

Quality and misinformation about health conditions in peer online support groups: Scoping review of information and advice

Bethan M. Treadgold, Neil S. Coulson, John L. Campbell, Jeffrey Lambert, Emma Pitchforth

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Quality and misinformation about health conditions in peer online support groups: Scoping review of information and advice??

Bethan M. Treadgold¹ PhD; Neil S. Coulson² PhD; John L. Campbell¹ MD, MBChB; Jeffrey Lambert³ PhD; Emma Pitchforth¹ PhD

¹Primary Care Research Group Health and Community Sciences University of Exeter Exeter GB

²Nottingham Centre for Public Health and Epidemiology School of Medicine University of Nottingham Nottingham GB

³Centre for Motivation and Health Behaviour Change Department for Health University of Bath Bath GB

Corresponding Author:

Bethan M. Treadgold PhD

Primary Care Research Group

Health and Community Sciences

University of Exeter

University of Exeter Medical School, St Luke's Campus, Magdalen Road, Exeter

Exeter

GB

Abstract

Background: The use of health-related peer online support groups to support self-management of health issues has become increasingly popular. The quality of user-generated health information and advice may have important implications for health and for the utility of such groups. There is some evidence of variable quality of online health-related information but the extent to which misinformation is a problem in peer online support groups is unclear.

Objective: To gain insight into the quality of information and advice about health conditions in peer online support groups and to review the available tools used to quality-assess such information.

Methods: A scoping review was undertaken following JBI scoping review methodology. Electronic databases (Medline (Ovid), CINAHL, Web of Science and ASSIA, ProQuest Dissertation and Theses, and Google Scholar) were searched for literature published before November 2023, as well as citations of included papers. Primary research studies, reviews, and grey literature that explored the quality of information and advice in peer online support groups were included. Title and abstracts were independently screened by two reviewers. Data was extracted and tabulated, and key findings summarised narratively.

Results: A total of 14 relevant papers, from 3136 identified, were included. Ten were primary research papers comprising of diverse quality appraisal methodologies, and four were review papers. All had been published between 2014 and 2023. The quality of information and advice in peer online support groups varied according to the health condition in focus and across online platforms. Across the literature, there was more evidence of poor-quality information and misinformation than of good quality information and advice, particularly around long-term and life-threatening conditions. Fellow peer online support group users often played an active role in correcting misinformation through replying to false claims or providing correct information in subsequent posts. Quality appraisal tools were reported as being used by researchers and medical professionals in appraising the quality of information and advice. Such tools included established tools for the appraisal of health-related information (e.g. DISCERN, HONcode criteria, JAMA benchmark criteria). No tools reported were specifically designed to appraise peer online support group content.

Conclusions: While there is good quality information and advice exchanged between users in peer online support groups, our findings show that misinformation is a problem. Confidence in the quality of information shared may determine the utility of peer online support groups for patients and medical professionals. Our review suggests that clinical and academic experts in health conditions could provide a valuable role in quality-assuring content. Several quality appraisal tools are available to support such an initiative.

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Original Manuscript

Quality and misinformation about health conditions in peer online support groups: Scoping review of information and advice

Authors

Bethan M. Treadgold¹, Neil S. Coulson², John L. Campbell¹, Jeffrey Lambert³, Emma Pitchforth¹

1. Exeter Collaboration for Academic Primary Care, University of Exeter Medical School, University of Exeter, Exeter, UK

2. Nottingham Centre for Public Health and Epidemiology, School of Medicine, Faculty of Medicine and Health Sciences, University of Nottingham, Nottingham, UK

3. Centre for Motivation and Health Behaviour Change, Department for Health, University of Bath, Bath, UK

Abstract

Background: The use of health-related peer online support groups to support self-management of health issues has become increasingly popular. The quality of information and advice may have important implications for public health and for the utility of such groups. There is some evidence of variable quality of online health information but the extent to which misinformation is a problem in peer online support groups is unclear.

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Results: A total of 14 relevant papers, from 3136 identified, were included. Ten were primary research papers comprising of diverse quality appraisal methodologies, and four were review papers. All had been published between 2014 and 2023. Across the literature, there was more evidence of poor-quality information and misinformation than of good quality information and advice, particularly around long-term and life-threatening conditions. There were varying degrees of misinformation about non-life-threatening conditions, and about mental health conditions. Misinformation about noncommunicable diseases were reported as particularly prevalent on Facebook, whereas misinformation about vaccines and drugs were reported as most prevalent on X (formerly Twitter). Fellow peer online support group users often played an active role in correcting misinformation through replying to false claims or providing correct information in subsequent posts. Quality appraisal tools were reported as being used by researchers and healthcare professionals in appraising the quality of information and advice. Such tools included established tools for the appraisal of health-related information (e.g. DISCERN, HONcode criteria, JAMA benchmark criteria). No tools reported were specifically designed to appraise peer online support group content.

Conclusions: While there is good quality information and advice exchanged between users in peer online support groups, our findings show that misinformation is a problem, which is a matter of public health concern. Confidence in the quality of information shared may determine the utility of peer online support groups for patients and healthcare professionals. Our review suggests that clinical and academic experts in health conditions could provide a valuable role in quality-assuring content. Several quality appraisal tools are available to support such an initiative.

Keywords

Quality; online; health; peer; online support group; forum; information; advice; approval; assessment

Introduction

Background

In recent years, there has been a rapid increase in peoples' use of online resources aimed at meeting health information needs (1, 2). Seeking health information and advice from the Internet has been described as the interaction of an individual (e.g., patient, caregiver or professional) with or through an electronic device or communication technology to access or to transmit health information (3). A large amount of online health information is generated by healthcare providers, pharmaceutical companies, and other public, private, and charitable health organisations, by virtue of websites for the public. At the same time, an increasing volume of online health content is being generated by individuals living with or caring for others with a health condition, via peer online support groups (4-10).

Peer online support groups, otherwise named online support communities, are virtual spaces where individuals exchange health-related information (i.e., factual knowledge, not based on a person's opinion), advice (i.e., a recommendation for action based on someone's experience) and peer-support (i.e., sharing personal experiences, and emotional, social or practical support with one another), often through asynchronous, text-based computer-mediated communication platforms (e.g., discussion forums and social media sites) (4, 10, 11). Exchanging health-related information and advice in peer online support groups has been found to empower people living with or caring for others with health conditions in learning new methods for managing their conditions, in feeling that their experiences are validated, in reducing a sense of loneliness, and in improving their navigation of healthcare services (7-9, 12-14). Peer online support groups have been described as a health care resource which is complementary to formal health care, with patients feeling equal contributors in the patient-provider relationship (10). Interactions through peer online support groups about health can also lead to the identification of health-related problems that healthcare professionals have not yet considered, and sharing health-related experiences through such groups has led to campaigns to improve health care (15).

Whilst peer online support groups have become increasingly popular, there is growing concern from healthcare professionals and researchers regarding the accuracy and safety of some health information on the Internet (16-19). The concept of information quality has multiple dimensions, centred around trustworthiness and scientific correctness (20). Increasing attention has been given to exploring the quality of health-related information and advice exchanged in peer online support groups, particularly around the medical accuracy of content, or conversely, the spread of misinformation (21-23). Health-related misinformation has been defined as a health-related claim of a fact that is false due to a lack of scientific evidence (24) and is usually attributed to misconceptions. Exposure to misinformation in peer online support groups and following false information and advice can detrimentally impact health outcomes (25-31). Several incidents of public health concerns arose out of misinformation spreading across social online platforms during the Covid-19 pandemic, including hospitalisation and casualties (32). Poor quality information often reproduces within discussion threads in peer online support groups, where like-minded people come together, and similar topics circulate (the 'echo chamber effect') (30). People with lower levels of health literacy may be particularly vulnerable to the detrimental impacts of misinformation (29, 31).

Rationale for the study

With the rapid spread of misinformation in peer online support groups posing significant threats to public health, a comprehensive scoping review of the quality of information and advice, and the methods used in quality appraisals, is needed. Knowledge about the quality of information shared in peer online support groups is directly relevant for patients, carers and healthcare professionals in supporting the management of health conditions. As potential moderators of the quality of

information and advice provided, an understanding of the methods of quality appraisal is also important.

Review objective

The objective of this scoping review is to map and summarise evidence about the quality of information and advice in peer online support groups across a range of health conditions, and to review the available tools used to quality assess such information and advice.

Review questions

1. What is known about the quality of information and advice exchanged within peer online support groups about health conditions?
 - a. To what extent is misinformation about health conditions a problem within peer online support groups?
 - b. How have researchers assessed the quality of information and advice exchanged in peer online support groups about health conditions?

Methods

Scoping reviews aim to identify and map the key concepts within a research area, in terms of its nature, features, and volume. Such reviews often address a broad research question and including a variety of study designs (33-35). This scoping review was conducted in accordance with the JBI methodology for scoping reviews (36-38) and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist for reporting (39). The review protocol was registered in January 2024 on the Open Science Framework Registries: <https://doi.org/10.17605/OSF.IO/U9XFY>. The PCC framework (population, concept, and context) (37) was followed as a guide to construct the review objectives, search strategy and eligibility criteria. Covidence systematic review software was used for all review stages (40).

Search strategy and procedure

The principal reviewer (BT) and second reviewer (EP) developed the search strategy, with assistance from a university research librarian. The search strategy aimed to identify published and unpublished literature and focused on three central concepts: 1) online support groups; 2) quality assessment; 3) health-related information and advice. An initial limited search was conducted of Web of Science and Medline (Ovid) to identify literature on this topic and keywords referring to the three central concepts of the search strategy (Table 1). Records identified through this initial search were reviewed to identify relevant literature, and text words contained in the titles, abstracts and keywords of relevant literature were used to identify additional keywords to develop the final search strategy (Supplementary file 1). An adapted search strategy was developed for each database.

Online support group search terms	Quality assessment search terms	Health-related information search terms
online support group online support groups online community online communities discussion forum discussion forums social media social networking sites	quality assessment quality assessment medical accuracy accuracy appraisal	information advice health

Table 1. Preliminary keywords referring to three central concepts (online support groups; quality assessment; health-related information and advice) used to develop the final search strategy for this scoping review.

Electronic databases (*Medline (Ovid)*, *CINAHL*, *Web of Science and Applied Social Sciences Index & Abstracts*) and sources of unpublished and grey literature (*Google Scholar and ProQuest Dissertations and Theses*) were searched from inception to November 2023. Google Scholar collates results from across the Internet and does not have internal functions for an advanced search as do the other included databases. Previous research indicated that most grey literature begins to appear after approximately 20 to 30 pages in Google Scholar results, therefore the first 100 results from page 20 onwards were screened (41). The reference lists of included review papers and citations of all included papers were hand-searched for additional relevant literature. Where full texts were not available, authors were contacted to request a copy.

Eligibility criteria

Inclusion and exclusion criteria reflected the focus of this scoping review on the quality of information and advice about health conditions in peer online support groups (Table 2).

Inclusion criteria	Exclusion criteria
Population	
Synchronous or asynchronous text-based peer online support groups, where individuals can exchange information, advice, and support about health conditions within an online community or group or through a discussion thread about a given topic (<i>e.g., Facebook support groups, Reddit, Twitter, Instagram, WhatsApp, Mumsnet, Health Unlocked, Patient, and charity-owned peer online support groups</i>).	Video-based social media sites, which do not involve joining a peer online community or group or the use of discussion threads (<i>e.g., YouTube, TikTok</i>).
Concept	
- The quality of information and advice about health conditions in peer online support groups (<i>e.g., medical accuracy, comparison of information with evidence-based guidelines and relevant literature, readability, and usability of content, degree of misinformation</i>). - Quality assessment tools and questionnaires (<i>e.g., DISCERN tool, Health on the Net Code of Conduct, and the Journal of the American Medical Association benchmark</i>) and their application to information and advice about health conditions in peer online support groups.	- The quality of information and advice on websites that only provide static information that cannot be contributed to or discussed in a peer online support group format (<i>e.g., the NHS website, WebMD, National Institute of Health, MayoClinic, and health-related charity websites</i>). - The quality of information and advice that is from a peer online support group that is not focused on a particular health condition (<i>e.g., health promotion, dieting, pregnancy</i>). - The quality of any health-related support services organised by healthcare professionals (<i>i.e., online support interventions conducted as part of a research trial</i>). - The quality of information and advice in non-online-based support groups (<i>e.g., in person support groups</i>).
Context	
- Primary peer-reviewed studies and reviews employing quantitative, qualitative, or mixed methods design, dissertations and theses, and grey literature that explored the quality of information and advice about health conditions in peer online support groups. - References within included review papers, and citations of included papers.	Conference abstracts and proceedings, commentaries, books, and editorials.

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Any geographical location, focusing on any type of health condition, published at any time and in any language.	
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Table 2. Eligibility criteria for identifying literature exploring the quality of information and advice about health conditions in peer online support groups.

Selection of included papers

All identified citations were collated and uploaded into the review software and duplicates were removed. Two independent reviewers (BT and EP) screened titles and abstracts against the inclusion criteria. In cases where the abstract signalled potential eligibility, the full paper was retrieved and imported into Covidence, read, and assessed for inclusion. Reasons for exclusion of papers were recorded as full text. Any disagreements at each stage of the selection process were resolved through discussion.

Data extraction

Data was extracted by BT using a data extraction tool developed by the wider review team (BT, NC, JC, JL, EP). The data extraction tool included predetermined study characteristics (i.e., author(s), year, country, research design methodology, and literature aim(s)); condition(s) in focus of peer online support group; key findings; details of quality assessment tools; study limitations). After extracting data from each included paper, BT sent completed data extraction to a second reviewer (EP) for consensus. The extracted study characteristics were discussed before agreeing on the final extracted content to be analysed and synthesised.

Data analysis

Data extracted from included literature were tabulated and summarised narratively. Given the diversity and heterogeneity of the literature concerning methodologies and findings, a narrative summary of findings was chosen in order to provide a comprehensive understanding of the literature. BT uploaded the full texts of included papers into NVivo qualitative data analysis software (42), and coded their content according to the three research questions of this scoping review. Codes were analysed descriptively and discussed with additional reviewers (EP and NC). Final summaries of each research question were developed with the wider review team (BT, NC, JC, JL, EP).

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Results

Included papers

The search strategy yielded 3136 results, of which 238 were duplicates. From the 2898 titles and abstracts reviewed, 2848 did not meet the inclusion criteria. The full texts of the remaining 50 papers were assessed, and a further 36 were excluded as they did not meet the inclusion criteria ($n = 35$) or were not attainable after contacting the author ($n = 1$). Overall, there were 14 papers included in our review. Figure 1 presents a PRISMA (43) flow diagram detailing the inclusion process.

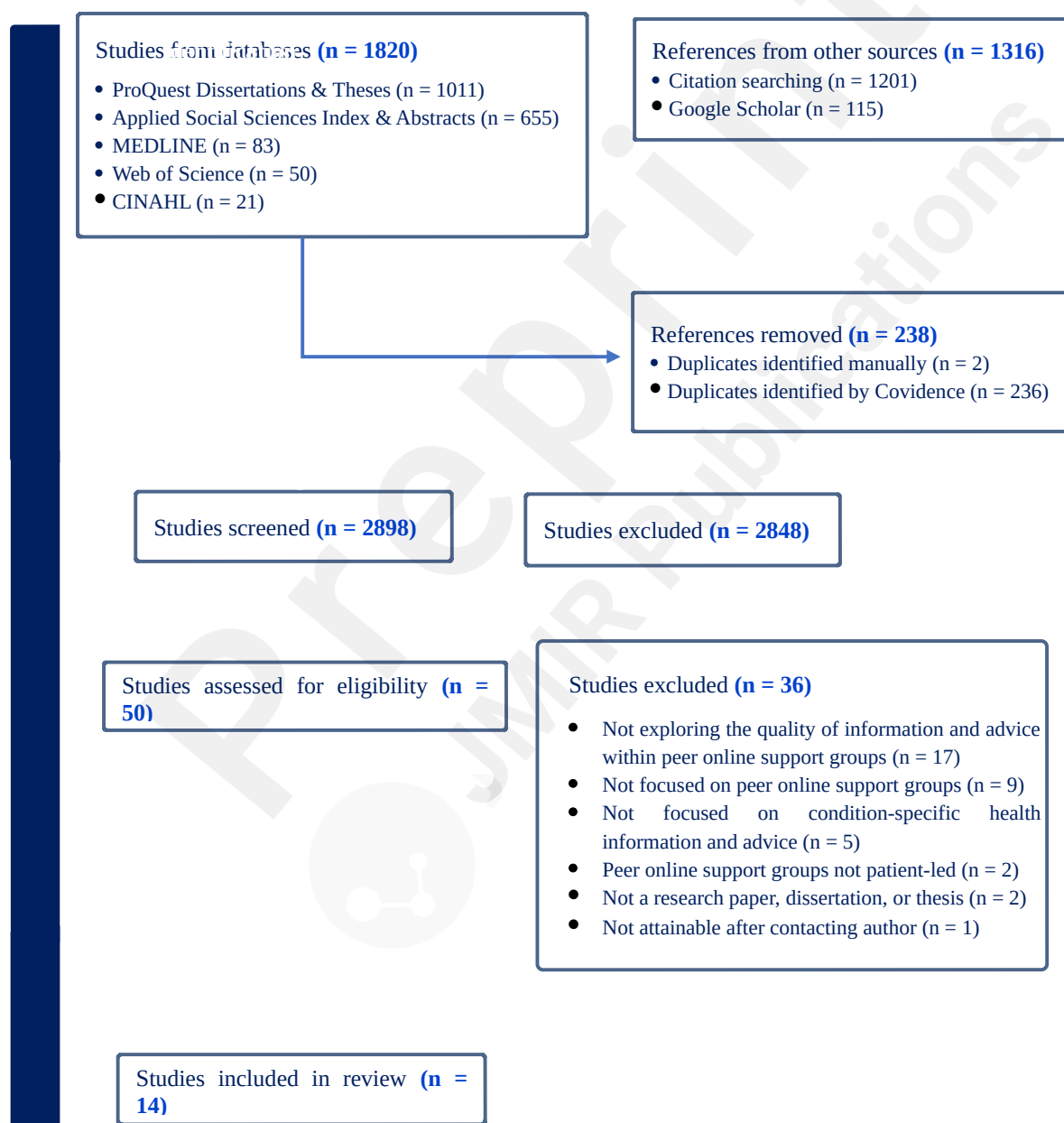


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram detailing the inclusion process for this scoping review on the quality of information and advice about health conditions in peer online support groups. As has been pointed out since 2017, our review primarily research papers which reported a quality appraisal of information and advice about health conditions

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in peer online support groups, and 4 were review papers. Six papers were published in the United States of America, 4 papers were published in the United Kingdom, and the remaining 4 papers were published in Ghana, Norway, Spain, and Korea. The included papers focused on a variety of health conditions, which sometimes fell into more than one category, including long-term conditions ($n = 14$), acute conditions ($n = 7$), physical health conditions ($n = 13$), mental health conditions ($n = 3$), and viruses ($n = 6$). Several online platforms were explored, including Facebook ($n = 8$), Twitter ($n = 7$) and Reddit ($n = 6$). Table 3 provides further details about the included papers.

Author(s) (ref)	Year	Countr y	Aim(s)	Research methodology	design	Online platforms explored	Condition(s) in focus
Slick, Bodas & Badawy et al. (44)	2023	USA	To assess the use of social media for medical information relevant to sickle cell disease, and the accuracy of information provided for and by individuals with sickle cell disease	Extraction of discussion threads from Facebook groups and quality assessment		Facebook	Sickle cell disease
Afful-Dadzie, Afful-Dadzie & Egala (45)	2023	Ghana	1. To review research that focuses on health topics, users, and social media platforms that are raising health information quality concerns 2. To review the suitability of existing criteria and instruments used in evaluating quality of social media health information	Literature review and content analysis		Twitter, Facebook, Instagram, WeChat	Cancer, dental/oral care, diabetes, heart condition/disease, sexual health, anorexia, alcohol, spinal disorder, eye, inflammatory bowel disease
Ulep, Deshpande & Beukes et al. (46)	2022	USA	To synthesize existing research studies related to social media use concerning hearing loss, tinnitus, and vestibular disorders	Systematic review and descriptive analysis		Twitter, Facebook, Instagram, Reddit, others unnamed	Hearing loss, tinnitus, and vestibular disorders
Skafle, Nordahl-Hansen & Quintana et al. (47)	2022	Norwa y	1. To synthesize the existing research on misinformation about COVID-19 vaccines spread on social media platforms and its effects 2. To gain insight and gather knowledge about whether misinformation about autism and COVID-19 vaccines is being spread on social media platforms	Rapid review and thematic analysis with narrative qualitative synthesis		Several social media platforms: whatsapp, facebook, Instagram, twitter and more	Coronavirus
Pollack, Emond & O'Malley et al. (48)	2022	USA	To quantify the presence of 4 types of obesity-related content on Reddit (misinformation, facts, stigma, and positivity) and identify psycholinguistic features that may be enriched within each one	Extraction of discussion threads from Reddit and using artificial intelligence (machine learning) to evaluate misinformation		Reddit	Obesity

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Author(s) (ref)	Year	Countr y	Aim(s)	Research methodology	design	Online platforms explored	Condition(s) in focus
Farnood, Johnston & Mair (49)	2021	UK	To understand the types of information people discuss when engaging with online health forums for heart failure and explore the quality of diagnostic advice provided	Extraction of discussion threads from online health forums and quality assessment		Public domain internet discussion forums (names not reported)	Heart failure
Towne, Suliman & Russell et al. (50)	2021	USA	To analyse the nature and accuracy of social media content related to endometriosis	Extraction of discussion threads from Facebook groups and content analysis		Facebook	Endometriosis
Suarez-Lledo & Alvarez- Galvez (51)	2021	Spain	To identify and compare the prevalence of health misinformation topics on social media platforms, with specific attention paid to the methodological quality of the studies and the diverse analytical techniques that are being implemented to address this public health concern	Systematic review (analysis method not reported)		Several social media platforms: twitter, Facebook, myspace, WhatsApp, VK	Noncommunicable diseases, pandemics, eating disorders
ElSherief, Sumner & Jones et al. (52)	2021	USA	To present machine learning and natural language analysis approaches to identify the characteristics and prevalence of web-based misinformation related to medication for opioid use disorder, to inform future prevention, treatment, and response efforts.	Extraction of discussion threads from social media sites and online discussion forums and using artificial intelligence (natural language analysis approaches) to identify misinformation		Twitter, Reddit, Drugs-Forum	Opioid use disorder
Du, Preston & Sun et al. (53)	2021	USA	To develop and evaluate an intelligent automated protocol for identifying and classifying human papillomavirus vaccine misinformation on social media using machine learning-based methods	Extraction of discussion threads from Reddit and using artificial intelligence (machine learning) to evaluate misinformation		Reddit	Human Papillomavirus Virus

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Author(s) (ref)	Year	Countr y	Aim(s)	Research methodology	design	Online platforms explored	Condition(s) in focus
Jo, Lee & Park et al. (54)	2020	Korea	To investigate the trends of online health communication, analyse the focus of people’s anxiety in the early stages of COVID-19, and evaluate the appropriateness of online information	Extraction of Q&As from an online discussion forum and using artificial intelligence (structural topic model) to evaluate content		The Naver Q&A forum	Coronavirus
Sepehripour, McDermott & Lloyd (55)	2017	UK	1.To quantify the quality of information for patients with microtia on social media compared with other websites 2.To compare physician and patient perspectives on the quality of patient information	Scoring of social media sites regarding quality		Facebook, Twitter	Microtia
Cole, Watkins & Kleine (56)	2016	UK	To provide an assessment of the quality and quality characteristics of information found in online discussion forums so that doctors, patients, and health care policymakers can better understand the online discussion forum environment and the information found there	Extraction of discussion threads from online discussion forum websites and quality assessment		Reddit, Mumsnet, Patient	Human immunodeficiency virus, diabetes, chickenpox
McGregor, Somner & Bourne et al. (57)	2014	UK	To assess the content and accuracy of material that patients with glaucoma can access on online social media platforms	Extraction of discussion threads from social media platforms and analysed using a combination of content analysis and simple thematic analysis		The International Glaucoma Association (IGA) forum, Facebook, Twitter, and Patient-Opinion.org.uk.	Glaucoma

Table3. Characteristics of the 14 included papers of this scoping review exploring the quality of information and advice about health conditions in peer online support groups.

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Narrative summary of findings

Research Question 1: What is known about the quality of information and advice exchanged within peer online support groups about health conditions?

The included papers explored a variety of long-term and acute, physical and mental health conditions (supplementary file 2). The quality of information and advice in peer online support groups varied according to the condition in focus and across online platforms. There were more reports of misinformation about health conditions in peer online support groups than of good quality misinformation, or mixed quality.

Good quality information and misinformation about long-term conditions

Ten included papers (56, 44-46, 48-51, 55, 57) explored the quality of information and advice about long-term physical health conditions in peer online support groups. Studies reported that the content about long-term life-threatening conditions such as cancer and diabetes raised the most substantial concerns regarding the quality of information, highlighting fake, misleading, and/or inaccurate information (45,51). With regards to cancer, information about treatments and surgical procedures were particularly described as poor quality (45). Conversely, one paper found that information about diabetes in peer online support groups was of reasonable quality and rarely contained inaccurate information (56). In the case of heart failure, most of the information exchanged in peer online support groups has been described as of low quality and not aligned with evidence-based guidelines, with some described as potentially harmful (49). Examples of harmful information and advice included when users confirmed diagnoses to other users, which were incorrect and were not supported by existing evidence or guidelines (49). Similarly, in the case of sickle cell disease most of the information and advice was rated as medically inaccurate, such as in relation to hydroxyurea medication, managing pain, and the use of natural supplements (44). Non-life-threatening conditions, such as endometriosis (50), microtia (55) and glaucoma (57) were found to include little misinformation in comparison to the life-threatening conditions. Some cases of misinformation were reported in glaucoma-focussed peer online support groups, which ranged from discussions about non-evidence-based treatments such as carnosine eye drops and complementary therapies, to more dangerous advice around the use of medical marijuana (57). In the case of ear-related disorders, a greater amount of misinformation about tinnitus was reported than about hyperacusis, though the specific types of information exchanged were not reported (46).

Good quality information and misinformation about viruses

There were mixed findings about viruses reported in six papers (56, 47, 49, 51, 53-54). In the case of coronavirus, information and advice about physical symptoms of coronavirus has been assessed as appropriate (54) whereas information about the coronavirus vaccine has been reported as misinformed (47, 51), with misinformation about side effects such as infertility, chronic illness, changes in DNA, physical deformities, mental illness, and conspiracy theories (47). Information and advice about human papillomavirus virus has been reported as being of mixed quality (51, 53). Examples of misinformation included the safety of the human papillomavirus virus vaccine, vaccine adverse effects, conspiracy theories about the government and pharmaceutical companies, and the prevalence of human papillomavirus virus (53). With regards to chicken pox, some non-evidence-based discussions around vaccination and herbal remedies have been reported, but little evidence of poor quality or inaccurate information and advice (56). Information and advice about human immunodeficiency virus has been similarly reported as of reasonably high quality with only a very small proportion considered to be factually incorrect or harmful (56).

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Varying degrees of misinformation about mental health conditions

Three papers (45, 51-52) reported on the quality of information and advice in peer online support groups relating to mental health conditions. One study on opioid use reported little misinformation despite anticipating the reproduction of a commonly held misunderstanding that medication-assisted treatment is simply replacing one drug with another (52). Another study found a moderate amount of misinformation related to eating disorders, such as around normalising eating disorders, changing eating habits, and using beauty as the final goal (51). Content related to eating disorders is frequently hidden or not evident to the public, as pro-eating disorder communities tend to use their own codes to reach specific audiences, thus the prevalence of misinformation related to eating disorders in peer online support groups may be even greater than what is clearly visible (51).

The quality of information and advice varies according to online platforms

Across the included papers, 18 different online platforms were represented (supplementary file 3). The most common online platform explored was Facebook. One review reported that more studies to date (2023) have explored Facebook than other online platforms, while other online platforms such as WhatsApp, Instagram, WeChat and country-specific online platforms are becoming more popular for seeking information and advice about health conditions (45). Misinformation about noncommunicable diseases and treatments has been reported as particularly prevalent on Facebook (51). Misinformation about vaccines and drugs have been reported as most prevalent on X (formerly Twitter) (51-52). On Reddit, misinformation about the human papillomavirus virus vaccine has been reported to cluster in 'subreddits' (53), which are smaller communities that are themed around a given topic (48), though the degree of misinformation on Reddit has been reported to have decrease over time, possibly due to public health campaigns and an increase in internet verification skills among users (53). In comparison to information and advice about health conditions in peer online support group, the quality of the online platform itself was scarcely explored across the included papers.

Research question 1a: To what extent is misinformation about health conditions a problem within peer online support groups?

Health-related misinformation was a central focus across many of the included papers. Some included papers solely focused on misinformation and negated exploring good quality information. Attempts in addressing the spreading of misinformation in peer online support groups were also reported.

Health-related misinformation receives greater attention in the literature than the overall quality of information

Misinformation was reported to varying degrees in all 14 papers, though misinformation received more attention than the general quality of information. Five papers (47-48, 51-53) specifically focused on variants of misinformation circulating in peer online support groups about various health conditions and did not consider the quality of information more broadly. As detailed above, misinformation in peer online support groups has been identified about long-term life-threatening conditions (44-45, 49, 51), viruses (47, 51, 53-54) and mental health conditions (51-52). Researchers have emphasised that in the event of a novel infectious disease outbreak where there is great uncertainty among the public, obtaining accurate information can be extremely difficult (54).

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Health-related misinformation can be negated through the activities of users

The degree of the problem of misinformation in peer online support groups can be reduced when fellow users address or correct false claims. Users have been observed to have corrected misinformation provided by other users, through replying to false claims or through providing correct information in subsequent posts (45, 53, 56). Some users have also been observed in signposting fellow users to additional resources that are reliable and helpful, in response to misinformation (49). Some peer online support groups such as Reddit operate a voting system on each discussion thread, whereby posts that contain good quality information and advice can be upvoted to the top of the discussion thread and lower quality posts can be demoted (24). The need for healthcare professionals to take an active role in correction misinformation in peer online support groups has been widely emphasised, a role which would involve dispelling false medical information that has the potential for spreading further online (45, 47, 51-52,). Organised online public health campaigns, composed of factual, evidence-based messages have also been promoted to combat misinformation (51-53).

Research question 1b: How have researchers assessed the quality of information and advice exchanged in peer online support groups about health conditions?

There were various processes for appraising the medical accuracy of content, in terms of the types of professionals conducting the quality appraisal, the use of a quality appraisal tool to record the appraisal and considering which quality indicators might be used when appraising content.

Involvement of healthcare professionals in quality appraising information and advice

Nine papers (44, 48-50, 54-57) reported involving academic or healthcare professionals in the quality appraisal. In some cases, discussions in peer online support groups were appraised by researchers or clinical academics researching the conditions in focus (48-50, 53), also by secondary care healthcare professionals who were specialists or consultants in the conditions (44, 55-57), general practitioners (54, 56), and patients and carers with lived experiences of managing the conditions in focus (56).

Comparison of information and advice with medical guidelines

Evidence-based guidelines relevant to the condition were often used in determining the quality of information and advice exchanged (44, 48-50). Guidelines mentioned included the Scottish Intercollegiate Guidelines Network (SIGN), National Institute for Health and Care Excellence (NICE), American Board of Obesity, and National Institute of Health National Heart, Lung, and Blood Institute (NIH-NHLBI). Current evidence in peer-reviewed scientific journals (50) and information provided on trusted charity websites dedicated to the condition in focus (49) were also used as a guide for quality appraising content.

Use of quality appraisal tools for recording the assessment

Five papers reported using specific quality appraisal tools (47, 54-57). The DISCERN instrument (61), the Health on the Net Code of Conduct (HONcode) (62-63) and the Journal of the American Medical Association (JAMA) benchmark (64) (Table 3) have been used in information quality evaluation across multiple social media and peer online support group platforms (45). None of these tools were specifically designed to appraise peer online support group content, though were still reported as being used for this purpose by healthcare professionals and patient users investigating the quality of such content. The DISCERN instrument which contains 16 items, focuses on rating the quality of health information

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written by consumers, about treatment choices (58), not necessarily online-based information or specifically for the assessment of information and advice in peer online support groups. The HONcode criteria contains 8 principles which are used as a guide in assessing the reliability and usefulness of medical information on health-related websites (59-60). The HONcode criteria has also been used to appraise content in peer online support groups (45-46), despite being devised for traditional health information websites. Similarly, the JAMA benchmark (61) contains 4 core standards which have been used (45) as a guide in assessing health information on websites. One paper reported developing their own tool specifically for the purpose of their research study instead of using an official quality appraisal tool (56). Some quality appraisal studies have reported combining two or more of the above quality appraisal tools to assess information and advice in peer online support groups (45), however the rationale behind this was not explained.

Quality appraisal tool	Aim of tool	Criteria/items
DISCERN (58)	To help users of consumer health information judge the quality of written information about treatment choices .	1. Are the aims clear? 2. Does it achieve its aims? 3. Is it relevant? 4. Is it clear what sources of information were used to compile the publication? 5. Is it clear when the information used or reported in the publication was produced? 6. Is it balanced and unbiased? 7. Does it provide details of additional sources of support and information? 8. Does it refer to areas of uncertainty? 9. Does it describe how each treatment works? 10. Does it describe the benefits of each treatment? 11. Does it describe the risks of each treatment? 12. Does it describe what would happen if no treatment is used? 13. Does it describe how the treatment choices affect overall quality of life? 14. Is it clear that there may be more than one possible treatment choice? 15. Does it provide support for shared decision-making? 16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices.
HONcode (59-60)	To assess reliability and usefulness of medical information on the Internet.	1. Authority 2. Complementarity 3. Confidentiality 4. Attribution 5. Justifiability 6. Transparency of authorship 7. Transparency of sponsorship 8. Honesty in advertising and editorial policy
JAMA benchmark	To evaluate the reliability and	1. Authorship 2. Attribution

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(61)	accuracy of medical websites.	3. Disclosure 4. Currency
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Table 2. Summary of the DISCERN, HONcode, and JAMA benchmark quality appraisal tools.

Quality mark indicators for appraising information and advice in peer online support groups

There are specific quality mark indicators that are important and exclusive to the assessment of information and advice about health conditions in peer online support groups (44-45, 48-49, 51, 54-56). The source of the information and advice, (45, 51), currency (45, 55), relevance (45, 54-55), accuracy (44, 51, 55-56), sensibility and coherence (55-56), and the usefulness of content (51, 56), were all reported as key quality indicators in appraising information and advice. Many of these quality indicators mirror criteria comprising the quality appraisal tools outlined above. The use of categories such as high-quality evidence down to low quality information (49), and 'fact vs misinformation' (48) have also been used in appraising content. Online platform-specific metrics such as 'number of posts and reposts', 'number of followers', 'likes' and 'author profile' have also been used in assessing the quality of content (45).

Use of artificial intelligence

Four studies (48, 52-54,) used artificial intelligence to identify and extract relevant information when assessing the quality of health information and advice. Forms of machine learning including natural language processing (52) and topic modelling (53), which is a field of study in artificial intelligence that attempts to extract general concepts from large datasets in the form of an algorithm (62), have been used in identifying specific concepts of misinformation around certain health conditions in peer online support groups (48, 52-54, 48).

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Discussion

Summary of evidence in context of wider literature

The objective of this scoping review was to gain insight into the quality of information and advice in peer online support groups about a range of health conditions, and to review the available tools used to quality assess such information and advice. This scoping review has identified that the quality of information and advice in peer online support groups varies according to the condition and to the degree of healthcare expert moderation present. While there was some evidence of good quality information and advice being exchanged (50, 54-56 50), there was more evidence of misinformation and of low-quality information and advice, particularly around long-term and life-threatening conditions (44-45, 49, 51) which is also consistent with wider literature (63-64). There were varying degrees of misinformation about non-life-threatening conditions (48, 50, 55, 57), viruses (56, 47, 51, 53-54), and about mental health conditions (51-52). In the event of a public health concern where there is uncertainty about the disease, obtaining accurate information can be extremely difficult (54).

Amongst platforms hosting online health-related peer support groups, Facebook presents the most misinformation about noncommunicable diseases and treatments, which may be due there being more space in posts to describe experiences with disease symptoms and treatments (51). X, on the other hand, appears to exhibit more misinformation about vaccines and drugs (51-52), which may be because the natural dynamism of the platform facilitates an ideal medium for discussions around different political or ideological perspectives (51). In addition, the use of algorithms by online platforms such as Facebook and X which place content on users' feeds that match their online search-related behaviours and engagement with other posts, may also mean that those whose beliefs align with misinformation are more likely to re-transmit such content (23). Effortless architecture constructed by online platforms such as the one-touch forward option on WhatsApp that enables users to forward messages simultaneously to multiple users, may also explain the prevalence of misinformation online (65).

Platforms such as Facebook and X do not typically monitor misinformation, which may be detrimental for the continued spread of misinformation about various health conditions on such platforms. However, in the event of a public health concern such as during the Covid-19 pandemic, platforms including Facebook, X, Reddit, Instagram and WhatsApp introduced measures to mitigate misinformation such as placing warning labels on content about the pandemic, removing content and banning accounts (66). This suggests that such interventions are possible, though are not rolled out routinely and thus may not be prioritised by platforms. The extent of the problem of misinformation in peer online support groups can alternatively be reduced by attempts from fellow peer online support group users in addressing and correcting misinformation (45, 53, 56). Current moderation solutions for misinformation rely heavily on reporting mechanisms and human-led moderation, though post-by-post moderation based on individual users has been described as unsustainable (21). Organised public health campaigns composed of factual, evidence-based messages distributed in the online world could also tackle the problem of misinformation (51-53). Digital literacy focused interventions that aim to teach people strategies to recognise misinformation have demonstrated effective outcomes, as well as interventions where platforms make content classed as misinformation less visible and de-incentivise the creation and sharing of such content (21).

Studies have typically involved researchers, clinical academics, and specialist clinicians who hold expertise in the specific conditions, to conduct quality appraisals of information and advice in peer online support groups (48-50, 54-57). This has been undertaken through comparing information and advice with evidence-based guidelines (44, 48-50), scientific

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journal papers (50) and information provided on trusted third sector websites (49). Quality appraisal instruments including the DISCERN instrument (58), the HONcode criteria (59-60) and the JAMA benchmark (61) have been used as a recording tool for appraising the quality of information and advice exchanged around a variety of conditions and disciplines (45), despite not being designed specifically for the online social world. Whilst criteria forming such tools were not instinctively developed for peer online support group content, the DISCERN instrument in particular, has been described as being suitable to evaluate any text-based health-related information (pertaining to treatment) (17). Today, the DISCERN instrument remains in use with over 150 published studies having reported use of the tool in evaluating health information (17) and is recognised as a reliable tool used by both healthcare professionals and patient users (67). In this review, specific quality indicators for appraising information and advice have been outlined, of which many mirror criteria forming the quality appraisal instruments discussed in this review, such as relevance (45, 54-55), sources of evidence (45, 51), currency (45, 55), accuracy (44, 51, 55-56), coherence (55-56), and the usefulness of content (51, 56). Research undertaken since conducting this review also highlights accuracy, credibility, and reliability as key quality indicators for appraising information and advice in peer online support groups (67). This suggests that the DISCERN instrument (58), the HONcode criteria (59-60) and the JAMA benchmark (61) could be appropriate quality appraisal tools for academics and healthcare professionals to use as a guide for appraising the quality of information and advice in peer online support groups. On occasions, these tools have been combined to assess information and advice in peer online support groups, thus there may also be a need for novel instruments that focus solely on online support group content which would take into consideration the nature and architecture of such content (45). Others academics have argued that because these tools were created to be applied across different health-related domains and are therefore called 'general instruments', they may be more appropriate to evaluate factors associated with the formality of content and/or the design of websites, rather than to evaluate the substance of content (e.g., its accuracy and completeness) which domain-specific instruments created by researchers for individual research based on medical guidelines, literature and expertise (68).

Strengths and limitations of the review

This is the first comprehensive scoping review considering the findings of a diverse and heterogeneous pool of literature and exploring the quality of information and advice in peer online support groups about various health conditions. This scoping review was conducted in accordance with JBI methodology (36-38). In doing so, this scoping review has successfully identified and mapped current key concepts around the quality of information and advice about various health conditions in peer online support groups, taking a broad, inclusive approach to evidence and in accommodating literature comprising of a range of diverse questions and study designs.

There are also some limitations that should be considered. Firstly, although six databases were searched, it is possible that some relevant studies were not identified. Secondly, though the search strategy was developed with the support of a specialist librarian, there are additional search terms that could have been used such as 'chat rooms' and 'computer-mediated support' (69) which were excluded from the search strategy as they yielded a considerable amount of irrelevant literature. Not including these terms may have meant that some relevant literature may have been missed. However, to alleviate these potential limitations, Google Scholar was also searched, as well as the reference lists of all the included studies. This yielded additional studies that were included in our review. Third, papers focusing only on information and advice about health conditions on video-based social media sites were excluded from this review as this paper focused on rich written information and advice generated in online communities dedicated to peer-to-peer support, rather than including comments on videos. Therefore, it is possible that some additional data was missed

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from comments sections on videos. Future research could compare the quality of health-related information and advice provided on video-based online platforms to traditional peer online support groups. Finally, the second part of the objective of this review was to review the available tools used to quality assess information and advice in peer online support groups. While this scoping review identified and mapped the available information about such tools, the papers themselves did not provide a substantive amount of information about quality appraisal tools which limited the extent to which it was possible to review them based the included papers in this review. Wider literature has been drawn on in the discussion of this paper.

Recommendations for clinical practice and future research

Where patients seek information and advice in the online world is a matter that requires more attention and improved conversations in consultations, between healthcare professionals and patients (44, 50-51). Healthcare professionals need to meticulously attend to supporting people with lower levels of health literacy (29, 31) and older people who may be particularly vulnerable to experiencing confusion and anxiety generated by coming across misinformation (70-71). To do this, healthcare professionals need to be better informed about what peer online support groups are, how they operate, and the benefits and harms that they can offer patients. There is a need for healthcare professionals to be more aware of content discussed in peer online support groups (48, 52-55, 58), and further, to take an active role in correcting misinformation (44-45, 47-48, 51). This activity is a current gap in provision and could be recommended for future career opportunities for healthcare professionals who may be seeking alternative roles to traditional clinical work, in meeting the health information and support needs of the public. In addition, there may be an opportunity for healthcare professionals in training to complete a quality appraisal task of online health information, and possibly to provide advice (within their field of competency) in peer online support groups. While some degree of moderation of information and advice in peer online support groups has been shown to be helpful in correcting misinformation, the extent to which healthcare professionals could or should be involved in moderating content as part of their duty of care, was not explored in the included papers in this review. Future research is needed to determine the acceptability of, and potential methods for, healthcare professionals moderating and contributing content in peer online support groups, from the perspectives of healthcare professionals and patient users of peer online support groups. Which type of healthcare professionals, whether they be general practitioners, nurses, secondary care clinicians or other, also needs to be further explored. Future research could also explore the resources used in terms of time, training and financing around asking healthcare professionals to quality appraise information and advice in peer online support groups, to better understand how feasible incorporating such a task would be alongside traditional clinical duties. Future research is needed to further assess the acceptability and usability of common quality appraisal tools used in appraising information and advice in peer online support groups such as DISCERN instrument (58), the HONcode criteria (59-60) and the JAMA benchmark (61), for healthcare professionals to use as a guide in such practice. A novel instrument tailored specifically to appraising health-related information in peer online support group, incorporating items focusing on reliability, credibility, accuracy, currency, coherence and usefulness forming the basis of the tool.

Conclusions

There is increasing concern regarding the quality of information and advice about health conditions exchanged in peer online support groups. While there is good quality information and advice exchanged between users, misinformation is also a problem, with some information and advice about common long-term and life-threatening conditions, viruses and mental health conditions being ill-advised. The extent of the problem of misinformation can

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be reduced with fellow users in peer online support groups addressing and correcting misinformation, and through public health campaigns organised in the online world. Healthcare professionals and patients need to discuss use of peer online support groups more regularly in consultations. Further, there is a need for healthcare professionals to play a more active role in quality assuring health-related information and advice in peer online support groups. This could be facilitated by using established quality appraisal tools such as the DISCERN instrument, the HONcode criteria and the JAMA benchmark as a guide in appraising content. Future research is needed, focusing on approaches to educating healthcare professionals around the benefits and harms that peer online support groups can offer patients, along with investigating the acceptability of, and potential methods for, healthcare professionals moderating and contributing content in peer online support groups.

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Conflicts of interest

None declared.

Contributions

BT and EP developed the search strategy, with assistance from a university research librarian. BT and EP screened all titles, abstracts and full-texts. BT also hand searched the reference lists of included review papers, and citations of all included papers for additional relevant literature. BT, NC, JC, JL, EP developed a data extraction tool for the included literature. BT extracted data from the included literature and sent to EP for consensus. BT coded data from the included literature, which was discussed with EP and NC. BT, NC, JC, JL, EP developed final summaries of each research question. BT wrote up this review paper, which was contributed to by NC, JC, JL, EP.

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Supplementary Files

Multimedia Appendixes

Final search strategy for all included databases and sources to obtain literature exploring the quality of information and advice about health conditions in peer online support groups.

URL: <http://asset.jmir.pub/assets/2ef4c8d96010b4462a31a5dca925b4f2.docx>

Health conditions explored and reported quality of information and advice across the 14 included papers, exploring the quality of information and advice in peer online support groups.

URL: <http://asset.jmir.pub/assets/c8f5926c4f7a91d5e5ddc69b724240b9.docx>

Online platforms explored across the 14 included papers exploring the quality of information and advice about health conditions in peer online support groups.

URL: <http://asset.jmir.pub/assets/4cbcc9800bd77e757ebc71126409c96d.docx>

CONSORT (or other) checklists

Completed Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

URL: <http://asset.jmir.pub/assets/2fef5ba3d0660270f26a5f2b9a1e8418.pdf>