**THE UNIVERSITY OF HULL**

# An exploration into the use of Facebook groups for health conditions

**Being a thesis submitted in partial fulfilment of the requirements for the**

**Degree of Doctor of Clinical Psychology**

**in the University of Hull**

**by**

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**Acknowledgements**

I would like to dedicate this thesis to my parents, without whom I'd not be in the fortunate position I am now. They have provided me with the opportunities, support and perseverance to continue on the lengthy road of training to qualify in an area of work I am passionate about.

I would like to thank all of the individuals who contributed to this study by sharing their thoughts, stories and experiences and I hope my words have done yours the justice they deserve.

Thank you to my supervisor, Lesley, whose positivity has helped me overcome the hurdles of the research process and brought me back on track when needed.

Finally, thank you to my friends, in particular Amy, Sam and Sarah who have provided endless support and understanding during difficult times.

## Overview

This portfolio thesis comprises of three parts.

The first part is a systematic literature review, in which empirical literature relating to the use of Facebook groups in health conditions is explored. It aims to provide an understanding of how individuals with health conditions use Facebook groups. The review concludes with recommendations for future research.

Part two is an empirical report of a study that used a qualitative approach of content analysis to explore the use of Facebook groups by those with a diagnosis of Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis (M.E.). Participants completed an online survey and data was extracted from a single Facebook group. Results were considered in relation to the Shifting Perspectives Model of Chronic Illness (Paterson, 2001). Methodological limitations, potential clinical implications and areas of future research are also identified

Part three comprises the appendices and reflective statement. These include a statement reflecting on the research process and supplementary information pertaining to the literature review and empirical study.

Overall Word Count: 23027

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# PART ONE

## Systematic Literature Review

**A Systematic Literature Review of Facebook groups for health conditions**

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This paper is written in the format ready for submission to the British Journal of Clinical Psychology. Please see Appendix A for the Author Guidelines.

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## Abstract

Objectives: This review aims to integrate the research literature to identify what we know about the use and existence of Facebook Groups for individuals with physical and mental health conditions. Implications will be considered.

Method: The following terms were used to search on PsycInfo, Academic Search Premier, CINAHL Complete, Medline and PsycArticles; "Facebook AND (social OR support OR group) AND (health OR chronic* OR long* OR illness OR condition OR disease OR disorder OR wellbeing OR well-being OR problem)"

Results: Ten studies met the inclusion criteria and were considered in relation to aims, sample characteristics, type of group, membership, purpose of group, activity within the group, suggested implications and considerations, and limitations of the study.

Conclusions: The review suggests that the use of Facebook for both physical and health conditions exists, both for support and other purposes such as raising awareness and fundraising, however current research has not considered the implications of this use. The review also highlights the difficulties associated with researching Facebook.


**Practitioner Points:**

- The evidence suggests that individuals with health conditions are sourcing support from Facebook, however the clinical implications of this has had little consideration. Facebook may be a tool which clinicians may be able to use to their benefit following further research
- A limitation of this study may be the reviewer's background. A clinical psychology perspective has been the underlying assumption for this review, yet a number of the included studies have been undertaken from a non-psychological position.

## Introduction

It is suggested that given the economic pressures on service provision and an already observed increase of the use of 'e-health' and online support groups (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004), individuals looking for support through digital avenues is likely to increase.

Facebook, a social media site reported to have 890 million daily active users on average (Facebook, 2015), has provided an accessible portal for new knowledge and support for patients, carers and professionals (Farmer, Bruckner Holt, Cook & Hearing, 2009).

In 2012, a review of Facebook research in social sciences was completed and it was found that research on Facebook could be organised in to 5 different categories; descriptive analysis of users, motivations for using Facebook, identity presentation, the role of Facebook in social interactions, and privacy and information disclosure (Wilson, Gosling & Graham, 2012). Despite this review considering 412 articles which met their inclusion criteria, none of these papers considered the impact of the use of Facebook on subjective well-being and this was therefore considered in 2013. It has been suggested that use of Facebook can result in a decline in subjective well-being in young adults (Kross et al., 2013), and Facebook's own controversial research in 2014 which showed emotional contagion through social networks (Kramer, Guillory & Hancock, 2014) suggests that Facebook may have negative impacts on those using it.

Given that there is also research to suggest that peer to peer support for health conditions can have both positive (Ziebland et al., 2004) and negative outcomes (Beenan et al., 2004; Caplan, 2003), and the existing knowledge of the potential for others' activity on Facebook to influence your own emotional state (Kramer, Guillory & Hancock, 2014), the use of Facebook groups for peer support for those with health conditions is of interest.

It may be of interest to have a greater understanding of the use and existence of Facebook groups for health conditions in regards to whether they exist, who uses them, how they are used, what function they serve, and whether they serve any benefit to the individuals that access them.

**Questions addressed by this review**

This review aims to integrate the research literature to identify what we know about the use and existence of Facebook Groups for individuals with physical and mental health conditions. Implications will be considered.

## Method

### Data sources and search strategy

A preliminary search was conducted in order to identify relevant databases and test the search terms and the strategy.

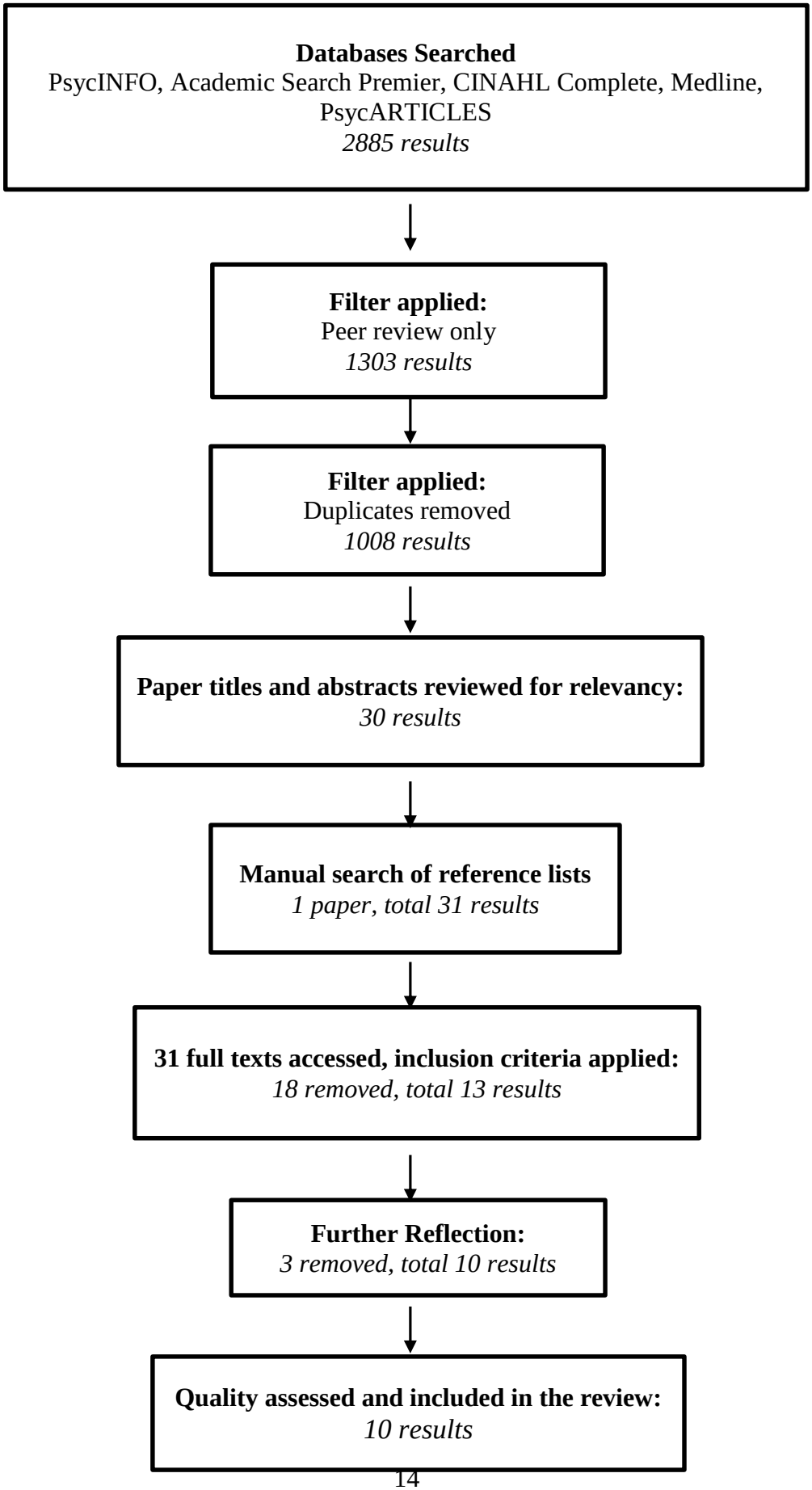
The following databases were selected to be searched for relevant journal articles; PsycInfo, Academic Search Premier, CINAHL Complete, Medline and PsycArticles. These were selected in order to cover a wide range of literature.

The strategy for the review searched for the terms "Facebook AND (social OR support OR group) AND (health OR chronic* OR long* OR illness OR condition OR disease OR disorder OR wellbeing OR well-being OR problem)". These terms were selected on the basis of preliminary searches and existing knowledge of the literature area. It was considered that these terms would define the area of interest whilst ensuring the greatest number of relevant studies were reviewed. The search took place between October 2014 and January 2015.

The initial search strategy identified 2885 papers. Once these had been filtered to include only peer reviewed papers and duplicates had been removed, 1008 results remained for consideration.

Articles were selected through consideration of the title and the application of selection criteria being applied to the abstract (see Table 1). Thirty papers were identified for a more thorough review and the full text was obtained. A manual search of bibliographies for articles was completed, with a single article identified. Application of inclusion criteria and reflection resulted in 10 papers for inclusion in the review (See Figure 1).

**Figure 1. Study Selection Process**



## Study selection criteria

To be included in the review, papers had to meet the following inclusion criteria. Articles had to focus specifically on groups on Facebook which considered any physical or mental health conditions, as opposed to pages or personal profiles due to the functionality differences. The research also had to consider only Facebook groups that were run, to the best of the author's knowledge, by peers rather than a professional organisation. It was important for the paper to focus purely on Facebook, or for results specifically for Facebook to be available for extraction from the paper. Both quantitative and qualitative papers were considered as the selection criteria, however they had to be published in peer reviewed journals in English and be locatable in English databases as the researcher was English speaking.

| **Studies were only included if they;** | **Studies were excluded if they were not;** |
|---|---|
| Considered only Facebook Groups which considered any physical or mental health conditions, not pages or personal profiles or other social networking sites | Written in English |
| Facebook Groups that were run, to the best of the author's knowledge, by peers rather than a professional organisation. | In peer review journals |

**Table 1. Study Selection Criteria**

Excluded studies: Initially, 13 papers were identified as suitable for the review, however on further reflection three were excluded (De la Torre-Diez, Diaz-Pernas & Anton Rodriguez, 2012; McGregor et al., 2014; Sajadi & Goldman, 2011). These studies were excluded due to the inclusion of analysis of other online support networks such as Twitter, which didn't allow the reviewer to identify specific knowledge about Facebook.

## Quality Assessment

The 10 studies identified for inclusion in the review were quality assessed using a checklist developed by the reviewer, although quality scores were not considered as an exclusion criteria. The checklist was developed using questions from existing quality assessment checklists Downs and Black (1998), the National institute for Health and Clinical Excellence (2009) and Long, Godfrey, Randall, Brettle and Grant (2002). Two raters quality assessed the articles using the developed quality assessment checklist. Where a discrepancy was found the scores were discussed and an agreed score was given.

The overall quality scores for each study can be seen in Table 2, however the full scores for each study can be seen in Appendix E. All papers were included in the review regardless of their quality score, however the process of scoring the papers highlighted the more general difficulties of completing research which involves Facebook, and the difficulties in reviewing the literature around it.

The quality of studies varied from 26 to 39 out of 44 with the main weaknesses being highlighted in relation to ethics (19/40) and the inclusion and exclusion criteria for the sample (9/20).

Internet based research, such as on Facebook, has prompted ethical concerns due to the lack of clarity about whether information shared is considered within the public domain. The steps taken to ensure ethical methods vary greatly amongst studies with some studies creating a profile to register in the groups and accepting friend requests whilst not posting or responding to any posts (Teufel et al., 2013) and others highlighting the need to consider privacy and only observe groups which did not require registration (Gajaria, Yeung, Goodale & Charach, 2011).

Another highlighted weakness was the lack of the researcher's position being highlighted through data collection and the assumptions and biases underlying analysis. In relation to the latter it can be suggested that this may have been due to the type of analysis that was completed on the data from Facebook groups.

Content analysis was the most prevalent analysis method and this was often used with the selection of pre-determined categories from previous research, potentially limiting the ability and requirement to identify the assumptions and biases of the researchers.

The extraction of data from the studies highlighted mathematical errors in the Farmer, Bruckner Holt, Cook & Hearing (2009) paper and whilst the overall findings are unlikely to have changed on the basis of this error, it potentially questions the quality of the numerical data.

**Data Extraction**

All relevant studies identified in this review used a qualitative methodology, however despite this the results did not allow for an elaborated understanding of the Facebook groups they considered.

On further analysis and reflection on the papers, eight categories for extraction were selected as detailed under the Results subheading.

**Data Synthesis**

Through the data extraction process it became apparent that the research in this area was diverse and therefore the synthesis of the data needed careful consideration. Review of the methods led to the decision to use a narrative approach to synthesising the data, allowing for discussion around the findings.

## Results

Ten studies met the inclusion criteria (see Table 2).

### Description of Studies

The ten studies considered in this review were of a qualitative nature and utilised content analysis or descriptive analysis in order to consider the aims of their study. Generally, the studies either considered the group itself, or its contents in relation to the posts.

The studies selected had a variety of aims and findings and assimilation was therefore difficult based on this alone. Similarly, it was not possible to make direct comparisons due to the nature of this review. The reviewer therefore considered each study and its findings and identified eight categories under which data could be extracted and considered in order to inform this review;

1. Aim of the study
2. Characteristics of the sample
3. Type of Facebook Group(s) identified
4. Membership of the Facebook Group(s)
5. Identified purpose of the Facebook Group(s)
6. Activity within the Facebook Group(s)
7. Suggested implications and considerations
8. Limitations of the study

## Table 2: Details of Included Studies

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| **Ahmed, Sullivan, Schneiders & McCrory (2010)**<br><br>**Quality Score 36/44** | To investigate the role and purpose of the postings on Facebook groups relating to concussion | Concussion<br>17 Publicly available Groups Included (after search results of 472 groups, 455 excluded due to focusing on severe TBI, post-concussion syndrome or not being relevant)<br><br>226 posts identified, 81 posts excluded due to being repeated posts by same individuals.<br>145 posts included in study | *Not considered in this study* | No. of members in groups: Ranged from 10 to 262<br>Demographics<br>Male: 57%, Female: 39%, Unknown: 4%<br><16: 10%, 16-25: 31%, >25: 12, Unknown: 47% (reflects traditional demographic of concussive brain injury)<br>USA: 63%, Canada: 24%, Other 4%, Unknown: 9% | 65% of posts were used to relate a personal experience of their own or a friend/family member or colleague.<br>8% sought information<br>2% offered explicit advice<br>14% Group Stimulation<br>11% Irrelevant Comment | Percentage of member's posting: 2.8% to 72.7%<br><br>Average 45 posts each year<br><br>14 of 17 groups included had less than 40% of members electing to post | Suggestion that Facebook provides a supportive function.<br>Reflects changing communication of 21st century.<br>Groups to be moderated by professionals in relation to sharing of health information as possibility of incorrect advice being shared, however could compromise anonymity of not directly communicating with healthcare providers. | Inability to establish authenticity of posts. Difficulty coding due to lack of information |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| **Bender, Jimenez-Marroquin & Jadad (2010)**<br><br>**Quality Score 33/44** | To identify the characteristics of Facebook groups in relation to their purpose, use and creators, for breast cancer | Breast Cancer. 620 groups included | Of the 620 publicly available Breast Cancer groups identified on Facebook;<br>Fundraising (44.7%)<br>Awareness (38.1%)<br>Product or service promotion related to fundraising or awareness (9%)<br>Patient/carer support (7%)<br><br>9% identified as having an additional purpose;<br>34% were also related to fundraising and support<br>27% to raise awareness<br>4% to support an external website | 1,090,397 members in 620 groups<br><br>47% of support groups established by students. These groups were associated with greater user contributions<br><br>The awareness groups contained by far the most members (87.8%), followed by the promote-a-site groups (5.9%), fundraising groups (4.7%), and support groups (1.5%).<br><br>The groups ranged in size from 1 to 772,815 members. Most groups (98.7%) contained 5000 or fewer members. On average, the promotion groups had the greatest number of members, followed by the awareness, support and fundraising groups. | *Not considered by this study* | 86.8% of groups had 25 posts or less.<br><br>The support groups had the greatest median number of wall posts, followed by the awareness groups, promote-a-site groups, and fundraising groups | Results may indicate that Facebook groups are being used by people affected by breast cancer. May play an important role in facilitating public engagement in health promotion and fundraising activities.<br>Further research required to examine the impact of participating in a health related group on Facebook. | Difficulty in identifying demographic information.<br>Self-reported data in relation to age and location.<br>Limited search functionality on Facebook. |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| **Farmer, Bruckner Holt, Cook & Hearing (2009)**<br><br>**Quality Score 26/44** | To ascertain whether Facebook has user groups connected with medical conditions.<br>To classify the user groups identified.<br>Identify number of individual users in them. | ICD-10 non-communicable diseases number of groups per condition;<br>*Malignant neoplasms 55*<br>*Diabetes 141*<br>*Endocrine 18*<br>*Neuropsychiatric 65*<br>*Cardiovascular Disease 137*<br>*Respiratory Disease 144*<br>*Digestive Disease 122*<br>*Genitourinary Disease 1*<br>*Skin Disease 27*<br>*Musculoskeletal Disorders 28*<br>*Congenital Abnormalities 15*<br><br>757* groups in total<br>(* Potential mathematical | Patient Groups 47.4% (peer support)<br>Support Groups 28.1% (relatives, sufferers or health professionals)<br>Fund Raising Charity Groups 18.6%<br>Other Groups 5.9% | 290, 962 users across 757* groups | *Not considered by this study* | *Not considered by this study* | Potential dangers in relation to scientific content, patient/carer anxiety, confidentiality and research ethics | Limited search functionality on Facebook.<br>People may be in multiple groups. |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| | | error within paper, actual total 753) | | | | | | |
| **Gajaria, Yeung, Goodale & Charach (2011)**<br><br>**Quality Score 38/44** | Examine what youth think about having ADHD in a naturalistic setting. | Attention Deficit Hyperactivity Disorder<br><br>25 groups identified<br>479 individual posts | *Not considered by this study* | *Not considered by this study* | Construction of group identity (dominant theme)<br>Creating an online support group<br>Defining the outgroup<br>Jokes about ADHD | *Not considered by this study* | Groups may be used as a way to mitigate stigma | Difficulty identifying demographic information |
| **Greene, Choudhry, Kilabuk & Shrank (2010)**<br><br>**Quality Score 30/44** | To qualitatively evaluate the content of communication in Facebook communities dedicated to diabetes | Diabetes<br>15 largest Facebook Groups<br>15 most recent wall posts from 15 largest groups<br>15 most recent discussion topics from 10 largest groups<br><br>690 comments | *Not considered by this study* | Average of 9289 people in each group. (Range 1,107 to 61,957) | 690 posts analysed<br>Advertisements 26.7%<br>Providing Information 65.7%<br>Requesting Information 13.3%<br>Support 28.8%<br>Irrelevant 3%<br><br>Themes identified:<br>Information sharing | 690 posts by 480 unique users<br><br>Posts extracted varied from 1 day ago to 587 days ago. | Suggest that users gain interpersonal support, specialised knowledge from peers and can actualise positive but realistic self-images. Little evidence of dangerous, misleading or self-medication behaviour being supported within Facebook groups | Not longitudinal. Might not apply to other conditions |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| | | | | | Patient-centred management<br>Community Building<br>Marketing and data collection functions | | | |
| **Niwa & Mandrusiak (2012)**<br><br>**Quality Score 39/44** | Analyse posts within Facebook groups to see how they are utilised. To explore the nature of interactions and frequency of themes. | Self-harm<br>4 most active self harm groups<br>998 posts | *Not considered in this study* | *Not considered in this study* | Informal offers of support (22.2%)<br>Trolling and flaming (21.6%)<br>Community (18.3%)<br>Venting (18%)<br>Miscellaneous (15.1%)<br>Addiction (10.8%)<br>Triggers (6.1%)<br>Offline help seeking (5.6%)<br>Suicidal Ideation (5%)<br>Online help seeking (4.1%)<br>Informative (3%)<br>Concealment (2.9%)<br>Identity (0.9%) | 998 posts over 3 months in 4 groups<br><br>77% of posts appeared to be by female, 23% from males | Observed individuals provoking a vulnerable population. Further research required to identify whether this environment is conducive to recovery.<br>Consideration in therapeutic treatment to discuss client involvement in online groups | Interpretation limited as observational in nature and therefore individuals not involved.<br>Demographics difficult to ascertain |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| **Teufel, Hoffner, Junne, Sauer, Zipfel, & Giel (2013)**<br><br>**Quality Score 34/44** | To analyse content and culture of Anorexia Nervosa groups on Facebook | Anorexia Nervosa<br>118 groups included out of 3524 results | Education 29/118<br>Anti Pro-Ana 34/118<br>Self Help 24/118<br>Professional Help 4/118<br>Pro-Ana 27/118 | English: 70.3%<br>German: 11%<br>Spanish: 8.5%<br>Italian: 6.8%<br>French: 3.4% | Motivation was evident in all groups. Social support most evident in pro-ana groups, although present in all. Professional help groups were limited. | Pro-ana groups were most active with 33% of posts within 24 hours being in a pro-ana group. Around half of the education and anti pro-ana groups had low activity levels with the last post being made around 3 months ago | Consideration regarding social networking being integrated into therapeutic strategies in the future. Awareness of clients potential to be accessing social networks. | Given Facebooks constant development, results may be difficult to reproduce. Limited access may have resulted in underestimation of groups, in particular for pro-ana. |
| **Thoren, Metze, Buhrer & Garten (2013)**<br><br>**Quality Score 36/44** | To qualitatively evaluate content of communication in Facebook communities dedicated to preterm infants | Preterm Infants<br>25 largest groups included in study.<br><br>500 posts analysed, evenly distributed between groups | Non profit fundraising 12/25 48%<br>Support 7/25 28%<br>General Awareness 6/25 24% | 91.5% posters were female<br>2/3 posters were mothers of pre-term infants<br><br>25 largest groups had between 321 and 14,986 members | Analysis of posts, primary and secondary purpose<br>Information sharing;31% and 14%<br>Interpersonal emotional support: 16% and 53%<br>General Awareness 16% and 16% | *Not considered in this study* | Further research is warranted to understand the implications and risks of dynamic online communication in relation to those using Facebook groups related to pre-term infants | Not longitudinal in nature. |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| | | | | | Fundraising 24% and 8%<br>Marketing 10% and 9%<br>Irrelevant to prematurity 3% and 0% | | | |
| **Walker (2014)**<br><br>**Quality Score 33/44** | To identify whether Thoracic Outlet Syndrome Facebook groups are used more for affective or cognitive content and what types.<br>To consider any relation to gender. | Thoracic Outlet Syndrome<br>1 group<br>292 pieces of data | *Not considered in this study* | *Not considered in this study* | 216 cognitive themes<br>125 (58%) information sharing<br>43 (20%) information seeking<br>29 (13%) advice sharing<br>15 (7%) promotion<br>2 (1%) advice seeking and self-diagnosis<br>156 affective themes<br>68 (44%) support/encouragement<br>44 (28%) complaints and concerns<br>44 (28%) gratefulness | 292 pieces of data, 218 by females, 74 by males<br>93 posts<br>199 comments in response to posts<br>Men found to be more likely to respond to a post where as women were more likely to initiate. No differences between men and women's cognitive and affective uses | Further research warranted to understand what people look for and gain within these groups. | Demographic data difficult to obtain, in particular coding of gender by profile picture may not be reliable. |

| Authors & Quality Score | Aim | Characteristics of Sample | Type of Group | Membership | Purpose of Group | Activity Levels | Implications | Limitations |
|---|---|---|---|---|---|---|---|---|
| **Zhang, He & Sang (2012)**<br><br>**Quality Score 32/44** | To explore characteristics of health communities on Facebook and understand their potential for promoting health information exchange. | Diabetes<br>1 Group, 31,860 members<br>1352 pieces of data (posts and comments) | *Not considered in this study* | 31, 860 members.<br>Patients and care givers<br>International members, overcome by online translation services | Themes<br>Information, emotion and community are main themes with personal experiences being shared as being the most prominent use.<br>Eliciting Information 12.1%<br>Providing Information 62.6%<br>Expressing emotion 13.7%<br>Seeking emotional support 0.7%<br>Providing emotional support 17.2%<br>Community building 5.4% | 154 initiated posts within a one week period.<br>88.3% of the 154 posts received a response.<br>1710 likes on 240 out of 1352 posts/comments<br><br>1352 pieces of data contributed by 479 unique participants.<br><br>77.7% of messages contributed Monday to Thursday, peak on Wednesday. 6.4% on Friday, 15.9% at the weekend | Group cultivate social support, including informational, emotional and appraisal support, imposing social influences and provided a sense of companionship.<br>Further research to explore how interactions influence behaviours and health outcome. | Observational study with no deeper understanding gained from participants |

1. Aim of the study

Studies varied as to their proposed aims but there were two main focuses; exploring the existence and characteristics of Facebook groups for the health condition, or exploring the purpose of the groups through focusing on the posts within them.

Two studies focused on ascertaining the existence and characteristics of Facebook groups for health conditions (Bender, Jimenez-Marroquin & Jadad, 2011; Farmer et al., 2009), whilst five studies focused more on the purpose of the groups (Ahmed, Sullivan, Schneiders & McCrory, 2010; Greene, Choudhry, Kilabuk & Shrank, 2010; Niwa & Mandrusiak, 2012; Walker, 2014; Zhang, He & Sang, 2012).

Teufel et al. (2013) and Thoren, Metze, Buhrer & Garten (2013) considered both focuses, whilst one study inadvertently provided relevant data for this review in relation to the purpose of the groups via an aim to examine what young people think about having ADHD utilising the naturalistic setting of an ADHD Facebook group (Gajaria et al., 2011).

2. Characteristics of the sample

All of the studies used pre-existing communications and groups as the sample and did not include direct contact with participants.

The studies considered both physical health conditions (Ahmed et al., 2010; Bender, Jimenez-Marroquin & Jadad, 2011; Farmer et al., 2009; Greene et al., 2010; Thoren, et al., 2013; Walker, 2014; Zhang, He & Sang, 2012) and mental health conditions (Gajaria et al., 2011; Niwa & Mandrusiak, 2012; Teufel et al., 2013). Details of the conditions considered in the papers are listed in Table 2.

Dependent on the aim of the study, as detailed above, the study sample was either detailed as the number of groups, number of posts or both.

All studies which considered groups (Bender, Jimenez-Marroquin & Jadad, 2011; Farmer et al., 2009; Teufel et al., 2013; Thoren et al., 2013) applied inclusion and exclusion criteria in order to ensure only relevant groups were considered and analysed a mean number of 379 groups (range from 25 to 753).

The studies which focused on the purpose of the groups by analysing the posts, including Gajaria et al. (2010), highlighted their sample as the number of posts or comments as unique pieces of data and analysed a mean number of 659 posts (range from 145 to 1352). (Ahmed et al., 2010; Greene et al., 2010; Niwa & Mandrusiak, 2012; Walker, 2014; Zhang, He & Sang, 2012).

The largest and most active groups were most commonly considered for data collection (Gajaria et al., 2011; Greene et al., 2010; Niwa & Mandrusiak, 2012; Thoren et al., 2013; Zhang, He & Sang, 2012) with some studies specifically considering only the groups which were public and therefore considered the posts to be available in the public domain (Ahmed et al., 2010; Bender, Jimenez-Marroquin & Jadad, 2011; Gajaria et al., 2011; Niwa & Mandrusiak, 2012).

3. Type of Facebook Group(s) identified

Four out of the ten studies considered the type of groups which exist for the health conditions.

The results suggested that support groups (Farmer et al., 2009) and fundraising/raising awareness groups (Bender, Jimenez-Marroquin & Jadad, 2010; Thoren et al., 2013), were most prevalent in their respective studies for the particular health condition they were considering. Teufel et al., 2013 found that anti pro-ana groups were most prevalent however it is unclear whether these were groups which raised awareness or were supportive to those with anorexia nervosa.

Furthermore, Bender, Jimenez-Marroquin and Jadad (2010) highlighted 9% of groups as having an additional purpose such as fundraising or raising awareness.

4. Membership of the Facebook Group(s)

Seven of the studies selected for review considered data in relation to the membership of the Facebook Group(s), although the collection of this data was not necessarily considered as part of their aim.

Six studies considered the number of members either for the specific group of analysis or across all groups considered within the study. A review of this data highlights a variety in relation to the number of members within groups. For example, Bender, Jimenez-Marroquin and Jadad (2010) considered 620 Facebook groups for breast cancer, identifying a range in size from 1 member to 772,815 members.

Studies considering diabetes reported identifying a Facebook group with 31,860 members (Zhang, He & Sang, 2012) and groups with an average of 9289 members across 15 groups (range 1,107 to 61,957) (Greene et al. 2010).

Bender, Jimenez-Marroquin & Jadad (2010) considered Facebook groups created for breast cancer. The most prevalent group type of fundraising did not have the most members however, with the awareness groups having greatest membership.

Whilst from the limited research it is not possible to draw any themes or conclusions, the membership numbers of groups may depend on the condition and its chronicity or severity.

Four out of ten studies considered gender differences within the groups.

Ahmed et al. (2010) identified a higher male prevalence in the groups for concussion, however, Niwa and Mandrusiak (2012) and Thoren et al. (2013) who considered self-

harm and pre-term infants groups found a higher prevalence of female members in the groups.

Walker (2014), who considered Thoracic Outlet Syndrome found that 74.7% of the posts analysed being written by females and 25.3% written by males and suggested that men were more likely to respond to posts, than initiate them.

5. Identified purpose of the Facebook Group(s)

Eight out of the ten papers selected for review considered the purpose of the group, in that they analysed the posts within the group to identify how individuals were utilising the virtual community.

A strong theme across the groups was that of sharing personal experiences, with a focus to provide information to others (Ahmed et al., 2010; Gajaria et al., 2011; Greene et al., 2010; Thoren et al., 2013; Walker, 2014; Zhang, He & Sang, 2012), with the theme of providing support being the second most evident purpose of the groups (Greene et al., 2010; Thoren et al., 2013; Walker, 2014; Zhang, He & Sang, 2012).

Gajaria et al. (2011) identified the construction of a group identity within the Facebook group with a high use of humour to discuss the symptoms of ADHD.

Whilst the papers identified other less prevalent uses, the identification of the purpose of the group for the studies considering mental health conditions did not follow the same themes (Niwa & Mandrusiak, 2012; Teufel et al. 2013). Teufel et al. (2013) did not identify the purposes of the group in great detail, but highlighted the presence of motivational support, and highlighting that social support, whilst present in all groups, was most evident in the pro-ana groups. Niwa and Mandrusiak (2012) also identified support as a theme in the purpose of the groups, however their focus identified other

factors such as ‘trolling’ (defined as intentionally provoking and attacking posts within Niwa and Mandrusiak, 2012), suicidal ideation and addiction.

6. Activity levels within the group

Seven out of ten articles detailed the activity levels within the groups they had analysed, however the method of identifying, analysing and reporting this data varied significantly between studies.

Teufel et al. (2013) noted that out of the groups for anorexia nervosa, the pro-ana groups were most active, with 33% of the posts in a 24 hour period being gathered from pro-ana sites however due to a lack of data it has not been possible to interpret this further.

It was possible to group the results from the other six studies however into 4 categories; response rate, number of posts across a set period of time, frequency of posting, and percentage of members posting.

Response rate:

Zhang, He, Sang (2012) commented on the response level for the posts within a diabetes group over a one week period, with 88.3% of 1352 posts receiving a response.

Number of posts across a set period of time:

Four of the studies considered how many posts within the Facebook group were identified within a set period of time, however different timescales were used in each study. In order to best understand this data it is possible to work out the approximate number of posts per day.

Walker (2014) observed a Thoracic Outlet Syndrome group and identified 292 posts between 9th October 2011 and 1st May 2012, a total of 198 days, and suggesting 1.47 posts per day.

Gajaria et al. (2011) found that within all 23 groups, 479 posts were made over a year, suggesting an average of 1.32 posts per day, although the distribution across the 23 groups is unknown.

Niwa and Mandrusiak (2012) noted that 998 posts were made across 4 self-harm groups over a 3 month period, suggesting approximately 11 posts per day.

Ahmed et al. (2010) noted that in one group, there were between 41 and 48 posts each year. As an average of 44.5 posts per year, it can be suggested that there were approximately 0.12 posts per day.

These results suggest that the self harm groups (Niwa & Mandrusiak, 2012) were the most active in relation to the number of posts.

Frequency of posting:

Whilst considering Facebook groups for diabetes Greene et al. (2010), extracted the most recent 15 posts. The time line for these posts varied between a single day and 587 days.

For breast cancer, it has been noted that 85.8% of the groups analysed had 25 post or less (Bender, Jimenez-Marroquin & Jadad, 2010).

Percentage of members posting:

Ahmed et al. (2010) considered 17 groups in their study and identified that the percentage of members posting within the groups varied from 2.8% to 72.7%.

7. Suggested implications or considerations

All of the studies selected for review highlighted potential implications and considerations on the basis of their results.

One theme which was apparent from reviewing this literature was around the lack of current knowledge and understanding around the impact and implications taking part in a Facebook group may have for an individual. Seven studies (Bender, Jimenez-Marroquin & Jadad, 2011; Farmer et al., 2009; Niwa & Mandrusiak, 2012; Teufel et al., 2013; Thoren et al., 2013; Walker, 2014; Zhang, He & Sang, 2012) discussed the current lack of knowledge and understanding around whether the environment of a Facebook groups was helpful and conducive for individuals, or whether there were potential risks associated with their use, and suggested a need for future research to focus on this area.

Given the findings that Facebook groups are utilised to share information two studies highlighted the potential risks associated with incorrect information being shared, eg scientific or medical information, resulting in harm (Ahmed et al., 2010; Farmer et al., 2009), although neither of these studies considered this as an aim of their study and were unable to advise whether this was occurring. Greene et al.,(2010) did consider this however and found little evidence of dangerous, misleading or self-medicating behaviour being supported within Facebook groups.

Positive findings of the Facebook group(s), such as cultivating support and mitigating stigma (Gajaria et al., 2011, Zhang, He & Sang, 2012), led two studies to detail the need for a consideration around social networking to be integrated into therapy, and also for clinician's to be aware that individuals may already be accessing this support and how it might influence their work (Niwa & Mandrusiak, 2012; Teufel et al., 2013). Both of these studies focused on mental health conditions.

## 8. Limitations

Given the difficulties in assimilating the information, and the weaknesses highlighted in the quality assessment process it felt important to consider the limitations that the studies had highlighted in order to provide some guidance for future research on Facebook.

The following difficulties were highlighted;

I. Given that Facebook is constantly developing, results may be difficult to reproduce (Teufel et al., 2013)

II. Privacy settings result in limited access to groups and demographic information (Bender, Jimenez-Marroquin & Jadad, 2011; Gajaria et al., 2011; Niwa & Mandrusiak, 2012; Teufel et al., 2013; Walker, 2014)

III. The study was not longitudinal in nature (Greene et al., 2010; Thoren et al.,, 2013)

IV. There was limited interpretation due to being observational in nature with no participant involvement (Ahmed et al., 2010; Niwa & Mandrusiak, 2012; Zhang, He & Sang, 2012)

V. Demographic information on Facebook is self-reported and due to joining restrictions and privacy settings, this may not be accurate (Ahmed et al., 2010; Bender, Jimenez-Marroquin & Jadad, 2011; Walker, 2014)

VI. The search facility function within Facebook is limited (Bender, Jimenez-Marroquin & Jadad, 2011; Farmer et al., 2009)

## Discussion

The aim of the review was to integrate the existing literature around the use of Facebook Groups for health conditions. This review has highlighted that up to now, research has used pre-existing communications and information on groups which has been readily available, leading to the approach of content analysis. Content analysis is regarded as a suitable approach to analyse pre-existing communications, typically resulting in an understanding of "who says what, to whom, why, how and with what effect?' (pp. 333, Babbie, 2010). Given the limited research in this area, an approach which provides this basic yet essential information is highly important, yet this has resulted in a lack of depth and richness to the literature, and therefore has provided little understanding in relation to the implications the use of these groups may have for both the individuals using them, and for clinical professionals in their work. As highlighted by three of the studies (Ahmed et al., 2010; Niwa & Mandrusiak, 2012; Zhang, He & Sang, 2012), their methodological designs resulted in no participant involvement, a limitation of all of the studies included in this review and future research may benefit from this inclusion.

The results of the studies which focused on mental health conditions differed from the trends found in the studies for physical health conditions (Niwa & Mandrusiak, 2012; Teufel et al. 2013; Thoren et al., 2013). The researchers for two of these studies were from a psychological background and it is unclear whether their results are due to the difference in coding and analysis, potentially influenced by the researcher's background, or whether this illustrates a difference between how those with mental health and physical health conditions utilise the groups.

Due to the qualitative approaches and wide variety of aims within the studies it is difficult to synthesise and discuss them in any great detail, however a number of observations can be made.

The ethics of researching Facebook and other online sources is a developing area. The majority of the studies analysed samples which would be considered to be available in the public domain, an approach which may be considered to be most ethical, this does however raise the question around the groups which are not as easily accessible to researchers.

The studies have shown a wide existence of Facebook groups for health conditions, resulting in relatively large samples however this may highlight the difficulty in analysis. Qualitative approaches were used in all the studies, however due to the expanse of data, the aims and findings of the studies have provided limited understanding of the area.

In relation to membership of the groups, the findings of the studies may suggest that membership of Facebook groups may be influenced by the severity and chronicity of the condition, and similarly by the gender ratio of the condition, however due to differing evidence in relation to gender ratio, and insufficient data provided within the studies, it is not possible to draw any conclusions.

The results of the studies that considered the number of individuals within the groups suggest that the prevalence of a type of group for a condition does not automatically imply greater membership, for example, whilst fundraising groups are most prevalent for breast cancer, they did not have the greatest membership (Bender, Jimenez-Marroquin & Jadad, 2010). These findings may suggest that those who are influenced by health conditions may create groups which are then not actively used or promoted.

Given the existing research that shows how emotions shared on Facebook can result in a similar response in that individual (Kramer, Guilleroy & Hancock, 2014), it may be of interest whether this is still the case when the purpose is for peer support, an area given little consideration in the existing literature. Given the findings of this review that suggests that Facebook groups are widely used to share experiences and gain and provide support to others, this may be an area of interest for future research.

The assimilation of information in relation to activity within groups is difficult in that the method of identifying, analysing and reporting activity has differed between studies, however it has potentially highlighted the differences in activity between groups with some groups being highly active (eg. 998 posts across 4 self-harm groups over a 3 month period (Niwa & Mandrusiak, 2012) and others having little activity (eg. Between 41 and 48 posts a year in a group for concussion (Ahmed et al., 2010). It also highlights the potential need to define what constitutes activity within Facebook, an area which may benefit from a systematic literature review.

In addition to those highlighted within the papers reviewed, there are a number of limitations in relation to researching Facebook. Facebook is a social networking site that has continued to expand since its creation in 2004. When Facebook was initially created however, membership was limited to those in education. In 2006 Facebook was opened to everyone over the age of 13 years old, with a valid email address, however the number of users was significantly less than the current figures. Bender, Jimenez-Marroquin and Jadad (2011) considered the creators of the support groups and found from the information available that 56% were college students, 37% were high school students and

7% were recent college graduates. Given the earlier requirement of being associated with an educational setting, the validity of these results may be brought into question as whilst individual's may have previously attended an educational establishment and therefore included this within their profile, it does not mean they are still in attendance meaning the information may be historic. Furthermore, the privacy settings which can be utilised on Facebook which prevents individuals from seeing your demographic information means collection of this information is difficult and as the awareness of the risks of privacy has increased, so has the use of privacy settings (Bender, Jimenez-Marroquin & Jadad, 2011), meaning demographic information is likely to become more difficult to observe and extract indirectly.

Another limitation for any research which considers the use of Facebook is the searches within Facebook. Searches on Facebook may not always provide the same results as results may be influenced by the user account and the friends they have, previous searches within Facebook and even the activity on the computer (Farmer et al., 2009; Bender, Jimenez-Marroquin & Jadad, 2011). Furthermore, as a social media platform, Facebook has continued to develop, meaning the specific analysis of certain functions of Facebook may no longer be relevant (Teufel et al., 2013). An example of this may have been highlighted in this review. In 2012 Zhang, He & Sang analysed the posts of a diabetes group with over 30,000 members on the basis of it being the top search result, yet an earlier study (Greene et al., 2010) highlighted a group with 61,957 members. Whilst the group with more members may have been deleted, and may have not been at the top of the search list for an explainable reason, this may be an example of the difficulties that can be faced with researching Facebook groups as the search function is currently an unknown entity.

Given the high number of limitations in relation to research using Facebook it brings into question the validity of the studies conducted so far which have focused on identifying the groups and their users rather than the experience of those using them.

Further research in this area may benefit from participant inclusion through interviews and use of outcome measures, rather than data extraction from existing Facebook groups, in order to gain a broader understanding of their use and any perceived or actual benefits to those using them. Whilst current research provides an evidence base to suggest that Facebook groups exist, and for what purpose they are used, it has provided little understanding of the experience of this and whether the use of Facebook influences behaviour or outcomes in relation to health conditions.

In summary, this review has highlighted the difficulties of synthesising research on Facebook and the difficulties others may have in conducting future research on the use of Facebook for health conditions. So far, the research suggests that the use of Facebook groups for both physical and mental health conditions does exist, for both support and other purposes such as raising awareness and fundraising, but that further exploration into the implications the use of Facebook groups may have on individuals with health conditions is required.

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# PART TWO

## Empirical Research

**An exploration of the use of Facebook groups by individuals with**

**Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**

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**Abstract**

Objectives: CFS/ME online forums have been found to be 10 times more active than other online health forums and this research aims to understand how those who use the Facebook groups experience them and what function they may serve in relation to the Shifting Perspectives Model of Chronic Illness (Paterson, 2001).

Method: A thematic content analysis was completed on data collected from an online survey and posts extracted from a Facebook groups in the public domain.

Results: Participants highlighted positives and negatives of the group but considered it to have helped them focus on wellness. The most prevalent type of posts were individuals sharing experiences or asking for advice.

Conclusions: The results of this study suggest that Facebook groups for CFS/ME have some potential risks associated with them, however these may not be of any greater concern than those posed to a member of any Facebook group. Rather, the Facebook groups seem to provide individuals with a perspective of wellness in the foreground by providing a shared experience and understanding which, potentially due to the current unexplained cause of the condition, is considered to be lacking in the 'real world'.

**Practitioner Points:**

- Individuals with CFS/ME found the accessibility, and emotional and practical support provided by Facebook groups, helpful. This may be a consideration when working with this population.

Keywords: 'chronic fatigue syndrome', 'cfs', 'myalgic encephalomyelitis', 'ME', 'Facebook', 'shifting perspectives model', 'online peer support'

## Introduction

Chronic Fatigue Syndrome (CFS) is a poorly understood illness with diverse symptoms. It is characterised by a newly recognised fatigue (unexplained by other conditions) which is persistent and has resulted in a reduction in activity (NICE, 2007). In addition to these fatigue symptoms, individuals often experience further symptoms, for example un-refreshing sleep, headaches and cognitive dysfunction (NICE 2007).

CFS is also known as Myalgic Encephalomyelitis (ME). There is controversy as to the grouping of CFS and ME as one diagnosis however the World Health Organisation have classified both CFS and ME as neurological conditions and this has been accepted by the Department of Health (NHS, 2013). For this reason the research will consider CFS and ME as one and the same.

Many theoretical models suggest that living with a chronic illness is a phased process with a linear and staged trajectory, with the terms 'acceptance' or 'denial' of the illness being traditionally used by healthcare professionals. The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) suggests that the experience of a chronic illness is ever-changing, allowing people to make sense of their experience and considers the ideas of both illness in the foreground (IitF), and wellness in the foreground (WitF), to depict "the dual kingdoms of the well and the sick" (Donnelly, 1993, p. 6). The concept of IitF focuses on the chronic illness being viewed as destructive to the self and others. Paterson (2001) suggests that this perspective has a protective or maintenance function to the

individual. The concept of WitF identifies individuals appraising the chronic illness as an opportunity for change, which sees the individual merging their self-identity with the identity of the illness. It is suggested that individuals gain the wellness perspective through education about their illness, being in supportive environments, identifying their own limits and body responses and sharing their knowledge and experiences with others.

The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) suggests that individuals can shift between both wellness and illness in the foreground. In relation to shifting from WitF to IitF it has been identified that a perception of threat to control plays a major factor. Threats to control may include a perceived lack of skill to manage the illness, stigma, and interactions which accentuate feelings of hopelessness or dependency. In contrast, a shift to wellness in the foreground requires individuals to identify that a shift to illness in the foreground has occurred and then requires an approach of reframing the situation and developing and implementing changes or interventions.

It has been found that interaction with a person with the same illness is often a major influence in individuals shifting to a wellness in the foreground perspective (Raleigh, 1992; Remien, Carball-Dieguez & Wagner, 1995). Paterson (2001) also highlighted however that self-help groups can cause a shift from the wellness in the foreground, to illness in the foreground perspective as it requires individuals to focus on the sickness role in order to participate and obtain membership status.

Considering the difficulties associated with CFS/ME such as stigma (Dickson, Knussen & Flowers, 2007), lack of support networks (Kelly, Soderlund, Albert & McGarrahan, 1999), and delegitimisation (Ware, 1992), the shifting perspectives model highlights how those individuals with CFS/ME may struggle to shift from illness in the foreground to wellness in the foreground. The complexity and the difficulties those with CFS/ME may face, may suggest however, that individuals with CFS/ME would benefit greatly from the appropriate support.

It has been identified that CFS/ME online forums have more than ten times the relative activity of any other disorder or condition related forum, such as those for diabetes, cancer and anxiety (Knudsen et al, 2012). The authors suggest a number of possible explanations for this including the ease of access to those with limited mobility and it being a space to air frustrations for those experiencing stigmatisation and feelings of dissatisfaction with treatment offered. Davison, Pennebaker and Dickerson (2000) identified that support seeking was higher for stigmatised conditions such as AIDS and alcoholism which suggests that stigma impacts on the need for support.

Research has identified individuals with CFS/ME as being 'action prone' (Van Houdenhove, Onghena, Neerinck & Hellin, 1995) and it was suggested that high levels of activity on the forums is an alternative expression of this tendency, however whether this affects the symptoms of CFS/ME is unknown but has been raised as a concern (Knudsen et al., 2012) in relation to the health anxiety model (Salkovskis & Warwick, 1986). Whilst Knudsen et al. (2012) do not expand on their thoughts behind this concern it may be that it is considered that the individuals being more action

prone, may be resulting in a form of checking behaviour and reassurance seeking, a factor within the health anxiety model (Salkovskis & Warwick, 1986).

It is suggested that given the economic pressures on service provision and an already observed increase of the use of 'e-health' and online support groups (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004), support for CFS/ME through digital avenues is likely to increase. Despite the current ubiquity of online support groups however, there is very little theoretical basis for their design (Helgerson and Gottlieb, 2000).

It has been identified that Facebook, a highly active social networking platform with 890 million daily active users on average (Facebook, 2015), has provided an accessible portal for new knowledge and support for patients, carers and professionals (Farmer, Bruckner Holt, Cook & Hearing, 2009) but that the quality and content of the information shared in these arenas is poorly understood (Greene, Choudhry, Kilabuk & Shrank, 2010). Furthermore Knudsen et al. (2012), following their findings that individuals with CFS/ME are more active on online forums than those with other conditions, identified a need for the type and quality of information that is provided within the forums to be considered. It has been suggested that use of Facebook can result in a decline in subjective well-being in young adults (Kross et al., 2013), and Facebook's own controversial research in 2014 which showed emotional contagion through social networks (Kramer, Guillory and Hancock, 2014) suggests that Facebook may have negative impacts on those using it.

Given that both positive and negative outcomes have been identified for online networks, it is important that the Facebook groups that exist for those with CFS/ME are investigated to consider how individuals experience them, why they may use them, and what function they serve in relation to the Shifting Perspectives Model of Chronic Illness (Paterson, 2001).

The research aims to consider;

1. For what purpose are the CFS/ME Facebook groups used?
2. How do those who use the CFS/ME Facebook groups experience them?
3. What are individuals' experiences of CFS/ME Facebook groups in relation the Shifting Perspectives Model of Chronic Illness (Paterson, 2001)?
4. What difficulties do those who use the Facebook groups and have CFS/ME experience? Does this provide insight into why they may use the groups?

# Method

## Design

As the purpose of this research was to explore the experience of those individuals with CFS/ME who use Facebook groups, a qualitative approach was considered to be most appropriate. The research consisted of two elements, an online qualitative survey and a qualitative analysis of Facebook posts within an open group for CFS/ME. The purpose of the online survey was to explore the experience of those using Facebook groups and to identify what function they may serve, if any, in relation to the Shifting Perspectives Model of Chronic Illness (Paterson, 2001). The online survey also ensured participant inclusion. The second element of this research, the analysis of the existing Facebook groups, had a purpose of identifying how individuals used the Facebook groups and what difficulties the individuals with CFS/ME experience, with an aim to provide an insight into why they may use the Facebook groups.

It was hoped that the two elements of this study would aid the researcher in interpreting the data, being guided by both elements in the consideration of the shifting perspectives model of chronic illness within Facebook groups.

## Ethics

The ethical responsibilities within this research were considered in detail. Research using information from the internet, including social media sites is a relatively new area and therefore clear guidelines and etiquette have not yet been established. Steps taken to ensure an ethical approach to this research are detailed under each research element and ethical approval was

provided by the research ethics committee of the Faculty of Health and Social Care, University of Hull.

**Element 1: The Survey**

The design was an online qualitative survey with participants sourced via Facebook. This is discussed in further detail within the Procedure subsection.

In order to be suitable for the survey participants were required to be at least 18 years of age and have a self-reported clinical primary diagnosis of CFS/ME (eg they considered their main health difficulty to be CFS/ME). Participants with other diagnoses were not excluded, however any other diagnoses needed to be considered by the participant as secondary to their CFS/ME. Exclusion criteria for the study was the inability to understand English.

**Measures:** The online survey collected demographic information and asked open ended questions (see Appendix H) in order to collect data in relation to how individuals experience the group. Questions were composed to ascertain the function of the groups in relation to the Shifting Perspectives Model of Chronic Illness (Paterson, 2001). In order to reflect the model, the questions were chosen by extracting statements from Paterson's paper (2001) which were written to illustrate the model.

**Procedure:** A search on Facebook for "M.E.", "myalgic encephalomyelitis", "ME", "CFS ME", "CFS" and "chronic fatigue syndrome" in January 2014 identified 148 groups. Within Facebook,

groups have the option to be open or closed groups, with content in open groups being visible without joining the group and only being visible in closed groups if accepted for membership. Participants were advertised for through open Facebook groups deemed to be most appropriate and in which permission had been sought from the group administrators. Whilst 148 groups relating to CFS/ME were identified, membership of some of these groups was limited. For the purpose of this study, the 3 groups with the largest membership and which were English speaking (although country of origin of groups could not be determined), in which permission was received from administrators within the group, were used for advertising of the online survey.

The online survey, which was created and run using British Online Surveys (www.survey.bris.ac.uk), was posted to the Facebook group and included a link and a brief overview detailing that the research was looking to explore the experience of individuals using Facebook Groups. Participants were provided with the study information sheet (see Appendix F) and the informed consent form (see Appendix G) prior to beginning the survey.

The survey was advertised for a 2 month period with intermittent 'boosts' from the researcher. Due to the nature of Facebook groups however, the post advertising the survey was quickly replaced with newer posts, a limitation to be considered.

**Ethical and safety considerations:** Written information about the study was provided to ensure informed consent and all data was anonymised

**Data Analysis Procedures:** Data analysis of the open responses was conducted using content analysis (Krippendorff, 2004) with descriptive statistics being applied for quantitative data such as demographic information. Content analysis was chosen as it is regarded as a suitable approach to analyse pre-existing communications (Babbie, 2010). The results of the survey were read and possible concepts or themes were annotated alongside the transcript, considering phrases rather than individual words. Following this, the annotations were considered to develop the concept categories in which the data could be coded for frequency. Each response was therefore coded in to the appropriate categories, with some responses being coded more than once due to the content.

## Element Two: Facebook Posts

**Design:** The design was of a qualitative nature and involved the extraction of posts from a specific Facebook group until sufficient data, of 300 posts or more, had been collected.

**Participants:** Whilst there was no participant recruitment, participants were considered to be those who submitted their posts to the open group.

**Measures:** No measures were used for this element of the research.

**Procedure:** In order to identify the themes that arose within the groups, one open group, and therefore in the public domain, was accessed and posts

between 1st and 23rd November 2014 were extracted, providing 360 posts for analysis. Only posts which originated within the time period chosen for data collection were analysed.

**Ethical and safety considerations:** Research of existing online groups has been considered in the BPS guidelines for Internet mediated Research (2013). It advises that in order for research of an existing online group to be ethical the online space needs to be perceived as 'public'. Whilst open Facebook groups are considered to be in the public domain, the Facebook group selected for this element of the research specified itself as an open group and clearly advised members that their posts could be seen both by others on Facebook and within an internet search and it was therefore reasonable to suggest that individuals posting in the group were aware that it was in an open forum which could be accessed by others.

Maximal anonymisation of the posts was implemented to limit the ability of quotes from the research being searched for on the internet and traced back to the original source and individual.

**Data Analysis Procedures:** Data analysis was conducted using categorical and thematic content analysis (Krippendorff, 2004). The posts were from a single group and therefore not representative of the activity across the groups in which the online survey was advertised, nor the other groups that exist within Facebook for CFS/ME. The posts were extracted from Facebook as a transcript and analysis began with reading each initial post whilst making comments on the transcript in an aim to identify concepts,

considering phrases rather than individual words. Following this, the concepts identified were considered in order to develop categories in which each post could be coded. Following this, a more thematic analysis around all the data extracted was completed, with the researcher adding additional, more interpretive comments to the transcript of posts. The aim of this was to provide a greater understanding of the difficulties individuals with CFS/ME may be experiencing, which may provide insight in to why they use Facebook groups.

## Results

### Element One: Online Survey

80 individuals diagnosed with CFS/ME completed the survey with 90% of the participants being female. Whilst there were 80 individuals who completed the survey, the questions were not all mandatory and therefore not all questions received 80 responses. The majority of participants were from the UK (64.1%) and had joined a Facebook group for individuals with CFS/ME after receiving their diagnosis (90%), with 72% of participants being members of more than one CFS/ME Facebook group. 64 of the 80 participants advised that they had additional physical and mental health conditions.

The collection of data in relation to employment and marital status, whilst can not show a causal link, shows an increase in unemployment since diagnosis, however due to analysing the data as a group set, rather than as individual surveys, little can be inferred in regard to marital status.

The majority of participants had found a Facebook group for CFS/ME through active searching, whether that be within Facebook or the internet (57.5%), although others found their Facebook groups through word of mouth or promotion elsewhere (See Table 2).

In relation to activity within the group, 83.5% of participants accessed the groups to read posts 2 to 5 times per week or more frequently. Results suggest 41% of participants accessed the groups to comment on posts 2 to 5

times a week or more frequently.  This suggests that people view the groups more than they post.

**Table 1:** Additional demographic data

| | **Unemployed (n)** | **Self-employed (n)** | **Full time (n)** | **Part time (n)** | **Student (n)** | **Prefer not to say (n)** | |
|---|---|---|---|---|---|---|---|
| ***Current Employment status*** | 49 | 3 | 6 | 9 | 0 | 0 | |
| ***Employment status at diagnosis*** | 11 | 3 | 44 | 7 | 7 | 1 | |
| | | | | | | | |
| | | | | | | | |
| | **Single (n)** | **Co-habiting (n)** | **Married (n)** | **Civil Partner (n)** | **Divorced (n)** | **Separated (n)** | **Prefer not to say (n)** |
| ***Current Marital Status*** | 19 | 13 | 27 | 1 | 13 | 2 | 3 |
| ***Marital Status at diagnosis*** | 24 | 14 | 28 | 0 | 9 | 3 | 1 |

**Table 2:** Participant Activity within Facebook Groups:

| ***How did you find out about Facebook groups for CFS/ME?*** | | **N** |
|---|---|---|
| *Search* | Search within Facebook | 24 |
| | Search on the internet | 7 |
| | Search (unspecified) | 15 |
| *'Word of mouth'* | Friend, someone else with CFS/ME | 15 |
| | Local community group | 6 |
| | Other websites | 2 |
| *Promotion* | ME websites | 4 |
| | Advertisement on Facebook | 8 |
| | Other Facebook groups | 2 |
| *Other* | Unable to recall | 4 |

**Table 3:** Participant activity within Facebook groups.

| Frequency of Access | Percentage of those accessing to read the posts on Facebook Groups (n. 79) % | Percentage of those accessing to comment on posts on Facebook Groups (n.78) % |
|---|---|---|
| *More than once a day* | 37.97 | 15.38 |
| *Daily* | 27.84 | 10.26 |
| *2 to 5 times a week* | 17.72 | 15.38 |
| *Weekly* | 5.06 | 19.23 |
| *Fortnightly* | 1.26 | 12.82 |
| *Monthly* | 2.53 | 7.69 |
| *When relevant* | 7.59 | 19.23 |

### *Helpful and Not So Helpful*

Given the existing literature (Knudsen et al., 2012; Van Houdenhoveet al., 1995), it felt important to ascertain how those who used the Facebook groups viewed them, rather than imposing the researcher's interpretation. Participants were asked what they found most helpful and not so helpful about Facebook groups.

Helpful (see Table 4)

Analysis of the data identified 3 main themes; accessibility, emotional support, and practical support, with 5 participants also stating that they had not found groups helpful.

*Accessibility*, with subthemes of; ease of access to reduce social isolation and the option to observe and not take an active role.

*Emotional support*, with subthemes of; shared understanding, sense of community, support, humour, a safe place to 'vent' and a place to discuss 'politics' of the condition.

*Practical support*, with subthemes of; identifying symptoms as part of CFS/ME, advice, gain knowledge, coping strategies and discuss treatments.

Not so Helpful (see Table 5)

Analysis of the data using content analysis identified 4 main themes; accessibility, content of posts, group dynamics and impact on 'real life', with 9 participants also stating they had found nothing which had been unhelpful.

*Accessibility* with subthemes of; unable to avoid distressing posts, structure of Facebook and lack of privacy in some groups.

*Content of posts,* with subthemes of; conflicting information, inaccurate information, religious posts, discussion around treatments and negativity around treatments.

*Group Dynamics*, with subthemes of; conflicts/arguments between group members, feelings of competition between members in relation to symptoms and severity and whining and negativity.

*Impact on 'real life',* with subthemes of; tiring to use, frustration/over involved, can affect your own mood or symptoms.

**Table 4:** What is helpful about Facebook groups for CFS/ME?

| Superordinate Themes | Subordinate Themes | Example Quotes | *N* |
|---|---|---|---|
| *Accessibility* | *Ease of access to reduce social isolation* | *It gives me access to the world outside* | *10* |
| | *Can observe, do not need to take active role* | *I don't have to post, but I can read others' posts* | *3* |
| *Emotional Support* | *Shared Understanding* | *To share my own story and hear others' to try and understand it more* | *13* |
| | *Sense of community, not feeling alone* | *I'm not the only one going through it* | *37* |
| | *Support* | *It means I have support on bad days* | *11* |
| | *Humour* | *Humorous silly things, like people's brain fog* | *3* |
| | *A safe place to 'vent'* | *To moan when others in your life don't understand* | *3* |
| | *Place to discuss 'politics'* | *Can discuss frustrations with psychological bias of NHS treatment* | *4* |
| *Practical Support* | *Identifying symptoms as part of CFS/ME* | *Learnt which symptoms are experienced by others* | *9* |
| | *Advice* | *Advice on how to explain the illness to others* | *6* |
| | *Gain knowledge* | *People post research articles* | *7* |
| | *Coping strategies* | *Reading how others cope is helpful for me to cope with my own symptoms* | *4* |
| | *Discuss treatments* | *Anything that other people have tried and have helped* | *10* |
| *Other* | *Not found it helpful* | *Misery likes company* | *5* |

**Table 5:** What is not so helpful about Facebook groups for CFS/ME?

| Superordinate Themes | Subordinate Themes | Example Quotes | N |
|---|---|---|---|
| *Accessibility* | Unable to avoid distressing posts | *Posts which are talking about giving up on life, if you look in the group you can't help but see them* | 6 |
| | Structure of Facebook | *Sometimes you know somebody posted about something you're now interested in but not easy to find* | 3 |
| | Lack of privacy in some groups | *As it's not private I don't post very often* | 2 |
| *Content of posts* | Conflicting information | *When you ask a question and you get people saying different things, can get more confused* | 4 |
| | Inaccurate information | *Sometimes people share information that's incorrect and newbies might not realise* | 6 |
| | Religious posts, non-science based posts | *I don't need someone to tell me that if I found Jesus, I'd be happier and healthier* | 6 |
| | Discussion around treatments | *Posts with psycho nonsense, psychiatric lies and alternative therapies* | 13 |
| | Negativity around treatments. | *The "ME is incurable and no treatments work" group of people annoy me.* | 9 |
| *Group Dynamics* | Conflicts/arguments between group members | *Hate the falling out that happens on some pages* | 21 |
| | Feelings of competition | *Seriously ill ME sufferers can be dismissive towards the less affected* | 6 |
| | 'Whining' and negativity | *A lot of whining and narrow minded people* | 15 |
| *Impact on 'real life'* | Tiring to use | *Can use a lot of energy that could be used for other things* | 3 |
| | Frustration - unable to offer more support, 'over-involved' | *Sometimes I want to do more for others, to support those struggling, but can't* | 3 |

| | | | |
|---|---|---|---|
| | Can affect your own mood or symptoms | *It can make you feel miserable, become a hypochondriac* | 8 |
| *Other* | Nothing has been unhelpful | *I can't really think of anything* | 9 |

**The Shifting Perspectives Model of Chronic Illness (Paterson, 2001)**

The online survey asked participants to consider the Shifting Perspectives Model of Chronic Illness in relation to the posts within the Facebook groups for CFS/ME (see Figure 1).

A greater proportion of people felt that the posts focused on being unwell, with most participants stating that they felt there was an equal balance of posts focusing on being well, as well as being unwell. Twenty one participants advised that they felt 'other' was an appropriate response to this question. All twenty one provided further details and these highlighted a theme of the participants experiencing the idea of them focusing on being well or unwell as a sensitive topic resulting in defensive responses, with some suggesting the research had ulterior motives to suggest that CFS/ME is a psychological illness;

*"I hope you are not trying to prove that ME is all in the mind or can be overcome by focusing on being well."*

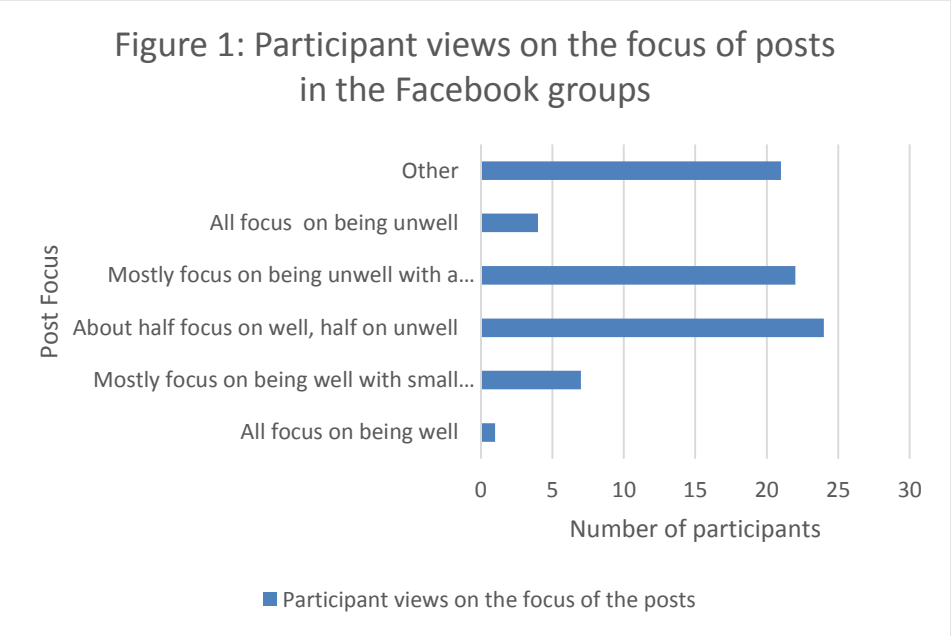

**Table 6:** Participant responses to how Facebook influences their perspective

| ***Facebook group members perspective Superordinate themes*** | **Example Quotes** | **N** |
|---|---|---|
| Recognise their perspective can fluctuate and be influenced by Facebook groups | *If I am having a relapse they can make me worse, but at other times they help me stay positive and help others* | 19 |
| Facebook groups make me focus on being well | *I have a much more positive outlook on my health after using Facebook, it helped me understand* | 24 |
| Facebook groups make me focus on being unwell | *I don't like to read so many posts about being unwell so I only use them for specific information* | 4 |
| Facebook groups have no influence on me | *I am not influenced in any way by peer groups or peer pressure* | 14 |
| Other responses | *Your emphasis on this idea is plain nonsense* | 7 |

A number of the responses in relation to the shifting perspectives model shared concerns about the model, with many misunderstanding the theory. As a result it was difficult to analyse the data. Due to this, it was not possible to analyse the answers provided to questions 20 and 21 of the online survey.

In response to how the Facebook groups influenced their own perspectives, participants gave mixed responses (see Table 6).

Sixty eight participants completed this question with twenty four suggesting that the Facebook groups had aided them in focusing on being well and nineteen recognising that their perspective can fluctuate and at times they regulate the use of the group. Four participants felt that Facebook groups made them focus on being unwell, and as a result used them purely for information purposes when required, whilst fourteen participants felt the groups had no influence on them. As previously highlighted, some individuals became defensive around this model and shared concerns, however seven out of sixty eight responses used offensive language to portray this.

**Element Two: Facebook Posts**

A content analysis on the 360 posts extracted from the Facebook group identified 13 categories of posts; sharing experiences, personal non-CFS/ME, motivational, research participation request, sharing of research findings, fundraising/awareness, CFS/ME related humour, non CFS/ME related humour, other group/blog promotion, explicit advice request, group dynamics, sharing advice, other CFS/ME related, other non-CFS/ME related (see Table 7, page 66).

Sharing experiences was a frequent concept and a further content analysis of the 106 posts in this category identified the following subthemes of; relating symptoms, updating the group, frustration with symptoms, frustrations with the impact of being ill, frustration with lack of understanding from friends/family, frustration with lack of understanding from professionals/'the system' and frustration with lack of understanding in general (see Table 8).

The group selected for extraction was closely monitored by the administrators (other individuals with CFS/ME) and there was evidence to suggest that posts or comments which were inflammatory or offensive were removed;

*Admin* I have deleted the recent post and blocked the individual concerned. Please do not raise the topic again.*

This has therefore eliminated these from the results of this study, yet it is important to note that these instances occurred.

**Table 7:** Concepts within Facebook posts

| ***Superordinate Themes*** | ***Example quotes*** | **N** |
|---|---|---|
| Sharing experiences | *I've just joined those amongst you who are vitamin D3 deficient. I'm sitting in front of my light pretending it's summer again. Nice!* | 106 |
| Personal non CFS/ME | *This is a pic of my beautiful daughters new hair colour, my husband says I'll suit it too, but I'm not so sure!* | 9 |
| Motivational | *Note to self, I don't have to take this day all at once, but rather, one step, one breath, one moment at a time. I am only one person. Things will get done when they get done.* | 10 |
| Research participation | *Can you take part in my study? It's for my dissertation about stereotyping illness* | 4 |
| Sharing research articles etc | *This makes me think CFS is more than just an immune system failure, people with CFS often can't eat or get up for this length of time. *Fasting for three days can regenerate the immune system, study finds – Telegraph** | 26 |
| Fund raising, awareness | *Thank you to everyone so far for supporting Invest in ME – you're all stars* | 30 |
| CFS/ME humour | *My goal this weekend is to move just enough each day so no one thinks I'm dead* | 8 |
| Non CFS/ME humour | *I'd have five pounds on the Dalai Lama, if I was a Tibetan man* | 22 |
| Other group promotion, blogs | **stay strong, live long* - new members welcome to our group* | 26 |
| Explicit advice request | *I've had ME for 3 years but only now getting a diagnosis, any advice on how to cope would be great as I have 2 children* | 71 |
| Group dynamics | *I got my PIP decision today, thanks for all your help, you guys are great!* | 7 |
| Other CFS/ME | *Disability and welfare petition – please sign* | 11 |
| Other non CFS ME | *Do people want to do a Christmas decoration swap this year again?* | 7 |
| Sharing advice | *As a lot of you know, I am currently undergoing treatment, I just wanted to share these resources with you. They've helped me.* | 23 |

**Table 8**: Sharing experiences concepts

| ***Superordinate Themes*** | **Example Quotes** | **N** |
|---|---|---|
| Relating symptoms | *Is anyone else bedridden or house bound with CFS like me?* | 21 |
| Updating the Group | *Eating today went slightly better…so that's an improvement amongst other little victories* | 49 |
| <u>Frustration</u> Symptoms | *I wish I knew when a crash was coming so I could plan my day!* | 8 |
| Impact/Loss | *I feel like my life is being taken away from me* | 11 |
| <u>Lack of understanding</u> Friends/Family | *My partner needs a reality check with this illness, I'm trying to tell him I need help and he doesn't get it* | 4 |
| Professionals/'the system' | *Waited two hours for my specialist appointment today to be told I just need to learn to live with it!* | 8 |
| Not specified | *Nobody gets it* | 5 |

The research has provided an insight into the difficulties those with CFS/ME experience and what is shared on Facebook groups. A thematic analysis of the Facebook posts suggested 4 main themes;

Feeling overwhelmed; "*I don't know how much longer I can play the juggling act"*

People within the groups shared feeling overwhelmed with their condition and the impact it has upon their life, with many detailing how they were feeling both physically and emotionally.

*"Checking in as I feel at my wits end from feeling so ill and tired all the time"*

*"I have no idea what I'm going to do, I have no energy to put in the effort needed"*

Furthermore, a theme of turning to the group for help was apparent;

*"I've tried all I can think of, does anyone have any suggestions?"*

*"I'm fed up, I can only turn to you guys to understand"*

Hope & Acceptance; *The silver lining of being young and sick*

Throughout the posts and comments there were individuals sharing positive stories;

*"It's going to make life much easier"*

At times when sharing feelings of being overwhelmed, responses tended to provide support to others in relation to hope and acceptance of the condition;

*"You will be able to do it, things can get better"*

*"I know it's so difficult, I feel the same, but we soldier on!"*

Feeling misunderstood; *Nobody gets it*

Two subthemes were identified within feeling misunderstood, with participants sharing their experiences in relation to personal and health professional encounters which left them feeling like no one understood the condition.

*"Eugh, no one gets it…'yes, your constant sickness? It's called hypochondria!'…this person has known me for over 4 years!!"*

*"Dr suggested it might be the muscles. I know it isn't but didn't discuss it with him"*

In contrast, people spoke about feeling accepted within the group;

*"I feel accepted as I am in this group"*

Developing an understanding; *Does anyone else…?*

A strong theme emerged around developing an understanding of the condition, in particular what symptoms can be attributed to the diagnosis;

*"Are people with CFS/ME more alcohol intolerant?"*

*"Do any of you experience a strange sensation in your teeth?"*

The idea around understanding prognosis and how others functioned on a day to day basis was also evident.

## Discussion

Given that CFS/ME online forums have more than ten times the relative activity of any other disorder or condition related forum, and the concerns around whether this affected their symptoms (Knudsen et al., 2012), this study aimed to explore the function Facebook groups serve in relation to the Shifting Perspectives Model of Chronic Illness (Paterson, 2001) and the experience of those who use them.

The results highlighted aspects of Facebook groups which were considered to be helpful and not so helpful. The accessibility of Facebook was considered as both a positive and a negative, due to its easy access and the resulting reduction in social isolation, however concerns were raised around the inability to avoid distressing posts. The accessibility of Facebook is a factor which may result in differences between other online forums and the Facebook groups. It is considered that this may result in Facebook being more active than other forums, and may also result in the perception of a more intimate network of support due to the likelihood of most individuals utilising the group inadvertently sharing information about themselves through their profile (dependent on their own privacy settings).

Support, of both an emotional and practical nature was considered to be helpful in the groups in varying forms, with participants being positive about their experience in the groups.

The group dynamics, content of posts, and the impact using Facebook could have on 'real life' were considered to be factors which were not so helpful about Facebook.

The analysis of the Facebook posts identified that the most prevalent type of posts were individuals sharing experiences or asking for advice. The concept of sharing

experiences was considered further and entailed individuals relating symptoms, updating the group and sharing their frustrations with having the condition.

The content of the posts could be considered to be of a nature which would increase symptoms, as may be expected by the health anxiety model (Salkovskis & Warwick, 1986), and may be considered to result in individuals focusing on illness. Given the unknown aetiology, the stigma of CFS/ME and the Shifting Perspectives Model of Chronic Illness (Paterson, 2001) however, it was considered that these posts may serve a more positive function.

In relation to the consideration of the Shifting Perspectives Model of Chronic Illness (Paterson, 2001), it could be suggested that Facebook groups serve a function to gain the wellness perspective. Paterson (2001) suggested that individuals gain the wellness perspective through education about their illness, being in supportive environments, identifying their own limits and body responses and sharing their knowledge and experiences with others, and the findings of this study suggest that the Facebook groups are used for this purpose. It may be however, that due to the lack of understanding around the aetiology and treatments of the condition, and the conflicts these can cause within the Facebook groups, there may be a risk of perspective being one of illness. The majority of respondents to the survey felt the Facebook group helped them focus on being well, despite posts appearing to focus on the illness, or seemed to recognise the potential of their perspective to fluctuate depending on group content.

A thematic analysis of the Facebook posts identified four main themes which highlighted the experiences of those individuals with CFS/ME and may provide insight into what Facebook groups provide for these individuals; a space to share feeling overwhelmed and misunderstood and to receive an develop a sense of hope and understanding in relation to the condition. A consideration of this may provide

professionals with an insight into the areas where individuals with CFS/ME may require additional support.

Furthermore, it has been identified that a perceived lack of skill to manage the illness, stigma, and interactions which accentuate feelings of hopelessness or dependency, may threaten a shift from WitF to IitF, however little evidence has been found to suggest the Facebook groups result in these threats, rather they provide an arena to support prevention of this.

The group considered was highly monitored, with posts which may have caused distress or offence to other members being deleted and those involved being removed from the group. This may be an example of the online disinhibition effect (Suler, 2004) whereby people may act in ways they would not in real life. Results from the survey suggest that this is not an uncommon experience. Therefore whilst the potential risk of these posts is diminished in this group, it may not be the case in others. Furthermore, given the offensive responses received by the researcher within the survey, it may be that online disinhibition effect (Suler, 2004) is something which needs consideration in relation to the impact of individuals who are targeted within these groups.

**Additional Observations**

Whilst the research was considered positively by the majority of individuals in the Facebook groups for CFS/ME, a number of individuals raised their concerns that Psychiatry and Psychology were considering their condition, with participants responding to the survey;

"*Would you do a similar analysis of support groups for diabetes, HIV, MS, lupus? Or is it because you think CFS/ME is in our heads?"*

Research has been completed on conditions such as Diabetes (Greene, Choudhry, Kilabuk & Shrank, 2010; Zhang, He & Sang, 2012), although these have only been observational in nature and not included participants. The inclusion of participants however has been a recommendation by a number of studies which have considered the use of Facebook groups for health conditions (Ahmed, Sullivan, Schneiders & McCrory, 2010; Niwa & Mandrusiak, 2012; Zhang, He & Sang, 2012). Throughout the study there was a strong theme around a lack of support from, and trust towards, professionals, particularly the psychology and psychiatry professions. As this was not the focus of this particular study it has received little attention, however future exploration around this may be of benefit to professionals working to support those with CFS/ME.

**Limitations**

A limitation of this study, and potentially for future research when advertising on groups within Facebook, is the rate at which the post advert was quickly replaced with newer posts and a systematic approach to 'boosting' the post to be prominent in the group was not in place. As a result, despite being advertised for a 2 month period, it may only have been visible to the group members for a few days at a time.

The analysis of the online survey was completed on the full data set, rather than for each individual survey response. It may be that treating each survey response as an interview, using an Interpretive Phenomenological Analysis approach (Smith, Flowers & Larkin, 2009) would have provided further understanding and the data may be re-analysed at a later date to consider this.

The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) felt appropriate for use within the study, however, as a model this may need further development as the process of identifying the perspectives was unclear and greatly interpreted by the

researcher. Furthermore, due to the emotive responses, and lack of understanding of the model by those who completed the survey, some answers were difficult to analyse. Further consideration may need to be given to making the model more accessible to those partaking in research around this area.

It may be considered a limitation that the survey was completed online rather than in person as an interview, as this results in a loss of understanding which one might attain from body language or intonations, however, given the theory of online disihibition effect (Suler, 2004), the survey, which also provided anonymity, may have provided the participants with the arena to speak more openly and truthfully.

As previously highlighted, the online survey evoked some offensive responses from participants which have provided an insight into the emotions some individuals with CFS/ME hold and may be of interest in relation to engaging this population.

**Conclusions**

The results of this study suggest that Facebook groups for CFS/ME have some potential risks associated with them, however these may not be of any greater concern than those posed to a member of any Facebook group. Rather, the Facebook groups seem to provide individuals with a perspective of wellness in the foreground by providing a shared experience and understanding which, potentially due to the current unexplained cause of the condition, is considered to be lacking in the 'real world'.

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# PART THREE

## Appendices

**Appendix A:**

Author Guidelines for the British Journal of Clinical Psychology

The British Journal of Clinical Psychology publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

• Papers reporting original empirical investigations

• Theoretical papers, provided that these are sufficiently related to the empirical data

• Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications

• Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

The word limit for papers submitted for consideration to BJCP is 5000 words and any papers that are over this word limit will be returned to the authors. The word limit does not include the abstract, reference list, figures, or tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length. In such a case, the authors should contact the Editors before submission of the paper.

3. Submission and reviewing

All manuscripts must be submitted via http://www.editorialmanager.com/bjcp/. The Journal operates a policy of anonymous peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

4. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from here.

• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided.

Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.

• All papers must include a structured abstract of up to 250 words under the headings: Objectives, Methods, Results, Conclusions. Articles which report original scientific research should also include a heading 'Design' before 'Methods'. The 'Methods' section for systematic reviews and theoretical papers should include, as a minimum, a description of the methods the author(s) used to access the literature they drew upon. That is, the abstract should summarize the databases that were consulted and the search terms that were used.

• All Articles must include Practitioner Points – these are 2–4 bullet points to detail the positive clinical implications of the work, with a further 2–4 bullet points outlining cautions or limitations of the study. They should be placed below the abstract, with the heading ‘Practitioner Points’.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.

• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

5. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author name and address are not included in the word limit.

6. Supporting Information

BJC is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at http://authorservices.wiley.com/bauthor/suppmat.asp

7. Copyright and licenses

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

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If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

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If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit our Funder Policy page.

8. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work

Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

9. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

10. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://authorservices.wiley.com/bauthor/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be

downloaded (free of charge) from the following web site:
http://www.adobe.com/products/acrobat/readstep2.html.

This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

British Journal of Clinical Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

**Appendix B:**

Epistemological Statement

As a researcher it is important to consider the underlying epistemological assumptions which may influence the development of the research question and the resulting methodology.

Two epistemological stances are Positivism and Interpretivism, which encompass the ideas of quantitative and qualitative research respectively (Snape & Spencer, 2003). .

Positivism is often considered to focus on a more objective view of the world and is considered to explain how and why things occur. It takes a scientific approach of obtaining facts, often using statistical logic and has been considered most suitable for the natural sciences. Positivism has been met with some criticism however in relation to understanding the social world, leading to an anti-positivist regime.

Interpretivism is considered to be an anti-positivism epistemological stance, which can be traced back to the work of Immanuel Kant in 1971, whereby research seeks subjective knowledge and aims to explore and develop an understanding rather than proving hypotheses. As a result, it is widely considered that Interpretivism is more suited to the social sciences.

My consideration of these epistemological stances has led me to consider them as resulting in a continuum on which research can be based, and through which, methodology can be chosen.

The underlying epistemological assumptions for this research developed due to my own viewpoints as an individual (and a member of the clinical psychology profession), the focus of the research, and the participants I was hoping to include in my study.

I consider myself to hold an interpretivist view point which highlights the importance of both observation and interpretation in order to understand the social world (Snape & Spencer, 2003).

My own viewpoint has naturally led me to my decision to undertake qualitative research, however the thesis focus was to consider an emerging aspect of the social world; the use of social networking sites on the internet, in particular, Facebook for those with CFS/ME, and as I have previously mentioned, social science has moved away from the more positivist research methodologies.

Whilst, therefore, the choice to undertake a qualitative piece of research seemed a natural one, the methodological design was particularly considered for this study as a result of the findings of the systematic literature review. The systematic literature review identified a lack of participant inclusion, and whilst an interpretive approach was taken, it was felt that the interpretation was very much one guided by the researchers, and did not take into consideration the individuals involved.

The seemingly most popular analysis technique of choice for research in this area, as identified in the systematic literature review, is that of content analysis. Whilst this satisfied the aims of the research, I felt the experience of participants and the richness of the data, was lost.

As a result, I felt it important to complement my analysis of a Facebook group for those with CFS/ME, with an online survey which allowed individuals to provide input on the interpretation of the existing data and conducted not only a content analysis, but also a thematic analysis of the data.

The thematic analysis of the data still resulted in a relatively superficial analysis of the data, however this is due in part to the ‘newness’ of the research area and the openness

of the research question to gain an insight into the use of Facebook groups by those individuals with CFS/ME.

Alongside the consideration of the 'newness' of the research area, this has received further consideration when choosing a qualitative approach. It has been proposed that the construction of knowledge online may be of a different entity to in the 'real world', (James & Bush, 2009). The study design chosen aimed to provide a view of the use of Facebook groups as one reality, and the survey to provide the opportunity for those within the groups to share their experiences independently of the group.

Furthermore, as influenced by my own personal experience of the Facebook groups, my experience of the condition, and the reading of research on the experience of having CFS/ME, I felt there was a theme of individuals not being heard or understood. This further influenced my decision to ensure participants could share their thoughts on the use of Facebook groups, rather than conclusions be drawn upon by the researcher without hearing from those having that experience.

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**Appendix C:**

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**Appendix D:**

| Qualitative Research Quality Checklist | |
|---|---|
| Paper Title: | |
| Author(s): | |
| Date: | Journal: |

| Quality Assessment Questions | Quality Rating Yes = 2, Unclear=1, No = 0 |
|---|---|
| Clearly focused research questions/aims | |
| Clearly focused rationale/hypothesis | |
| Methodology most appropriate to meet research questions/aims | |
| Ethics<br>• Was ethical approval reported<br>• Was consideration given to the privacy and accessibility of Facebook groups | |
| Methodology<br>• Time span of data collection reported<br>• Sampling strategy reported<br>• Data collection methods reported | |
| Participants (groups, posts or individuals)<br>• Inclusion and Exclusion criteria stated<br>• Sample considered to be representative | |
| Data Collection<br>• Role of researcher identified<br>• Sufficient detail and depth | |
| Data Analysis<br>• Strategy reported<br>• Appropriate for data collected<br>• Adequate evidence eg data extracts provided<br>• More than one rater identified | |
| Main findings<br>• Valid<br>• Relevant to aims of the study<br>• Interpreted within context and theory | |
| Conclusions are in keeping with aims of the study | |
| Underpinning assumptions and biases outlined | |
| Limitations reported | |
| Total Quality Assessment Score | |

**Appendix E:**

| | | Ahmed, Sullivan, Schneiders & McRory, 2010 | Bender-Jiminez-Marroquin & Jadad, 2010 | Farmer, Bruckner-Holt, Cook & Hearing (2009) | Gajaria, Yeung, Goodale & Charach, 2011 | Greene, Choudhry, Kilabuk & shrank, 2010 | Niwa & Mandrusiak, 2012 | Teufel et al. 2013 | Thoren, Metze, Buhrer & Garten, 2013 | Walker, 2013 | Zhang, He & Sang, 2012 | Total / 20 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Introduction:*** | Aims | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 20 |
| | Hypothesis | 0 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 18 |
| ***Ethics:*** | Reported approval | 2 | 2 | 0 | 2 | 0 | 2 | 2 | 0 | 0 | 0 | 10 |
| | Privacy considered | 1 | 1 | 0 | 2 | 0 | 2 | 1 | 1 | 0 | 1 | 9 |
| ***Methodology*** | Appropriate | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 2 | 18 |
| | Time span of data reported | 2 | 2 | 1 | 2 | 2 | 2 | 0 | 2 | 2 | 2 | 17 |
| | Sampling strategy reported | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 19 |
| | Data collection method reported | 2 | 0 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 17 |

| | | Ahmed, Sullivan, Schneiders & McRory, 2010 | Bender-Jiminez-Marroquin & Jadad, 2010 | Farmer, Bruckner-Holt, Cook & Hearing (2009) | Gajaria, Yeung, Goodale & Charach, 2011 | Greene, Choudhry, Kilabuk & shrank, 2010 | Niwa & Mandrusiak, 2012 | Teufel et al. 2013 | Thoren, Metze, Buhrer & Garten, 2013 | Walker, 2013 | Zhang, He & Sang, 2012 | Total / 20 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ***Participants*** | Inclusion/Exclusion stated | 2 | 2 | 0 | 1 | 0 | 1 | 2 | 2 | 0 | 1 | 11 |
| | Representative Sample | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 2 | 2 | 1 | 17 |
| ***Data Collection*** | Role of researcher identified | 2 | 0 | 2 | 0 | 0 | 2 | 2 | 2 | 0 | 0 | 10 |
| | Sufficient detail and depth | 1 | 0 | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 17 |
| ***Data Analysis*** | Strategy reported | 2 | 2 | 0 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 17 |
| | Appropriate | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 18 |
| | Adequate evidence | 2 | 0 | 0 | 2 | 2 | 0 | 2 | 2 | 0 | 1 | 11 |
| | Inter-rater reliability | 2 | 2 | 0 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 17 |
| ***Findings*** | Valid | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 19 |
| | Relevant to aims | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 19 |

| | | Ahmed, Sullivan, Schneiders & McRory, 2010 | Bender-Jiminez-Marroquin & Jadad, 2010 | Farmer, Bruckner-Holt, Cook & Hearing (2009) | Gajaria, Yeung, Goodale & Charach, 2011 | Greene, Choudhry, Kilabuk & shrank, 2010 | Niwa & Mandrusiak, 2012 | Teufel et al. 2013 | Thoren, Metze, Buhrer & Garten, 2013 | Walker, 2013 | Zhang, He & Sang, 2012 | Total / 20 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Interpreted within context and theory | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 1 | 2 | 2 | 18 |
| | Conclusions in keeping with aims | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 18 |
| | Underpinning assumptions outlined | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| | Limitations reported | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 18 |
| ***Total Quality Assessment scores / 44*** | | **36** | **33** | **26** | **38** | **30** | **39** | **34** | **36** | **33** | **32** | |

**Appendix F:**

Information Sheet

Thank you for visiting this page. I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you.

**Please read the information below. If you have any questions please get in touch using the contact details given below.**

**What is the purpose of the study?**

Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis (ME) is a poorly understood illness which currently has a high presence of Facebook support groups.

There is currently little research to understand the experience of those using Facebook support groups for this condition.

Furthermore, previous research identifies a Shifting Perspectives Model of Chronic Illness, which suggests people view their illness in different ways at different times in life in order to cope and to reach their current goal in relation to their illness.

This research hopes to explore how individuals with CFS/ME use the groups, and whether this impacts on their perspectives of their illness.

**Why have I seen the advertisement for this study?**

The survey is being conducted as part of my thesis on the Clinical Psychology Doctorate course (I am a Trainee Clinical Psychologist). It is open to anyone whose main health problem is a diagnosis of Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME) and is over the age of 18.

**What will happen if I decide to take part?**

The survey will include questions to collect information about you, and your experiences of using the Facebook Groups for CFS/ME. The purpose of the study is to explore the experience of using Facebook groups for those with CFS/ME. Participation involves completion of the online survey which is a mixture of multiple choice questions and open ended questions. Due to this, completion times may vary from individual to individual,

dependent on how much information they wish to provide. It is estimated that the survey will take a minimum of around 30 minutes to complete.

I will look for themes in yours and others answers to help provide an understanding of how you and others experience Facebook Groups for CFS/ME. The survey will be open until sufficient responses have been collected in order to allow me to thoroughly explore the information you and others will provide.

**What are the possible disadvantages and risks of taking part?**

The survey may be though provoking however I foresee no possibly disadvantages or risks to you taking part in this study. If, however, you feel uncomfortable in any way during completion of the survey, you have the right to decline to answer any question (by pressing the next button), end the survey (by exiting the web page by closing your browser) or to contact the researcher for further information.

**What are the possible benefits of taking part?**

There will be no direct benefits to you for taking part but it is hoped that this research will help in informing our understanding of the increasing use of Facebook for peer support in CFS/ME.

**What will happen to my information?**

Results of the survey will be published but the findings will not be personally identifiable and all of the information you do provide will be handled according to ethical and legal practice. Completing the survey is optional and there is no reward for participation. If you do decide to take part, your answers will be anonymous, and you will not be asked for your name or any other personal details such as your contact details.

All of the data collected in this study will be stored securely for ten years after publication. The survey has been peer reviewed and approved by the Faculty of Health and Social Care Ethics Committee at the University of Hull.

**What will happen if I decided I no longer wish to take part?**

You can exit the survey at any time and your data will not be saved. However, once you have completed the survey you will not be able to withdraw your answers due to the anonymous nature of answers.

**What if there is a problem?**

Should you have any concerns about this research please feel free to contact the researcher who will do her best to answer your queries. If you remain unhappy and wish to complain about the research, please contact the Associate Dean of Research and Enterprise, Professor Kathleen Gavlin, University of Hull, Cottingham Road, Hull, HU6 7RX or by email at K.T.Galvin@hull.ac.uk.

**Any questions?**

Please contact Gerri Moxon, Trainee Clinical Psychologist, University of Hull, Cottingham Road, Hull, HU6 7RX, g.moxon@2008.hull.ac.uk

If you wish to participate in this research project please proceed to the next page.

**Appendix G:**

Informed Consent

My participation in this project is voluntary. I understand that I will not be paid for my participation and that I may withdraw and discontinue participation at any time without penalty. (*tick box to indicate they have read and understood the information)*

I understand that the survey may be thought-provoking. If, however, I feel uncomfortable in any way during completion of the survey, I have the right to decline to answer any question (by pressing the next button), end the survey (by exiting the web page by closing your browser) or to contact the researcher for further information. Contact details for the researcher are available at the end of this page and will be available on the online survey and can also be found on the original advertisement on the Facebook group. (*tick box to indicate they have read and understood the information)*

I understand that the researcher will not identify me by name in any documents using information obtained from this survey, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions. Results of the survey will be published but the findings will not be personally identifiable. (*tick box to indicate they have read and understood the information)*

I have read and understand the explanation provided to me and I voluntarily agree to participate in this study. (*tick box to indicate they have read and understood the information prior to pressing a button to begin survey)*

**Appendix H:**

Questions for Online Survey

1. Have you been diagnosed with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis by a professional?
    - *NB:Those who do not select yes will have the survey ended with a message advising them that they are not eligible for the current survey but we thank them for their time.*
    - Yes
    - No
2. Are you aged 18 or over?

- *NB:Those who do not select yes will have the survey ended with a message advising them that they are not eligible for the current survey but we thank them for their time.*
- Yes
- No

3. Is Chronic Fatigue Syndrome or Myalgic Encephalomyelitis your main health problem?

- Yes
- No

4. Country of Residence
    - *NB: Drop down box with list of countries*
    - Prefer not to say
5. Are you English speaking?

- *NB: Those who do not select yes will have the survey ended with a message advising them that they are not eligible for the current survey but we thank them for their time.*
- Yes
- No

A Few Questions about you;

6. Gender
    - Male
    - Female
    - Prefer not to say
7. Current age
    - *NB: Text box to type in age*
    - Prefer not to say
8. Are you currently employed?

- No
- Yes, self-employed
- Yes, full time
- Yes, part time

- Student
- Other, please give details
- Prefer not to say

9. Current marital status

- Single
- Co-habiting
- Married
- Civil Partner
- Divorced
- Separated
- Other
- Prefer not to say

A few questions about you at the time you were diagnosed;

10. Age at diagnosis
    - *NB: Text box to type in age*
    - Prefer not to say
11. Employment status at time of your diagnosis

- Not employed
- Yes, self-employed
- Yes, full time
- Yes, part time
- Student
- Other, please give details
- Prefer not to say

12. Marital status at time of diagnosis

- Single
- Co-habiting
- Married
- Civil Partner
- Divorced
- Separated
- Other
- Prefer not to say

Your use of Facebook Groups;

13. How did you find out about the Facebook groups for CFS/ME?
    - *NB: Text box to type answer*
14. What do you find helpful about using Facebook groups for CFS/ME?
    - *NB: Text box to type answer*
15. What do you find not so helpful about using Facebook groups for CFS/ME?
    - *NB: Text box to type answer*
16. How often do you read the posts in your Facebook Group?
    - More than once a day

- Daily
- 2 to 5 times a week
- Weekly
- Fortnightly
- Monthly
- Other, please give details

17. How often do you comment on other people's posts in the Facebook group?

- More than once a day
- Daily
- 2 to 5 times a week
- Weekly
- Fortnightly
- Monthly
- Other, please give details

18. How often do you start a post in the Facebook Group?

- More than once a day
- Daily
- 2 to 5 times a week
- Weekly
- Fortnightly
- Monthly
- Other, please give details

Theory currently suggests the idea of a Shifting Perspectives Model of Chronic Illness. It suggests that people with chronic illnesses sometimes focus on being well, and at other times focus on being unwell.

They refer to this as either Illness in the Foreground (focusing on being unwell) or Wellness in the Foreground (focusing on being well).

It argues that neither of these are 'right' or 'correct' but instead are ways that people cope with the situations they are in.

This research aims to find out whether the Facebook groups focus on illness and being unwell, or wellness and how to recover, or both, and how this impacts on the group members.

<u>Illness in the Foreground</u>

Below are a number of statements that suggest a focus on the illness and being unwell. If you recognise these ideas and thoughts as being discussed by people in Facebook groups, please tick. You may select as many as you wish.

- People describe feeling overwhelmed with the illness.

- People focus on the sickness, suffering, loss and burden associated with living with CFS/ME.
- People focus on being unwell and the impact of having CFS/ME because others expect them to be ill
- People focus on being unwell in order to obtain professional/medical input.
- People focus on being unwell in the hope it will provide evidence to others that the illness is real.
- People focus on the illness in order to learn more about CFS/ME and to come to terms with it.

The statements you have just read focus on being unwell and would suggest a theme of Illness in the Foreground.

<u>Wellness in the Foreground</u>
Below are a number of statements that suggest a focus on being well and recovering from CFS/ME. If you recognise these ideas and thoughts as being discussed by people in Facebook groups, please tick. You may select as many as you wish.

- People see CFS/ME as an opportunity for meaningful change in their life.
- People would describe their health as good or excellent, despite having impaired physical functioning.
- People describe CFS/ME as something they experience, but not as their whole identity.
- People are not overwhelmed by the CFS/ME and can focus on the emotional, spiritual, and social aspects of life, rather than on being unwell.
- People try to help others with CFS/ME
- People have adapted their ideas of what is possible or normal in life now that they have CFS/ME.

The statements you have just read, focus on being well and recovering and would suggest a theme of Wellness in the Foreground.

19. What focus do you feel the posts in the Facebook groups have?
    - All focus on being well
    - Mostly focus on being well with a small focus on being unwell
    - About half focus on being well and half focus on being unwell
    - Mostly focus on being unwell with a small focus on being well
    - All focus on being unwell
        - *NB: Tick boxes*

- Please feel free to provide any further information here
    1. *NB: Text box to type answer*

20. In as much detail as you can, can you describe what sort of things are posted within the Facebook groups that make you think the people are focused on being **well**?
    - *NB: Text box to type answer*

21. In as much detail as you can, can you describe what sort of things are posted within the Facebook groups that make you think the people are focused on being **unwell**?
    - *NB: Text box to type answer*

22. Thinking again about the ideas we have previously described which suggest that sometimes people need to focus on being well, and other times people need to focus on being unwell, what, if any, impact have the Facebook groups had on your own focus? How much does being a part of the Facebook groups influence whether you focus on being well, or being unwell? Please give as much detail as possible.
    - *NB: Text box to type answer*

Thank you for your time in completing this survey. Should you have any queries or concerns please don't hesitate to contact the researcher;

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07879 338550
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If you have been caused any distress in the completion of this survey please don't hesitate to contact the researcher on the above details or you may wish to get in touch with the ME Association;

www.meassociation.org.uk

0844 576 5326 – ME Connect Helpline. Open every day 10am to 12noon, 2-4pm, and 7-9pm. You can also email meconnect@meassociation.org.uk

The ME Association also has a page of Helpful Services which you may wish to contact;
http://www.meassociation.org.uk/these-advertisers-support-the-me-association-please-support-them/

Should you have any concerns about this research please feel free to contact the researcher who will do her best to answer your queries. If you remain unhappy and wish to complain about the research, please contact;

Associate Dean of Research and Enterprise,
Professor Kathleen Gavlin,
University of Hull, Cottingham Road, Hull, HU6 7RX
or by email at
K.T.Galvin@hull.ac.uk.

**Appendix I**:

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**Appendix J:**

## The Empirical Paper

### The decision to research CFS/ME

The decision to undertake research on Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis (ME), seemed an easy one. Having had personal experience of a diagnosis it was an area I felt was important to research. As a user of Facebook and a member of a number of Facebook groups for health conditions, including CFS/ME, I had observed, and been a part of, what I felt to be both positive experiences and negative experiences. This was echoed during the study, something I will reflect on under the subheading During the Study.

The increasing use of Facebook and e-health developments made me wonder how helpful a move towards online peer support might be for health conditions, in particular CFS/ME.

Through observations within the Facebook groups and the reviewing of existing literature in relation to those with CFS/ME, it became apparent that it was a condition with a number of challenges, a number of which I recognised from my own experiences.

The uncertainty around the aetiology of CFS/ME appears to often be a source of contention for those in the CFS/ME community. As an individual with psychological training I understand CFS/ME using a bio-psycho-social approach, however my gexperiences in the Facebook Groups for CFS/ME have demonstrated that a number of individuals are unwilling to consider psychological or social influences on their condition. My understanding is that this is due to individuals' experiences in relation to being told they are hypochondriacs, and a number of people appear to have been sent to mental health services and prescribed anti-depressants before receiving a diagnosis of

CFS/ME. Discussions within the Facebook groups seem to suggest this has influenced how people consider psychology and psychiatry (with little understanding of the differences) in relation to their condition. I felt that individuals with CFS/ME were often defensive against psychological explanations for any aspect of their condition as they had to defend against CFS/ME being a physical illness. I wonder whether the research completed by others, such as Simon Wessely (Williams, 2013) has influenced this.

Patterson (2001) developed a theory of the Shifting Perspectives Model of Chronic Illness which I felt might have addressed these concerns well. It highlighted how people may respond differently and may need to focus on their symptoms at times to have their needs met, eg to feel like others recognise the existence of their condition and they are unable to 'just snap out of it'.

The experiences of stigma and delegitimisation of the illness appeared to me to have led to Facebook groups being defensive about psychological or social influences on their condition. Individuals even seemed unwilling to consider that having the illness affected their psychological wellbeing.

So, whilst I felt that the Facebook groups were often a place of great support, I also wondered whether they led to individuals being stuck in a focus of illness in the foreground. I was aware however that as I had chosen a qualitative approach, I needed to ensure I was aware of my own potential assumptions.

<u>The development of the research proposal</u>

During the development of the research proposal I spent more time observing on the Facebook groups to help me consider how to complete the research. My experience doing this made me realise how important the research may be. Whilst I had since

received an alternative diagnosis and treatment which had improved my symptoms dramatically, I found that reading the posts and spending time on the Facebook groups accentuated any symptoms I had. As one may expect when considering the health anxiety model, a focus on a symptom can accentuate it and I found this could often be the case with my own symptoms. Identifying with those who were advising how exhausted they were and how they were in pain and unable to get up, often left me feeling in a similar way, despite the fact I had been functioning.

The ethical process

The use of the internet for research is a new area with new ethical considerations. Facebook is something which is of particular interest in this regard as there are conflicting views on the ethical approaches to Facebook. People who use Facebook may consider the content they post to be private, and it is therefore an ethical issue as to whether this data can then be used for research purposes, however it is also becoming increasingly recognised that data online is less than private. Due to this however the extraction from an existing Facebook group was chosen to be from a group which openly advised all new members that the group was open, could be found in search engines and was therefore not considered private. This may however influence the content of this page, something which as an individual in the group I have noticed, however it felt the most ethical approach and was hoped it would still provide a valuable insight into the use of Facebook groups.

During the study

As I have previously mentioned I have had personal experience of CFS/ME and after careful consideration I chose to share this whilst advertising for my study. On reflection I felt that due to the difficulty in relationships with professionals, particularly those from psychiatry or psychology, this may aid engagement. Whilst I received some

positive responses on the advertisement, others within the group stated that they felt targeted by the world of psychiatry and that my efforts should not be spent on researching their condition as it is not a mental health condition. Some responses from the online survey echoed this, however I was struck by a) how aggressive and offensive these responses were and b) how factually incorrect I would consider them to be. As a group of individuals who disagreed with the research, they seemed to have little understanding between psychology and psychiatry and stated that my area of research would never be considered for other health conditions such as diabetes. As my systematic literature review has evidenced, this is not the case, and input from the psychological community does not mean it's a mental health difficulty. Despite explaining this to the individuals who commented on my advertisement, their views appeared to remain unchanged.

Of most concern to me was the negative and offensive responses that the survey and advertisement received, responses which I would assume I would never receive in person, yet something about being behind a computer screen allowed these individuals to perform what felt like a personal attack. I had shared that I had experienced the condition and yet received comments such as

*"you clearly have no idea about ME"*

*"you need to consider another job as you clearly have no idea what you are doing"*

Stepping into this from a research perspective the emotional impact of these responses was limited, yet they still evoked strong negative feelings in me. These were the type of comments I'd observed within the groups towards others who had suggested certain treatments or shared positive stories of recovery and it has made me consider the impact this could have on those individuals.

Data and the Analysis

The analysis of the data was somewhat of a task. I'd completed my systematic literature review and had often commented on how there seemed to be little depth to the information I'd reviewed, how we still didn't really know what using the Facebook groups was like for individuals with health conditions. Completing my own research it was soon evident why. Facebook seemed like an easy idea, extracting data from an easily accessible source which I already found myself spending hours procrastinating on, how could I not enjoy analysing the data from it? The extraction of the data from the Facebook group was almost impossible, and the size of the .pdf file that it resulted in was unmanageable, resulting in me needing to print 600 pages of Facebook posts and their comments. I didn't print 600 pages however, I printed 300, with 2 pages to a sheet. I have learnt from this process that whilst a consideration for the environment is important, analysing 300 pages of what resulted to be around a size 6 font is not a pleasant experience. Given the vast amount of paperwork my research had already accumulated with papers and drafts, I found myself hesitant to print anything out but have since established that like many, I work much better with pen and paper than computer screen and mouse and in future research will accept this early on rather than making an already difficult task, much harder.

The data I extracted was vast, and much more than I think I'd expected, with some posts having over 100 comments, leaving me little choice but to only analyse the original post in relation to its content, but applying a more thematic approach in relation to additional observations for the entire data set. I have since wondered whether others who have decided to consider the use of Facebook groups, as those in my systematic literature

review, have also found themselves overwhelmed with the data, resulting in a more categorical content analysis approach.

Thankfully, I also completed the online survey which provided a much richer, yet more manageable, dataset and I feel this is a strength to my study – to have provided those that use the groups a voice to share their experiences, rather than relying purely on the analysis and interpretations of the data extracted, which whilst vast for analysis, is relatively small in comparison to the overall activity within the groups.

As I have previously mentioned, I did potentially start this research with my own ideas on the use of Facebook groups, however the results I collected and interpreted have not provided the discussion points or conclusions that I would have expected. I would like to think that this suggests that my own assumptions have not tainted the data.

The write-up has probably been the most difficult part of the research. An experience I was looking forward to became an overwhelming task with a looming deadline and limited time. Having experienced my own health difficulties over the three years of my research period, potentially a relapse of a CFS/ME diagnosis, I have had to learn to practice self-care, something I have established I'm not overly skilled at.

Furthermore, I've found myself being very aware of wanting to ensure the thesis provides an accurate account of the experience of those with CFS/ME. My position in writing this research has hopefully been as unbiased as possible, having been in the shoes of the participant, and seeing it from a professional and researcher's perspective, however given the controversy and difficulty in professional relationships around CFS/ME I have been aware of wanting to try bridge this gap, rather than cause further ruptures. It is this feeling that I believe resulted in my reflection on whether to include reference to the negative and offensive comments received within the study, not wanting to paint CFS/ME individuals in a 'bad light' yet acknowledging this was the

very types of behaviours and beliefs evident in some Facebook groups that had made me feel this research area was so important.

Following my viva voce and any corrections, my next task will be to feed back my results to the groups where the study was advertised. I am excited yet apprehensive about this due to the reactions I may receive from those who voiced their grievances during the study process, but hope that my words have done theirs justice and provides an unbiased, yet potentially more fair (due to my own personal experiences), account of the experience of those individuals with CFS/ME using a Facebook group.

## The Systematic Literature Review

Whilst the process of developing your own piece of research is difficult, it was the systematic literature review that I feel was the most difficult section of the thesis.

It is perhaps the necessity of the review being 'systematic' that caused these difficulties. Weaved between my empirical paper, other course requirements and the little bit of personal life I had left, it felt almost impossible to keep track of the process I had taken to conduct searches and quality assess. I found myself avoiding any aspect of the review unless I could be assured of at least 4 hours of interrupted time to focus on it. As a trainee clinical psychologist and an individual with a tendency to 'flit' between tasks, 4 hours of interrupted time never seemed an option. This resulted in me returning to my previous strategy of jumping in and out of the process, but this often left with me little recollection of the process I'd undertaken and I found myself repeating each step every time I re-engaged with the task. Furthermore, I'd often have a number of copies of search results, ideas and parts of the write up saved on my computer, laptop and encrypted memory stick, just in case I found myself with some spare time, yet I wasn't

always organised enough to ensure I had the most up to date version, resulting in a lot of confusion and questioning of my own sanity.

On reflection, this probably reflects my difficulty in juggling a number of tasks, and this is something I will take forward to develop in other aspects of my life, clinical work and future research.

References

Williams, M. (2013). *Professor Sir Simon Wessely – Right or Wrong?* Peer commentary retrieved from http://www.meactionuk.org.uk/Right-or-Wrong.htm