option (Daly and Hartz, 2007).

HCPs, reportedly, would rather refer a more qualified professional to counselling than a blue collar worker who presented with the same symptoms (Scott et al., 1995). HCP's viewed themselves as "case managers" that referred on to more knowledgeable HCP's and specialists and thought that their role was just to give advice and to "push along" the patient down the line of HCPs (Woodward et al., 1995). Five main reasons for a lack of correct referral as highlighted in a 2004 article and are: lack of familiarity with mental health management, believed that CFS could be managed in a primary care setting, perceived resistance of the patients to psychological management, lack of knowledge about local resources available and doubts about the quality of evidence for alternate interventions (Raine et al., 2004).

Despite these reasons for lack of correct referral, 65.9% of HCP's referred CFS/ME patients to tertiary institutions for further management (Thomas and Smith, 2005). More than half (56.7%) were aware of consultants that specialized in CFS/ME in their area, however there was no common referral clinic with general medical out-patient clinic the most common at 16.7% (Thomas and Smith, 2005). Some HCP's were unaware of their role in the management of CFS and the value of an appropriate referral (Chew-Graham et al., 2009). This was demonstrated when the HCP's response was often "what can we do?" to the question of referral (Chew-Graham et al., 2010). However, a separate sample of HCPs in 2010 thought that they were referring more quickly and accurately than previously (Horton et al., 2010). The lack of fatigue clinics in the

UK was a barrier to referral for some HCP's in 2014, as they felt that they could not refer patients to another type of clinic (Ali et al., 2014). HCP's who commonly dealt with younger CFS/ME patients referred to teachers, physiotherapists, and psychologists in the diagnosis and management of CFS/ME (Knight et al., 2014).

DISCUSSION

The results have clearly shown the importance that knowledge, attitudes and beliefs have on the HCPs practice. There have been many links between the availability of knowledge and how it is transferred to HCPs and the inherent attitudes or beliefs that HCPs then develop from that knowledge base. These links became quite evident with the development of four main sub-themes. These sub themes are: the use of a biomedical model by HCPs, the need for guidelines, labelling of patients and empathy towards patients.

The Biomedical model used by HCPs affects their knowledge about CFS/ME as well as their attitude and beliefs about CFS/ME. More and more HCPs are acknowledging that CFS/ME is a disease, however, putting this knowledge into action still seems to be a difficult process as skepticism about the biological cause of the disease has led to beliefs that it is not a real disease or that the patients are just malingerers. HCPs viewed the disease as a psycho-somatic disorder and therefore treated it as such by the highly prevalent use of antidepressants and the underuse of CBT and counselling for CFS/ME patients. Combined with this was the labelling of CFS/ME patients as “time wasters” and “non-copers”, which creates a negative atmosphere for these CFS/ME patients and does not promote a welcoming, encouraging health seeking behaviour.

The majority of papers recommended that to combat these negative beliefs and attitudes was to educate HCPs in the biological nature of the disease. However, HCPs reported that the main effect on their beliefs and attitudes towards CFS/ME was when they socially knew an individual with CFS/ME and understood the daily effect of the disease on the individual. Some HCPs reported that education sessions did not improve their Knowledge, Attitudes and Beliefs (KAB) towards CFS/ME, but this could be because those sessions were not targeted towards their audiences. HCPs were quite clear that they desired sessions to be interactive, to include current CFS/ME patients so that they can gain experience of what the disease looks like and that HCPs desired a biopsychosocial approach towards the training.

There have been many questions as to the quality of the evidence about the disease as many believed that their peers would not accept a referral of CFS/ME and therefore changed the referral to suit what

may have been accepted by the recipient. This was highlighted by one group of HCPs when they stated that CFS/ME was still too new a diagnostic term in 2008. In a primary care setting, where most CFS/ME patients are first captured into the system, there is often not much time to spend with the patient and the CFS/ME patient will take time to explain the complexity of their symptoms. This mismatch of expectations and desires can lead to a breakdown in the HCP-Patient relationship.

The most consistent request from HCPs, in light of the lack of training that they had received and time they had with CFS/ME patients, was for guidelines to be provided. This links back to their lack of knowledge or training as guidelines were available, HCPs were just unaware of them. Dissemination of these guidelines needs to be accurate and easily available. The best way to do that, according to HCPs, was to use different sources of media, conference proceedings and interactive education sessions. The use of guidelines would certainly help with better management of CFS/ME because patients with CFS/ME, regardless of their socio-economic status or demographic would theoretically then receive the appropriate treatment according to those guidelines, regardless of the HCPs beliefs.

A common theme for HCPs when discussing their knowledge of CFS/ME and the management of the disease was their lack of experience (Chew-Graham et al., 2009). This lack of experience was enhanced by regular occurrences of the theme of knowing a CFS/ME patient socially increasing the HCP's sympathy and increased likelihood of diagnosing CFS/ME. It seems clear that CFS/ME patients need to be included in the training of HCPs about CFS/ME as this will help the HCP, to see the nuances of the disease. Combined with this, there needs to be an emphasis on the rehabilitation aspect of the disease. The absence of an instant cure does not mean there is no treatment to be offered to a patient. Rehabilitation orientated HCPs, such as Occupational Therapists and Physiotherapists, often had a better attitude towards CFS/ME than their primary care counterparts. Understandably, in a primary care setting, these patients might be considered time consuming, but appropriate referral to a rehabilitation HCP is vital for the CFS/ME patient's continued management.

"Labelling" was briefly mentioned earlier, but was prevalent in its own right in almost every section analyzed. HCPs labelled CFS/ME and the patients who suffered from the disease for many different reasons. Primary among those reasons was the HCPs' skepticism of the disease, when they are more

skeptical of the biological nature of the disease they felt that the patient was not as truthful about their symptoms as they claim to be. The result of this is a breakdown in communication between the HCP and the patient. This problem was highlighted by one of the review articles (Stenhoff et al., 2015), and is often a result of a lack of knowledge of CFS/ME. By training HCPs appropriately, a cycle of uninformed HCPs training students to be negative towards CFS/ME can be broken, which would lead to better management of the disease and a decreased burden on the primary care structures of the HCP.

Empathy towards the patients was shown by some HCPs to be key to the patient's recovery from CFS/ME. The main way this helps the HCP, is that it builds a positive therapeutic relationship with the patient and maintains communication channels with the patient which can overcome the breakdown mentioned earlier. HCPs sometimes desire to be the authoritative figure in the relationship and potentially showing empathy, and not the negative attitudes that they do show, would be a method to maintain their authority without belittling the patient.

These issues need to be addressed when HCP's are trained. The time pressure for primary care HCPs means that they don't have as much time as allied health or tertiary care HCPs to assess their patients. When there is doubt there needs to be clear guidelines for pressured HCPs to follow. These guidelines are available but due to the stigma of the labels attributed to CFS/ME patients, they are not followed. Incorporating CFS/ME patients in their training sessions seems to be the most effective way of increasing experience and clinical knowledge necessary to identify the subtleties of the CFS/ME disease. Having CFS/ME patients in a training session would also allow for HCPs to address any problems with empathy. The reason for this, is it would allow for greater understanding of a CFS/ME patient and the difficulties they face when coming to an HCP for assistance.

As one article describes (Stenhoff et al., 2015), it is often the HCP's students learn from at clinical settings where the labelling of patients is initially encouraged. Obviously, some training needs to focus on those who are no longer studying and are currently working as HCP's. The difficulty lies in getting practicing HCPs to training sessions on CFS/ME. This is often because continuous professional development (CPD) training sessions, needed for licensing as an HCP, is choice based. It seems unlikely HCPs would choose to attend a CFS/ME training session if they often label CFS/ME patients

“malingerers”. The use of the media was often cited by primary and tertiary care HCP’s as a source of information. Media campaigns might be necessary to stimulate HCP’s interest in the disease and to challenge them on what the patient actually experiences. The use of media could be through two main directions: mainstream, non-clinical media and through dissemination of journal articles.

Suggestions for Further Research

Further research should focus on studies in lower to middle income countries to enable a comparison to the KABs about CFS/ME and if patients in lower and middle income countries are treated in the same manner as higher income countries, especially in consideration of the disease burden of both groups of countries.

Many HCPs requested more training in CFS/ME. More research is needed to find better training methods than can encourage student HCPs and professional HCPs to grow in their understanding of the patients’ perspective and in the base knowledge of less prevalent and non-communicable diseases. Regarding knowledge of CFS/ME many HCPs reported that the media plays a role in their understanding and knowledge of the disease. The scope and impact that the media have on HCPs, with regards to diseases such as CFS/ME, has yet to be researched and could add a valuable resource for improving KABs in HCPs.

CONCLUSION

In conclusion, CFS/ME is still widely misunderstood as a disease. This is not helped by negative beliefs about the disease and poor attitudes towards the patients. There are clear areas for improvement with respect to HCPs knowledge of the disease and the impact it has on the patient. Training needs to include live case studies with expert patients for students and HCPs using interactive educational methods to allow for greater participation by HCPs.

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