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Protocol for a scoping review of how people with ME/CFS use the internet

Diane Louise Shortland [1], Qulsom Fazil [2], Nutmeg Hallett [3], Anna Lavis [4]

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[1]Institute of Applied Health Research, School of Medicine and Dentistry, University of Birmingham Edgbaston Campus, Spalding, UK
[2]Institute of Applied Health Research, School of Medicine and Dentistry, The University of Birmingham, Birmingham, UK
[3]School of Nursing and Midwifery, University of Birmingham, Birmingham, UK
[4]Institute of Applied Health Research, School of Medicine and Dentistry, University of Birmingham, Birmingham, UK

Correspondence to
Diane Louise Shortland;
DLS760@student.bham.ac.uk

ABSTRACT

Introduction Myalgic encephalomyelitis (ME) is a chronic neurological illness affecting many bodily systems, commonly the nervous and immune systems. Also known as chronic fatigue syndrome (CFS), key symptoms are extreme fatigue, post-exertional malaise, cognitive problems and sleep disturbance. With reported higher levels of online activity for people with ME/CFS than other patient groups (Westerby 2013 cited in Ytre-Arne) it is crucial to gain more knowledge of usage characteristics and experience of online use, and its integration into everyday life. This scoping review protocol details the proposed methods for gaining insight into this little known phenomenon.

Methods and analysis This review uses the methodological framework for conducting a scoping review by Arksey and O'Malley, with further guidance by Levac *et al*, and the Joanna Briggs Institute. It also refers to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols reporting guidelines. The following bibliographic databases will be searched: Embase, Medline, PsychINFO, Cinahl, AMED, and ASSIA, plus Web of Science, ProQuest Dissertations and Theses Global, Scopus, and Google Scholar for grey literature. Reference lists of included papers will be studied. Two reviewers will independently screen title abstracts, and then full text of studies against inclusion criteria. Remaining studies will be quality assessed using appropriate critical appraisal tools. Findings will be charted and mapped to gain in-depth knowledge of the use of the internet in people with ME/CFS.

Ethics and dissemination The findings from this review will be disseminated through peer-reviewed publication and a report for leading charities of ME/CFS. The review will collect secondary data only and therefore does not need ethical approval.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ To our knowledge this is the first scoping review to map out the online usage and experience of people with myalgic encephalomyelitis/chronic fatigue syndrome.
- ⇒ A strength of the review will be the rigorous and transparent approach based on a solid methodological framework and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist.
- ⇒ The quality of the scoping review will be enhanced by the use of a second reviewer for study selection and charting of results.
- ⇒ Eligible studies will be quality assessed in accordance with their study design.
- ⇒ The review is confined to English language which may exclude other language studies that may contain valuable data.

INTRODUCTION

Myalgic encephalomyelitis (ME)—meaning inflammation of the brain and spinal cord—is a long-term chronic neurological illness, often fluctuating in nature, that causes many symptoms affecting many bodily systems, most commonly the nervous and immune systems.[1–7] Since 1988, the illness has also been known as chronic fatigue syndrome (CFS). Many publications and researchers use both ME and CFS terms interchangeably and so we have operationalised both names as suitable for inclusion in this review. It is worth noting however, that debate exists in defining and classifying the two and there is evidence of distinct historical trajectories of ME and CFS, with distinguishing features of diagnosis and as such, including both names together could create additional issues surrounding the illness.[8] Studies have reported however, that despite this debate, certain core symptoms of the illness do appear to be consistently present across both classifications, namely extreme fatigue, post-exertional malaise, neuro-cognitive difficulties and sleep disturbance.[1]

People with ME/CFS are significantly more impaired in both physical and social functioning than other long-term illnesses.[9–11] The illness has a negative impact on people's relationships and social networks, with suicide ideation endorsed more frequently in those experiencing unsupportive interactions and social distancing.[12 13] Due to the contested nature of the condition (there is yet no available biomarker for the condition and its diagnosis is therefore subjective, raising a debate over the decades between the medical and psychological realms as to its aetiology and treatment), legitimacy of the illness is often questioned in immediate social support networks, causing additional stress.[13 14] As

Bowling states,[15] lack of social support, participation and contact is associated with increased mortality risk and delayed recovery from disease. In a survey by Action for ME,[16] 94% of participants had stopped or reduced social contact, and up to 97% of the 4038 participants said they felt socially isolated because of their condition. Patients describe feeling overwhelmed and let down when disbelieved. When seeking help was unsatisfactory, sufferers responded to this by taking more responsibility for their illness management via 'self-help' tactics.[17]

There are reported higher levels of online activity among people with ME than other patient groups (Westerby 2013 cited in Ytre-Arne[2]). Online peer-to-peer support in the form of interactive websites and social media, is now highly valued in chronic illness as a way to connect to others who share the same illness.[18 19] Transcending geographic boundaries, the internet is convenient to those with limited mobility.[20 21] Online communities provide support for people with long term illness with a growing reliance on social media in patients experiencing social isolation and who fear marginalisation because of their illness.[22 23] It also offers support to people otherwise limited by disability or stigma when accessing support offline.[24]

Uncertainty surrounding illness appears to be a driving factor for internet use[25] with internet itself being an increasingly public experience as people share personal information and interact in public spheres.[26] As Beck *et al* state,[27] 'users of the world wide web are no longer passive audiences of data consumers … but are active participants controlling the content of the information. They shape the quality of the data … (facilitating) the expression of emotions (output) and the input of emotional messages, thus developing and reinforcing important social ties between users, forming a system of relationships similar to ties of family and friendship' (p46). Receiving problem-focused and emotion-focused support from others aids coping and thus becomes a primary driver of willingness to offer such support to others.[28] Online users describe 'social overload' however, where people feel they're giving too much social support to others and experience online group exhaustion.[29]

So how does online usage interplay with the 'real world', particularly for ME patients who are often housebound due to the chronicity of their condition? In general, there is a 'sharp distinction between concepts from the virtual world online and the 'real world' offline' but 'technology enters and is gradually integrated into people's daily lives' (Lie and Sorensen 1996 cited in Beck *et al*[27]) by a process of 'domestication' where people adapt new technologies and bring them into their home, transferring elements of the physical world into the virtual environment, merging the two worlds and creating a much broader definition of reality. Understanding how people with ME use the internet to aid their illness management and enhance their experience of daily life, is crucial in gaining insight into how informational and social support is found and used online and offline. It will shed light on how people's overall support networks are created and maintained, as well as identify the benefits of such illness behaviour.

Kingod *et al*[30] studied how people with chronic conditions experience online peer-to-peer social support and its influence on everyday life, in a systematic review of 13 papers, but none of them covered the illness ME. They found four main themes: identity, social support and connectivity, experiential knowledge that both strengthened social ties and supported offline ties, and collective voice and mobilisation. Allen *et al*[31] also looked at chronic illnesses which included ME in a primary study of 30 people across varying conditions. They found that online support was sought in response to deficits in offline support; it was used to assist offline ties as well as substitute offline support.

Both Kingod *et al*[30] and Allen *et al*[31] stressed the need for further research into understanding the boundaries of online and offline social dimensions and relevance in daily life; how the role of online ties serve within personal networks. Essentially how do people decide who to turn to now they have greater choice in who contributes to their everyday illness management and coping? Having further advancement of knowledge in this area will inform healthcare practice social support initiatives and aim to improve services to those housebound with ME/CFS. It will also gain knowledge into the lack of support present in the home life of people with ME/CFS.

Initial searches revealed a lack of studies conducted in this area that focused on ME/CFS. Studies on other chronic illnesses have an element of transferability of their findings to ME/CFS and several papers were found here highlighting a topic worthy of attention. Preference for online support over offline support was highlighted in cancer and diabetes patients[32] with a lack of real world social support predicting active participation in online groups.[33] The benefits of using social media in health communication include interaction with others, the availability of shared knowledge, widened access to health information, social and emotional support, and empowerment in their healthcare process.[34 35] Investigating the perceived impact of online participation, Morehouse *et al*[36] found people gained a sense of belonging, validation and supportive friendships, decreasing feelings of depression and increasing quality of life. As much as 75% of a sample studied by Kummervold *et al*[37] found it easier to discuss personal problems online than face-to-face. Virtual communities appear to play an important role in meeting patients social needs; sense of community is positively associated with cancer patients' well-being in areas of personal relations and personal growth.[38]

Caplan[39] found that depressed people may develop preferences for online social interaction but this in turn leads to negative outcomes associated with internet use, and Allen *et al*[40] concluded that internet use may indicate an avoidance or absence of offline support. Moreover, Chung[32] found those dissatisfied with their offline relationships were more likely to develop preference for online social interaction and this can become problematic when excessive reliance increases disengagement from offline interaction. Findings are largely positive in that using the internet appears to improve everyday life, however there are studies that highlight negative impacts. Given that ME/CFS is a contested illness with legitimacy issues and increased stigma, will data collected from the ME/CFS community produce similar or different themes to other conditions?

This scoping review will aim to explore the online usage characteristics of ME/CFS patients and inter-relatedness within everyday life of their online and offline worlds. To prevent unnecessary duplication, a preliminary search for existing scoping and systematic reviews on the subject was carried out in May 2022. To our knowledge, a comprehensive synthesis of related studies on ME/CFS in this field remains absent.

METHODS/DESIGN

In order to capture the broadest scope of literature on the topic of online usage in people with ME/CFS, we decided to use a scoping review method. A scoping review is ideal for mapping out the scope or coverage of a body of literature on a given topic when the emerging evidence is still unclear and more specific questions cannot presently be posed.[5] They give a clear indication of available literature, regardless of study design, and an overview of its focus, identifying characteristics of studies to provide an overall picture of current evidence.[41] To map our field of study and examine the extent, range and nature of research activity to date, as well as identify any knowledge gaps in research, our protocol was developed using a framework set out by Arksey and O'Malley.[3] We have also incorporated later improvements to this framework by the work of Levac and colleagues,[4] and the Joanna Briggs Institute.[5]

Traditionally a scoping review concerns itself with summary of results and does not evaluate the quality of included studies. Revisions have noted the value of quality assessment for future researchers however (p6)[42] and so we intend to incorporate this into our review. Guidance from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist (PRISMA-ScR)[6] has been consulted to yield greater transparency and reproducibility. Arksey and O'Malley's framework proposes five mandatory stages (outlined below) and a sixth optional stage: consultation with stakeholders.[3] Our current review does not involve this due to the nascent stage of the project. However, the findings of this review will inform a translation of knowledge engagement exercise which will involve consultation with stakeholders.

STAGE 1: IDENTIFYING THE RESEARCH QUESTION

The research question for this proposed scoping review aims for comprehensiveness and so will be broad to cover the full breadth of evidence in the field. We aim to answer the following question: *How do people with ME/CFS use the internet?* This aim will be achieved by addressing the following objectives:

- Examine the usage characteristics of people with ME/CFS' using the internet. (What do they do online, when and for how long?)
- Examine people with ME/CFS' experiences of online usage. (Why do they go online and what do they gain from going online?)
- Examine people with ME/CFS' online usage inter-relating with their offline lives. (For example, how does using the internet fit alongside offline informational and social support?)

Arksey and O'Malley[3] saw scoping as an iterative methodological skill and as such it may be appropriate and acceptable to add questions based on emerging findings during the review process. We may notice other important data that could be useful to extract.[5] Any changes or amendments will be clearly stated and explained.

STAGE 2: IDENTIFYING RELEVANT STUDIES

Study eligibility

We will aim to find both published and grey literature studies. Loosely using a PCC (Population, Concept, Context) framework to develop our inclusion criteria, to align with our objectives and research questions, our population will be adults with a formal diagnosis of ME/CFS, from any symptom classification criteria in operation (Oxford, Fukuda, Canadian Consensus Criteria, NICE, International Consensus Criteria, SEID), as well as those without an official diagnosis but who self-identify as having ME/CFS. This is included since historically the illness has suffered endless definition, classification and standardisation issues which have resulted in many people with the condition not receiving a correct diagnosis. In an attempt to avoid missing any relevant data, this broad use of the term ME/CFS will be used. All levels of severity will also be included in data collection as it is anticipated that many studies may not specify severity, plus those that do will provide a useful means of comparison against internet usage frequency and type. Our concept of interest is internet use. We define 'internet use' as the computer network that allows users to connect with other users and content from all over the world.[43] Online information, content and social support exist through many various technological avenues nowadays. Kaplan and Haenlein[44] operationalised 'social media' usage in five main categories: collaborative projects, blogs, content communities, social networking sites and virtual worlds. Gaming is also an online social experience now as it is shared live with other users. The context is loosely any available knowledge that involves personal use of the internet and not organised institutionalised treatment agendas. Internet use therefore, for the purposes of this review, will only be relevant if it has some direct relation to ME/CFS, for instance, searching for information and guidance of the illness, the sharing of ME/CFS related knowledge, social participation online with other people

Table 1 Search strategy example for web of science

Population	‘ME’ OR ‘M.E.’ OR ‘Myalgic Encephalomyelitis’ OR ‘CFS’ OR ‘Chronic Fatigue Syndrome’ OR ‘ME/CFS’ OR ‘CFS/ME’
And	
Concept of interest	Online OR ‘online us*’ OR ‘online activit*’ OR ‘online platform’ OR ‘online discussion’ OR ‘online social media’ OR ‘online communit*’ OR ‘online social network’ OR ‘online group’ OR ‘online health communit*’ OR ‘online support’ OR ‘online peer-to-peer’ OR ‘online user experience’ OR ‘online virtual’ OR internet OR ‘internet us*’ OR ‘internet activit*’ OR ‘internet discussion’ OR ‘internet communit*’ OR ‘internet-based’ OR ‘internet forum’ OR ‘internet communication’ OR ‘internet group’ OR ‘internet support’ OR ‘internet peer-to-peer’ OR ‘internet user experience’ OR ‘internet virtual’ OR Facebook OR YouTube OR gaming OR Instagram OR TikTok OR ‘message boards’

who have ME/CFS, or the use of social media and forums linked to the illness in some way.

Search strategy

Guidance by the Joanna Briggs Institute[5] recommends a three-stage process to searching the literature of which we have included all advised stages. An initial search of limited databases has been conducted and from analysis of these results, key words and index terms have been identified. A reference librarian was consulted in preparation, and a systematic search plan was formed with search terms incorporating Medical Subject Headings as well as text words combining comprehensive terms for contemporary social media, and Boolean operators ‘AND’ and ‘OR’ (table 1 shows an example search strategy of keywords for Web of Science. This will be adapted to suit individual databases). Since scoping is an iterative process,[3] a pilot of searching will take place and terms will be refined if deemed necessary.

Second, we intend to include extensive electronic searches of the following bibliographic databases (conducted in August to November 2022): EMBASE, Medline, Cinahl, PsychINFO, AMED and ASSIA. Bramer *et al*[45] found that optimal searching to ensure a minimum risk of missing studies, should use four key databases: Embase, Medline, Web of Science and Google Scholar. This produced a 98.3% recall of studies. Because online communities in relation to health have been explored across a range of professional, theoretical, sociological, psychological and healthcare settings however, additional databases have also been covered. Third, Grey literature will be searched (during November 2022) via Scopus, Web of Science, and ProQuest Dissertations and Theses Global. Web searching via Google Scholar will also take place as well as citations and references of key papers searched by hand.

All eligible studies that meet our inclusion criteria (adults over 18 years of age, located anywhere in the world, identified as having ME/CFS, found in English language peer-reviewed primary studies, on internet use) will be saved on an Excel spreadsheet. Our exclusion criteria are children under 18 years of age, those not identified as having ME/CFS, and systematic reviews since their content is already secondary in nature, so analysis would further dilute and potentially bias findings. Consideration was given to restricting studies to a date limitation since the advancement of internet-based platforms such as social media is a relatively new and still growing area. However, it is not possible to confidently put a time limit on when such social media support truly began, so doing so would risk losing valuable studies.

STAGE 3: STUDY SELECTION

The primary researcher will run the initial searches, retrieving titles and abstracts, removing duplicates and saving all files into a suitable data management storage. Two reviewers will go through the title and abstract of each study and screen them to identify studies that meet the inclusion criteria and will document all results in a ‘screening’ form. Any uncertainty regarding if a study is eligible or not, will be included at this stage to ensure nothing is missed. If multiple papers are found that describe the same data, we will include the paper that describes the most comprehensive findings. By citation chaining, reference lists of included studies will then be examined by the lead reviewer to identify any eligible studies that meet the inclusion criteria and added to the database findings. Forward searching of papers, via Scopus, that have been cited, will also be checked. To further minimise location bias, authors and researchers of studies will be contacted.

Two independent reviewers will then read the full text of all provisionally included studies, to assess further against the inclusion and exclusion criteria. The devised extraction form (online supplemental file 1) will be piloted to ensure it contains all relevant information needed. Studies will be included or excluded against the pre-determined eligibility criteria. Any missing data will attempt to be found by contacting the study authors for additional information. Any discrepancies will be resolved through consultation with the wider research team. All reviewers will agree on the final list of included studies. A PRISMA-ScR flow diagram following the process of the scoping review will be used to demonstrate the selection process (online supplemental file 2).

Critical appraisal

Contrary to the methodological framework originally set out by Arksey and O'Malley,[3] we intend to appraise the remaining eligible studies for quality assessment. This will take place after the data extraction of full text studies. Pham *et al*[46] reported only 22.38% of studies included an element of quality assessment. McColl *et al*[47] argue that the emphasis of a scoping review is on comprehensive coverage and not standard of evidence. More recent refinements to guidelines however, support the use of some form of critical appraisal.[4 5] Brien *et al*[48] believe a lack of quality assessment makes results more challenging to interpret and Grant and Booth[49] believe it limits uptake of findings into policy and practice. Daudt[42] considers quality assessment a necessary component of any scoping review and encourages the use of validated tools since use of reporting checklists increases transparency of methods and allows the reader to use the research appropriately. Pham *et al*[46] also recognises that some form of quality assessment would enable the identification of gaps in the evidence base rather than just where research is lacking.

A quality assessment form will be used to extract relevant data for appraisal. Since it is expected that the majority of studies will be qualitative in nature, we have chosen the Critical Appraisal Skills Programme (see online supplemental file 3).[50] If we identify any mixed methods studies then we will use the Mixed Methods Appraisal Tool (see online supplemental file 4).[51] If any quantitative data is found we will use a checklist suited to the study design from the selection available at JBI, most likely the Checklist for Analytical Cross Sectional Studies (see online supplemental file 5).[52] Any discrepancies between reviewers on quality assessment will be discussed with the wider research team. No exclusion of eligible studies will take place as a result of appraisal since such studies can still contain rich and useful qualitative narrative. Poor quality studies will be highlighted and reflected on within the data summaries. The outcome of each study assessment, along with all study files will be included in an Excel spreadsheet alongside other data extraction details.

STAGE 4: CHARTING THE DATA

Two independent reviewers will perform a full-text review of provisionally included studies. Piloting of a small sample will take place, in accordance with advice from Levac *et al*[4] to ensure agreement is reached on extraction consistency. Charted data extracted and documented in a designed extraction form will include, but not be limited to, the following:

- Article title, authors, year of publication.
- Study research aims.
- Study design and setting.
- Number of participants.
- Characteristics of the population.
- Study inclusion criteria.
- Online usage information.
- Data collection and analysis methods.
- Study findings/outcome.

As previously mentioned the review will take an iterative approach and so the content of extraction can be updated with discussion of the research team. This allows for the variables and themes to be included to best be able to answer the review question and meet its objectives.

STAGE 5: SUMMARISING AND REPORTING THE RESULTS

Levac and colleagues[4] encourage a rigorous approach to analysis that includes descriptive numerical summary as well as thematic analysis. Using the information extracted, data charting will involve visual summaries as well as narrative that describes the aims of included studies, their areas of focus, online user characteristics and findings to determine how the studies to date inform the current knowledge base. Any quantitative or mixed method studies will be 'qualitized' by extracting data from quantitative or mixed method studies and transforming it into textual descriptions to integrate with qualitative data and form a single summary comprising themes of narrative across the review studies.[5] Developed in an inductive manner without a set of a priori themes, these scoping study summary methods, in accordance with Braun and Clarke,[53] will enable us to ascertain broad themes of what is known about how people with ME/CFS use the internet, their experience of doing so, and how this fits within their daily lives as per our research objectives. Two reviewers will perform all analysis independently before reaching consensus of themes and any discrepancies will be resolved with the wider research team.

ETHICS AND DISSEMINATION

All data generated will be stored on pass-protected computers. The authors will disseminate the findings through submission for publication in a peer-reviewed academic journal and a report will be written for leading charities of ME/CFS. The review itself will only deal with secondary data and therefore ethical approval is not required. Our findings will be used to inform the design of a future study aiming to gain greater knowledge of online social support in people with ME/CFS. Patient and Public Involvement will take place in the dissemination stages of this review and will guide all future research plans.

Patient and public involvement

Since this is a protocol only, it does not have any involvement with patients. Any data regarding patient participation is secondary through already published papers.

DISCUSSION

A global comprehensive systematic scoping summary of primary data on internet use in people with ME/CFS, in terms of both usage and characteristics, and in relation to offline daily life, will be conducted to fill a gap in knowledge surrounding this under-researched area. In relation to online worlds, we frequently find ourselves asking research questions that contain complex medical, sociological and social concepts. This type of research resists easy quantification and by aiming to critically reflect on the material found via this scoping review, we aim to capture the complexity inherent in such questions involving people's experiences.[30] In writing up the research findings we will be guided by enhancing transparency in reporting the synthesis of qualitative research.[54] Dissemination will be relevant to academic knowledge sharing, charities for ME/CFS that offer support and online services, as well as healthcare professionals and patients.

Twitter Anna Lavis @Annalavis

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ORCID iDs

Diane Louise Shortland http://orcid.org/0000-0003-4046-710X
Nutmeg Hallett http://orcid.org/0000-0003-3115-8831

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