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Social media to improve health outcomes: a scoping review

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Abstract

Objective: To map the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Design: Scoping review.

Data sources: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest (2000-2012).

Study selection: Studies reporting primary research on the use of social media (collaborative projects, blogs/microblogs, content communities, social networking sites, virtual worlds) by patients or caregivers.

Data extraction: Two reviewers screened studies for eligibility; one reviewer extracted data from relevant studies and a second performed verification for accuracy and completeness on a 10% sample. Data were analyzed to describe which social media tools are being used, by whom, for what purpose, and how they are being evaluated.

Results: Two hundred eighty four studies were included. Discussion forums were highly prevalent and constitute 66.6% of the sample. Social networking sites (14.8%) and blogs/microblogs (14.1%) were the next most commonly used tools. The intended purpose of the tool was to facilitate self-care in 77.1% of studies. While there were clusters of studies that focused on similar conditions (e.g., lifestyle/weight loss (12.7%), cancer (11.3%)), there were no patterns in the objectives or tools used. A large proportion of the studies were descriptive (42.3%), however there were also 48 (16.9%) randomized controlled trials (RCTs). Among the RCTs, 35.4% reported statistically significant results favouring the social media intervention

being evaluated; however 72.9% presented positive conclusions regarding the use of social media.

Conclusions: There is an extensive body of literature examining the use of social media in patient and caregiver populations. Much of this work is descriptive; however with such widespread use, evaluations of effectiveness are needed. In studies that have examined effectiveness, the positive conclusions are not necessarily reflective of the findings.

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Article summary

Article focus

- The use of social media in health care has been widely advocated, but there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations.
- We mapped the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Key messages

- There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations.
- Most studies have been descriptive; however with such widespread use, evaluations of effectiveness are needed.
- In studies that have examined effectiveness, the positive conclusions are not necessarily reflective of the actual findings.

Strengths and limitations of this study

- Our search was comprehensive and we included an extensive body of literature, across conditions, populations, and study designs.
- Social media is constantly evolving, leading to challenges in keeping the search updated.

Introduction

The use of social media in health care has been widely advocated;[1-8] however, there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations. It is clear, though, that patients are increasingly active online.[9] As of 2010, the average Internet user spent nearly six hours per day on social media;[10] 61% of patients sought support and medical information online;[11] and looking for health care information became the third most common online activity.[12] As social media continues to evolve, its momentum shows no sign of diminishing, instead finding new niches with unique applications.

Social media can be defined as a group of online applications that allow for the creation and exchange of user-generated content, and can be categorized into five groups: 1) collaborative projects (e.g., Wikipedia); 2) blogs or microblogs (e.g., Blogger, Twitter); 3) content communities (e.g., YouTube); 4) social networking sites (e.g., Facebook); and 5) virtual gaming or social worlds (e.g., Second Life).[13] Table 1 provides an overview of the categories of social media tools.

Advocates of the use of social media in health care suggest that these tools allow for personalization, presentation, and participation – three key elements that make them highly effective.[14] The content can be tailored to the priorities of the users, the versatility of the different platforms creates numerous options for the presentation of information, and the collaborative nature of social media allows for a meaningful contribution from all user groups. The idea of a synergistic relationship between social media users is one of the main perceived advantages of using these platforms.[15] However, criticisms of the use of social media in health care have also arisen. The availability of misinformation is a risk, as health care providers are unable to control the content that is posted or discussed.[1,16] Inappropriate substitution of online information or advice for in-person visits to a health care provider can also potentially lead to harmful results, and this has been cited as a limitation of the use of social media and of the Internet generally.[1.17]

The objectives of this study were to map the existing literature examining the use of social media in patient and caregiver populations, to determine the extent and type of evidence available to inform more focused knowledge syntheses, and to identify gaps for future research. The specific questions guiding this scoping review were: 1) What social media tools are being used to improve health outcomes in patient populations? 2) For what purposes are social media tools being used in patient populations (e.g., to improve health literacy, to improve self-care)? 3) For what patient populations and disease conditions are social media tools being used? 4) What types of evidence and research designs (i.e., qualitative, quantitative) have been used to examine social media tools?

Methods

This scoping review on the use of social media in patient and caregiver populations was conducted in parallel with a review on the use of social media in health care professional and trainee populations;[18] therefore the literature search and screening for study eligibility were conducted concurrently. The review followed a protocol that we developed *a priori*.

Search strategy

A research librarian searched 11 databases: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest. Dates were restricted to 2000 or later, corresponding to the advent of Web 2.0. No language or study design restrictions were applied. The search strategy for Medline is provided in the Appendix.

Study selection

Two reviewers independently screened titles and abstracts of studies for eligibility. The full text of studies assessed as "relevant" or "unclear" was then independently evaluated by two reviewers using a standard form. Discrepancies were resolved by consensus or adjudication by a third party.

Studies were included if they reported primary research (quantitative or qualitative), focused on health care issues related to patients or caregivers, and examined the use of a social media tool. Social media was defined according to Kaplan and Haenlein's classification scheme,[13] including: collaborative projects, blogs or microblogs, content communities, social networking sites, and virtual worlds. We excluded studies that examined mobile health (e.g., non-social media apps), one-way transmission of content (e.g., podcasts), and real-time exchanges mediated by technology (e.g., Skype, chat rooms). Electronic discussion forums and bulletin boards were included as they incorporate user-generated content and were judged to fall within the spectrum of social media. Outcomes were not defined *a priori* as they were to be incorporated into our description of the field. Likely categories for objectives and outcomes were adapted from those outlined in Coulter and Ellins' proposed framework for strategies to inform, educate, and involve patients.[19,20]

Data extraction

Data were extracted using standardized forms and entered into Microsoft Excel (Microsoft, Redmond, WA) by one reviewer and a 10% sample was checked for accuracy and completeness by another.[21] Reviewers resolved discrepancies through consensus. Extracted data included study and population characteristics, description of the social media tools used, objective of the tools, outcomes measured, and authors' conclusions.[22] Additional data were collected for randomized controlled trials (RCTs), including the primary outcome and its statistical significance.

Data synthesis

Data were synthesized descriptively in order to map different aspects of the literature as outlined in our key questions. Studies were grouped according to tool, audience, and study design, with data from RCTs examined in more detail. As discussion forums were not included in our original classification scheme, findings are presented both for all included studies and for studies that investigated tools other than discussion forums. Descriptive statistics were calculated using StataIC 11 (StataCorp, College Station, TX).

Results

Two hundred eighty four studies were included in the review. Figure 1 outlines the flow of studies through the inclusion process and Table 2 provides a description of included studies. Most studies (179/284; 63.0%) were conducted in North America, with more than half of the total sample (154/284; 54.2%) carried out in the United States and 8.8% (25/284) conducted in Canada. The median start date was in 2006 (range 1997 – 2011); when studies evaluating discussion forums were excluded, the start date was more recent (median 2008, range 2000 – 2011). Studies tended to be fairly short, with a median duration of 5 months (range 1 – 117 months). Nearly all included studies were published as journal articles (255/284; 89.8%); however, when studies of discussion forums were excluded, the proportion of dissertations written on the use of social media increased (14/284 to 12/95; 4.9% to 12.6%).

Social media tools used

The social media tools studied are outlined in Table 3. The use of discussion boards and online support groups (combined as discussion forums due to their common structure and intent) dominated the literature, encompassing 189 (66.6%) included studies. Social networking sites (42/284; 14.8%) and blogs or microblogs (40/284; 14.1%) were also commonly evaluated, followed by content communities (16/284; 5.6%), collaborative projects (6/284; 2.1%), and virtual worlds (6/284; 2.1%). In 116 (40.9%) included studies, the social media tool was included as part of a complex intervention. Where existing and publicly available social media applications were studied, Facebook (16/284; 5.6%), YouTube (12/284; 4.2%), and Twitter (10/284; 3.5%) were evaluated most frequently (Figure 2).

Purposes of social media use

The most common intended use of social media was for self-care, which was described as an objective of the tool in 219 (77.1%) studies (Table 3). This was particularly relevant to discussion forums, in which 166/189 (87.8%) studies were related to self-care. Other tools were often established with similar functions to discussion forums: they provided a platform on which users could post and share their experiences with peers. Collaborative projects were often used to address health literacy, and social networking sites were commonly used for patient safety purposes, largely for documentation of adverse events. While there were few studies that addressed clinical decision-making, these were almost exclusively conducted using discussion forums.

We categorized the outcomes measured in each of the studies under patients' knowledge, patients' experience, use of services and costs, health behaviour and status, and other (Table 4). Measures of patients' experience, specifically peer-to-peer communication (135/284; 47.5%), were most common and were often outcomes related to social support among members of an online community. Measures of psychological well-being (e.g., reports of anxiety levels) and changes in self-care activities (e.g., increases in physical activity) in relation to use of the tool were also commonly evaluated (78/284 and 63/284; or 27.5% and 22.2%, respectively).

Social media user groups

A wide range of conditions were covered in the included studies (Figure 3). The largest proportion fell under the lifestyle and weight loss category (36/284; 12.7%), followed by cancer (32/284; 11.3%), and studies in the general population (22/284; 7.8%). The general population studies tended to be surveys focused on usage, demographics, and user preferences relevant to social media use for health-related purposes. No strong trends emerged showing differences between user groups in the objective of the type of social media tool or the specific application used (data not shown). In nearly all conditions investigated, the social media tool studied was intended to facilitate self-care. One exception was seen in the case of infectious disease, where 7/12 (58.3%) relevant studies were focused on health literacy. This was mainly driven by large-scale strategies to provide updates on influenza or H1N1. For specific applications used, there were clusters of studies that examined condition-specific modalities. Social networking sites were common in studies of diabetes and metabolic syndrome due to the use of TuDiabetes, an online community targeted to those affected by diabetes. Similarly, Twitter was commonly used in the context of H1N1/influenza, and PatientsLikeMe was used for a group of chronic conditions including amyotrophic lateral sclerosis, fibromyalgia, human immunodeficiency virus, mood disorders, multiple sclerosis, and Parkinson's disease. Aside from these small clusters, most studies across all conditions were conducted using discussion forums.

Evaluation of social media use

The majority of the included studies were descriptive: 63 (22.2%) were cross-sectional and 57 (20.1%) used content analysis to outline how social media is being applied (Table 2). Qualitative studies comprised 22.9% (65/284) of the total sample; mixed methods studies 11.6% (33/284); observational studies 3.9% (11/284); and experimental studies 19.4% (55/284). Of the 33 mixed methods studies, 11 included a cross-sectional component and 20 included content analyses. Forty-eight RCTs were conducted, 45 of which were evaluating discussion forums as at least one component of the intervention.

Overall, 186/284 (65.5%) studies concluded that there was evidence for the utility of social media, while only 15/284 (5.3%) concluded that there was not. The subset of RCTs was examined in more detail; while 35/48 (72.9%) studies presented positive conclusions, only 16/35

(45.7%) reported a statistically significant effect in relation to the primary outcome (Figure 4). All but one study with significant findings evaluated the use of a discussion forum; the other study evaluated a blog. Clusters of conditions appeared in the RCTs: 6 studies were related to lifestyle and weight loss, 3 were related to tobacco and substance use, 2 were in mental health, and 6 were in other conditions (diabetes, irritable bowel syndrome, multiple sclerosis, hearing loss, and breast cancer). The primary outcome in each of these studies was related to health behaviour and status, except two that evaluated patients' experience and one that measured website use. The social media tool was one component of a complex intervention in all studies, making it difficult to tease out any effect specific to its use. However, improvements were found in outcomes such as changes in body weight and activity levels, tobacco or substance use, and quality of life.

Discussion

There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations. While diversity exists in terms of the tools used, their intended purposes, and the conditions studied, the majority of studies evaluate discussion forums. Given their role in facilitating support groups, the prevalence and popularity of discussion forums suggests that patients and caregivers are interested in seeking out "someone like me" in addressing their health care concerns.

While general tools with broad applications (i.e., discussion forums) are commonly used, the promise of social media lies in its adaptability. Unique applications such as PatientsLikeMe and TuDiabetes have evolved out of the need to address the specific concerns of particular online communities, demonstrating the success that can be realized through tailoring a tool to the requirements of a chosen target audience. Conversely, a general tool such as Twitter has shown that it can be applied to a variety of different purposes, but has also found a specific niche in disseminating public health alerts. The ability of these platforms to be customized for different purposes is highly consistent with the principles underlying successful knowledge translation interventions.[23]

Most studies were descriptive, but our sample also included 48 RCTs. Nearly all of the trials evaluated the effectiveness of discussion forums, leaving a research gap in the evaluation of the performance of other social media tools. Given the rapid proliferation of social media, a plethora of platforms are being used and an investigation of their benefits and harms is a logical progression of the research agenda. Similarly, next steps in research could focus on isolating the effect of the social media tool, particularly as it relates to improved patient outcomes. All of the included RCTs evaluated a complex intervention, of which the social media tool was just one component. More focused efforts to determine whether social media has an impact on its own; or whether any observed effects are attributable to the intervention overall or to the non-social media components, would be a research priority. Further, additional research is needed to clarify whether the use of social media truly confers an advantage, or if the novelty of the medium is solely responsible for its use.[24] The contrast between the statistical significance of the primary outcome in the RCTs and the positive conclusions reported suggests that issues such as selective outcome reporting (e.g., choice of groups to compare), misrepresentation of conclusions (e.g., focus on change over time within a group, rather than differences between groups), and spin in reporting (e.g., emphasis on a positive trend) may play a more substantial role in the promotion of social media use than actual effectiveness.

Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing supportive online communities and could have widespread applicability and utility within the health care setting.

Social media is a relatively new concept and is continually undergoing transformations. As such, there is no universal definition, adding complexity to the process of determining study eligibility. The constantly changing nature of social media also proved challenging in defining the literature search, and the novelty of the topic made it difficult to keep the search updated due to a steady influx of new reports. However, as the focus of this scoping review was to identify broad categories of social media uses, the addition of studies published after the literature search would be unlikely to change the results.

As our inclusion criteria were intentionally broad, we included a number of different study designs, encompassing both quantitative and qualitative research. While this introduced challenges in addressing the nuances of each type of study, the end result is a comprehensive overview of the state of the literature. Further syntheses of the evidence in specific clinical areas will be able to provide more focus on some of these details.

Conclusions

This scoping review provides a map of the existing literature evaluating the use of social media in patient and caregiver populations. The available evidence is extensive, and most studies to date have been descriptive in nature. Given such widespread use of social media, evaluations of effectiveness are also needed. While positive conclusions are commonly reported, these may not be reflective of the actual findings.

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Contributors: MPH, SDS, LMG, and LH designed the study. MPH coordinated the project and is guarantor. MPH, AC, and JS screened articles and performed data extraction. AM contributed to the conception of the study and conducted the literature search. MPH, AC, JS, and LH interpreted the data. MPH drafted and all authors critically reviewed the manuscript. All authors read and approved the manuscript.

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Table 1. Categorization of social media tools

Tool	Description	Examples
Collaborative projects	Enable the joint and simultaneous creation of content by many end-users.	Wikis (e.g., Wikipedia) Social bookmarking applications (e.g., Mendeley)
Blogs or microblogs	Websites that display date-stamped entries. They are usually managed by one person but provide the opportunity to interact with others through the addition of comments.	Wordpress Twitter (microblog)
Content communities	Allow for the sharing of media content between users, including text, photos, videos, and presentations.	BookCrossing Flickr YouTube Slideshare
Social networking sites	Enable users to connect by creating personal information profiles that can be accessed by friends and colleagues, and by sending emails and instant messages between each other.	Facebook MySpace LinkedIn
Virtual worlds	Platforms that replicate a 3D environment in which users can appear in the form of personalized avatars and interact with each other as they would in real life.	Second Life

Table 2. Description of included studies

Variable	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Continent of corresponding author		
Asia	12 (4.2)	5 (5.3)
Australia	14 (4.9)	3 (3.2)
Europe	78 (27.5)	19 (20.0)
North America	179 (63.0)	67 (70.5)
Not reported	1 (0.4)	1 (1.1)
Study start date – median (range)	2006 (1997 – 2011)	2008 (2000 – 2011)
Study duration – median (range)	5 months (1– 117)	3 months (1 – 117)
Sample size – median (range)	124 (1 – 16,703)*	130 (2 – 16,703)*
Publication type		
Journal article	255 (89.8)	75 (79.0)
Abstract	15 (5.3)	8 (8.4)
Dissertation	14 (4.9)	12 (12.6)
Study design		
Quantitative		
Randomized controlled trial	48 (16.9)	6 (6.3)
Non-randomized controlled trial	6 (2.1)	1 (1.1)
Controlled before-after	1 (0.4)	-
Observational	11 (3.9)	3 (3.2)
Cross-sectional	63 (22.2)	33 (34.7)
Qualitative		
Case study	1 (0.4)	-
Case series	3 (1.1)	2 (2.1)
Ethnography	3 (1.1)	2 (2.1)
Grounded theory	6 (2.1)	2 (2.1)
Phenomenology	6 (2.1)	1 (1.1)
Qualitative (other/not specified)	46 (16.2)	16 (16.8)
Mixed methods	33 (11.6)	9 (9.5)
Other		
Content analysis	57 (20.1)	20 (21.1)
Authors' conclusions		
Positive	186 (65.5)	56 (59.0)
Neutral	65 (22.9)	23 (24.2)
Negative	15 (5.3)	10 (10.5)
Indeterminate	18 (6.3)	6 (6.3)

*Excluding one study that examined >3,000,000 tweets.

Table 3. Description and objectives of social media tools used (N=284)

Tool	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Collaborative project	6 (2.1)	5 (83.3)	-	-	-	1 (16.7)
Blog or microblog	40 (14.1)	11 (27.5)	-	24 (60.0)	4 (10.0)	9 (22.5)
Content community	16 (5.6)	8 (50.0)	-	5 (31.3)	2 (12.5)	4 (25.0)
Social networking site	42 (14.8)	10 (23.8)	1 (2.4)	24 (57.1)	8 (19.1)	9 (21.4)
Virtual world	6 (2.1)	3 (50.0)	-	3 (50.0)	1 (16.7)	1 (16.7)
Discussion forum	189 (66.6)	23 (12.2)	6 (3.2)	166 (87.8)	3 (1.6)	17 (9.0)
Component of a complex intervention	116 (40.9)	16 (13.8)	3 (2.6)	108 (93.1)	4 (3.5)	3 (2.6)

*Percentages do not add up to 100 due to the possibility of multiple tools and multiple objectives per study.

Table 4. Outcomes measured by social media tool

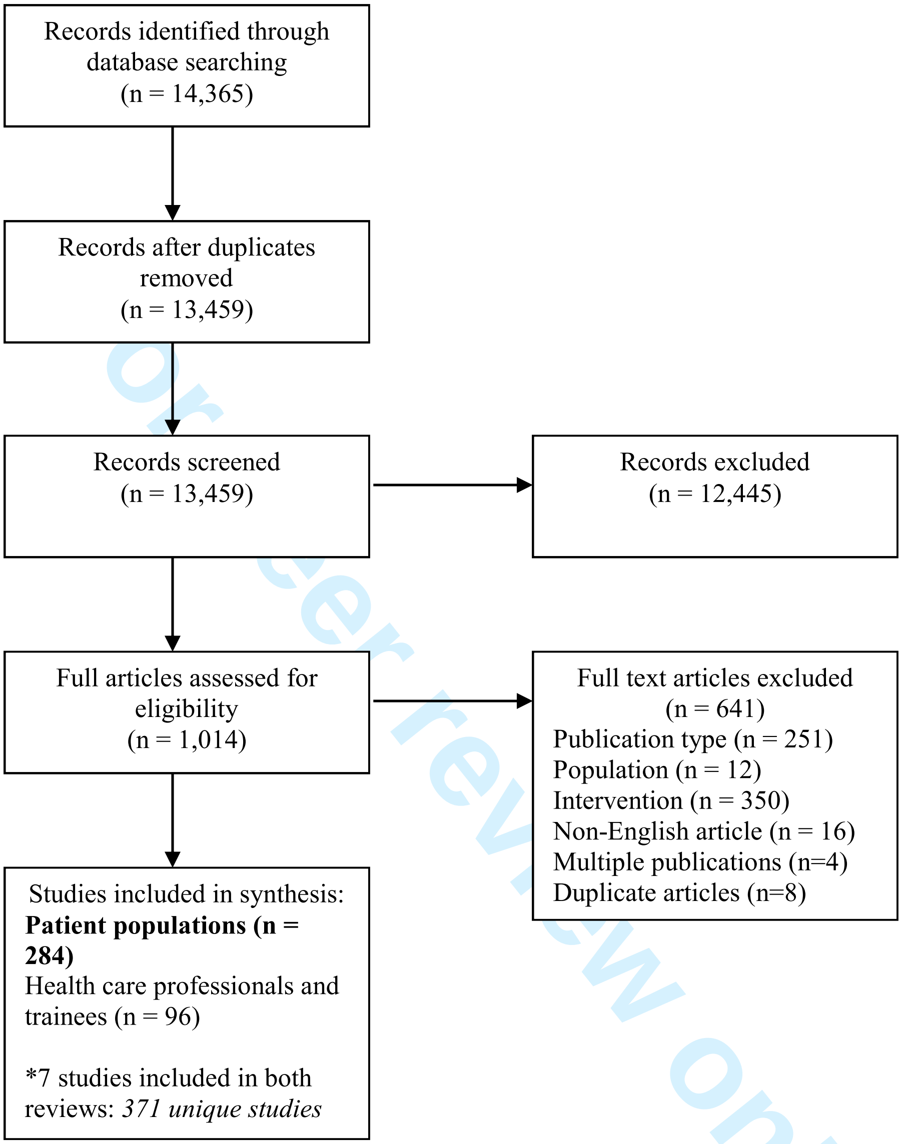
Outcomes	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Patients' knowledge		
Conditions and complications	54 (19.0)	22 (23.2)
Self-care	60 (21.1)	17 (17.9)
Treatment options	22 (7.8)	10 (10.5)
Comprehension	2 (0.7)	1 (1.1)
Patients' experience		
Satisfaction	69 (24.3)	21 (22.1)
Clinician-patient communication	39 (13.7)	16 (16.8)
Peer-to-peer communication	135 (47.5)	44 (46.3)
Quality of life	20 (7.0)	2 (2.1)
Psychological well-being	78 (27.5)	21 (22.1)
Self-efficacy	32 (11.3)	4 (4.2)
Involvement and empowerment	22 (7.8)	6 (6.3)
Use of services and costs		
Hospital admission rates	4 (1.4)	2 (2.1)
Emergency admission rates	2 (0.7)	-
Number of visits to general practitioners	7 (2.5)	2 (2.1)
Cost effectiveness	4 (1.4)	3 (3.2)
Health behaviour and status		
Self-care activities	63 (22.2)	15 (15.8)
Treatment adherence	13 (4.6)	1 (1.1)
Severity of disease or symptoms	17 (6.0)	4 (4.2)
Physical functioning	21 (7.4)	6 (6.3)
Mental functioning	25 (8.8)	8 (8.4)
Clinical indicators	23 (8.1)	3 (3.2)
Other		
Attitudes and preferences	14 (4.9)	7 (7.4)
Content and accuracy	33 (11.6)	21 (22.1)
Usability	9 (3.2)	2 (2.1)
Usage and demographics	106 (37.3)	34 (35.8)

*Percentages do not add up to 100 due to the possibility of multiple outcomes per study

Table 5. Social media objectives by authors' conclusions (N=284)

Conclusions	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Positive	186 (65.5)	28 (59.6)	6 (85.7)	149 (68.0)	14 (73.7)	21 (53.8)
Neutral	65 (22.9)	12 (25.5)	1 (14.3)	47 (21.5)	1 (5.3)	13 (33.3)
Negative	15 (5.3)	5 (10.6)	-	7 (3.2)	3 (15.8)	3 (7.7)
Indeterminate	18 (6.3)	2 (4.3)	-	16 (7.3)	1 (5.3)	2 (5.1)

Figure 1. Flow diagram of included studies



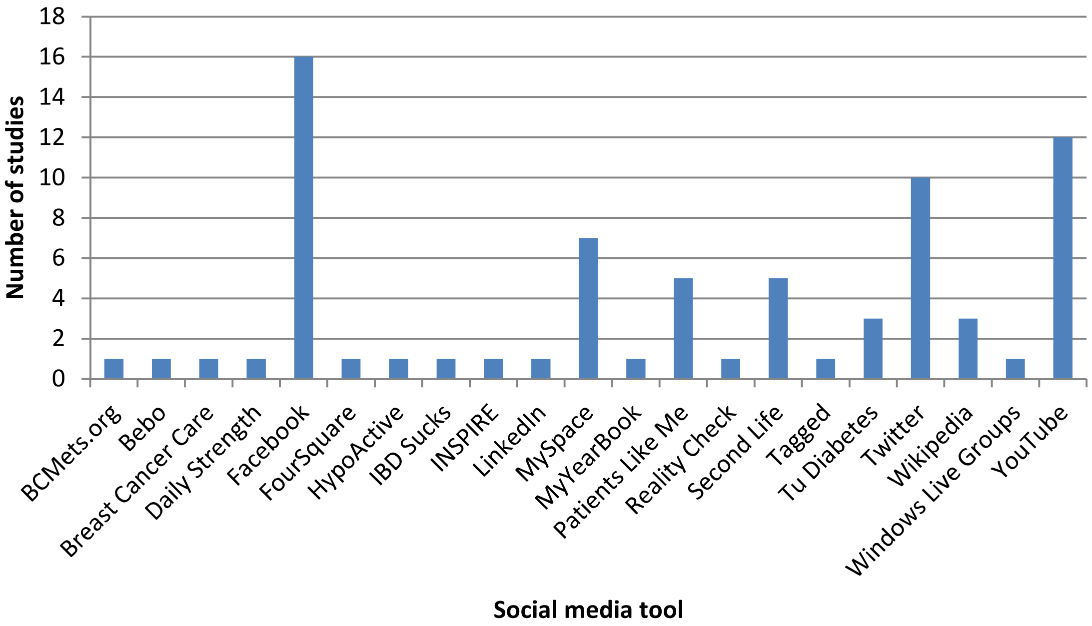


Figure 2. Specific social media tools described in included studies

Figure 3. Word cloud representing the conditions included in the study populations. The size of each term is proportional to its representation in the review.

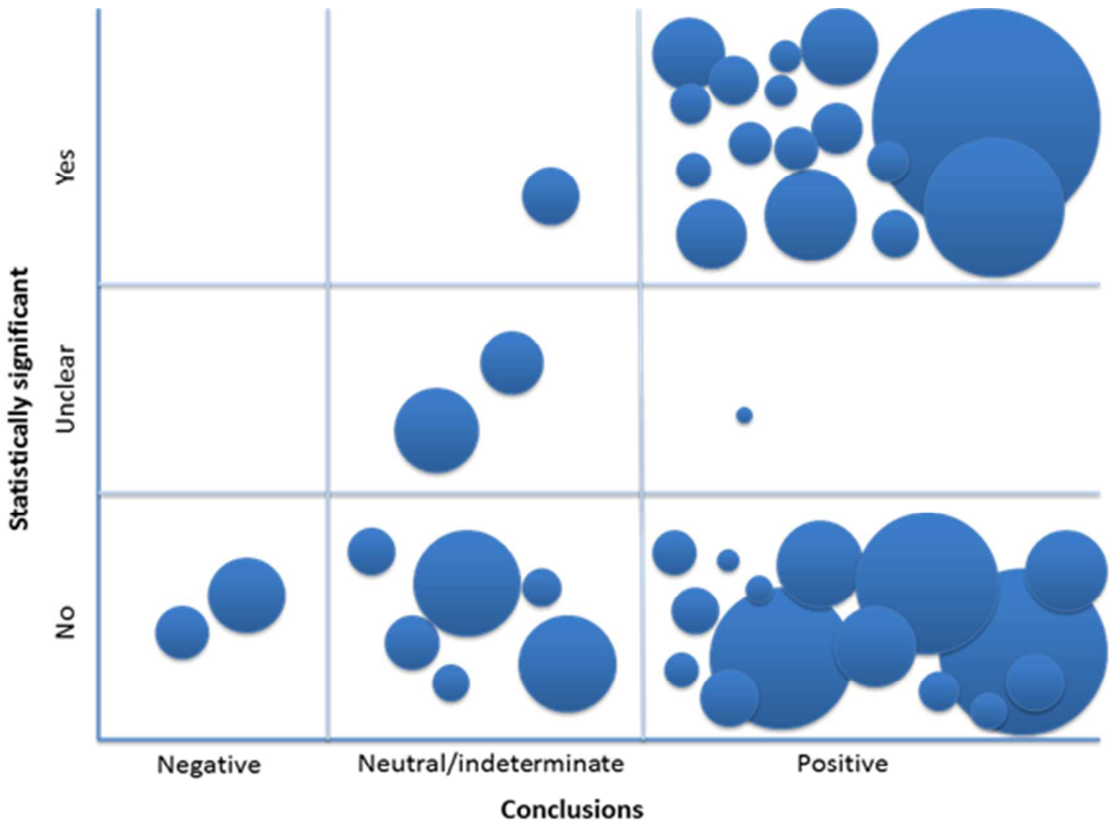


Figure 4. Authors' conclusions by statistical significance and sample size among randomized controlled trials. Each bubble represents one study and its size is proportional to the number of individuals evaluated.

Appendix. Search strategy for Medline

Database: Medline via Ovid <1946 to Present>

Search Title: Social Media Scoping Review 1.4 all SD filters | Medline – 15Dec2011 – AM

Date Searched: 13 January 2012

Limits: Year of publication ≥2000; RCT/CCT, SR, observational, qualitative study filters applied

Results: 5,468 (Ovid duplicate removal function applied)

Internet and social media related MeSH [Medical Subject Headings] 1. exp Internet/ 2. Electronic Mail/ 3. Mass Media/td, ut 4. Hypermedia/ 5. Online Systems/td, ut 6. Medical Informatics/ 7. User-Computer Interface/ 8. Computer-Assisted Instruction/ 9. Computers/td, ut 10. Search Engine/ 11. Computer Communication Networks/ 12. Information Dissemination/ 13. Therapy, Computer-Assisted/ 14. "Marketing of Health Services"/ 15. Social Marketing/ 16. exp Social Environment/ 17. **Internet.mp. and (or/12-16)** [Internet combined with broader social network/computer terms]
Internet and social medial related keywords 18. (digital adj5 platform*).mp. 19. (website* or web site* or webpage* or web page*).mp. 20. Googl*.mp. 21. Facebook*.mp. 22. YouTube.mp. 23. Second Life.mp. 24. PatientsLikeMe.mp. 25. WebMD.mp. 26. elluminate.mp. 27. flickr.mp. 28. moodle.mp. 29. picsearch.mp. 30. skype.mp. 31. ustream.mp. 32. zotero.mp. 33. ((e or electronic) adj3 newsletter*).mp. 34. (viral adj5 market*).mp. 35. (banner adj5 ad*).mp. 36. ("Web 2.0" or "Web 2").mp. 37. "Health 2.0".mp.

38. "Medicine 2.0".mp.
39. (Social adj3 network*).mp.
40. linkedin.mp.
41. blog*.mp.
42. wiki*.mp.
43. podcast*.mp.
44. really simple syndicat*.mp.
45. (rss adj3 (reader* or feed*)).mp.
46. (forum* adj3 (internet or web* or chat*)).mp.
47. content communit*.mp.
48. user generated content.mp.
49. microblog*.mp.
50. (twitter or tweet*).mp.
51. (("peer to peer" adj5 network*) or P2P).mp.
52. (social adj3 media*).mp.
53. i-phone*.mp.
54. myspace.mp.
55. smartphone*.mp.

56. **or/1-11,17-55** [Internet/social media MeSH and keywords] (**92,578**)

Health care education/promotion terms

57. exp Health/
58. "Delivery of Health Care"/
59. health behavior/
60. exp Health Education/
61. exp Health Promotion/
62. Patient Care/
63. Patient Participation/
64. medical education/
65. ((patient* or physician* or nurse* or pharm* or "health care profession*") adj2 (teach* or train* or instruction* or intervention* or program* or inform* or educat* or outcome*)).mp.

66. **or/57-65** [Health promotion/health outcome terms] (**624,172**)

67. **and/56,66** [social media + health promotion/outcome terms] (**15,219**)

Search filters to stream out non-research papers

RCT Filter

68. randomized controlled trial.pt.
69. controlled clinical trial.pt.
70. randomized.ab.
71. placebo.ab.
72. exp Clinical Trials as Topic/
73. randomly.ab.
74. trial.ti.
75. or/68-74
76. exp animals/ not humans.sh.
77. **75 not 76** [Cochrane RCT filter to max sensitivity and precision] (**730,963**)

SR Filter

78. meta analysis.mp,pt.
79. review.pt.
80. search*.tw.
81. **or/78-80** [HIRU SR filter to balance sensitivity and specificity] (**1,779,109**)

Observational Study Filter

82. epidemiologic studies/
83. exp Case-Control Studies/
84. exp Cohort Studies/
85. case control.tw.
86. (cohort adj (study or studies)).tw.
87. cohort analy*.tw.
88. (follow up adj (study or studies)).tw.
89. (observational adj (study or studies)).tw.
90. longitudinal.tw.
91. retrospective.tw.
92. cross sectional.tw.
93. Cross-Sectional Studies/
94. **or/82-93** [SIGN observational study filter] (**1,508,983**)

Qualitative Research Filter
95. interview*.tw.
96. experience*.mp.
97. qualitative.tw.
98. **or/95-97** [HIRU qualitative study filter] (**756,921**)

99. or/77,81,94,98 [combination of all search filters] (**4,143,826**)

100. and/67,99 [combination of social media terms + health ed terms + SD filters] (**6,589**)

101. limit 100 to humans (**6,234**)
102. limit 101 to yr="2000 -Current" (**5,524**)
103. remove duplicates from 102 (**5,468**)

Social media use among patients and caregivers: a scoping review

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Manuscript ID:	bmjopen-2013-002819.R1
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Date Submitted by the Author:	08-Apr-2013
Complete List of Authors:	Hamm, Michele; University of Alberta, Pediatrics Chisholm, Annabritt; University of Alberta, Pediatrics Shulhan, Jocelyn; University of Alberta, Pediatrics Milne, Andrea; University of Alberta, Pediatrics Scott, Shannon; University of Alberta, Nursing Given, Lisa; Charles Sturt University, Education Hartling, Lisa; University of Alberta, Pediatrics
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Social media use among patients and caregivers: a scoping review

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Ethical approval: Not required.

Abstract

Objective: To map the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Design: Scoping review.

Data sources: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest (2000-2012).

Study selection: Studies reporting primary research on the use of social media (collaborative projects, blogs/microblogs, content communities, social networking sites, virtual worlds) by patients or caregivers.

Data extraction: Two reviewers screened studies for eligibility; one reviewer extracted data from relevant studies and a second performed verification for accuracy and completeness on a 10% sample. Data were analyzed to describe which social media tools are being used, by whom, for what purpose, and how they are being evaluated.

Results: Two hundred eighty four studies were included. Discussion forums were highly prevalent and constitute 66.6% of the sample. Social networking sites (14.8%) and blogs/microblogs (14.1%) were the next most commonly used tools. The intended purpose of the tool was to facilitate self-care in 77.1% of studies. While there were clusters of studies that focused on similar conditions (e.g., lifestyle/weight loss (12.7%), cancer (11.3%)), there were no patterns in the objectives or tools used. A large proportion of the studies were descriptive (42.3%), however there were also 48 (16.9%) randomized controlled trials (RCTs). Among the RCTs, 35.4% reported statistically significant results favouring the social media intervention

being evaluated; however 72.9% presented positive conclusions regarding the use of social media.

Conclusions: There is an extensive body of literature examining the use of social media in patient and caregiver populations. Much of this work is descriptive; however with such widespread use, evaluations of effectiveness are required. In studies that have examined effectiveness, positive conclusions are often reported, despite non-significant findings.

Word count: 297

Article summary

Article focus

- The use of social media in health care has been widely advocated, but there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations.
- We mapped the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Key messages

- There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations.
- Most studies have been descriptive; however with such widespread use, evaluations of effectiveness are needed.
- In studies that have examined effectiveness, positive conclusions are often reported, despite non-significant findings.

Strengths and limitations of this study

- Our search was comprehensive and we included an extensive body of literature, across conditions, populations, and study designs.
- Social media is constantly evolving, leading to challenges in keeping the search updated.
- More in-depth analysis is needed on specific topics, conditions, and populations to guide the use and implementation of social media interventions.

Introduction

The use of social media in health care has been widely advocated;[1-8] however, there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations. It is clear, though, that in addition to seeking out traditional sources of health care information, patients are increasingly active online.[9] In 2011, looking for health care information was the third most common online activity;[10] in September 2012, 72% of adult Internet users sought support and medical information online,[11] and in December 2012, 67% of Internet users were using social media.[12] As social media continues to evolve, its momentum shows no sign of diminishing, instead finding new niches with unique applications.

Social media can be defined as a group of online applications that allow for the creation and exchange of user-generated content, and can be categorized into five groups: 1) collaborative projects (e.g., Wikipedia); 2) blogs or microblogs (e.g., Blogger, Twitter); 3) content communities (e.g., YouTube); 4) social networking sites (e.g., Facebook); and 5) virtual gaming or social worlds (e.g., HumanSim®).[13] The collaborative environment to which social media belongs represents a shift in technology and functionality from “Web 1.0,” in which static online content and applications were created and published by individuals, to “Web 2.0,” in which there is continuous modification and participation by all users.[13] Table 1 provides an overview of the categories of social media tools.

Advocates of the use of social media in health care suggest that these tools allow for personalization, presentation, and participation – three key elements that make them highly

effective.[14] The content can be tailored to the priorities of the users, the versatility of the different platforms creates numerous options for the presentation of information, and the collaborative nature of social media allows for a meaningful contribution from all user groups. The idea of a synergistic relationship between social media users is one of the main perceived advantages of using these platforms.[15] However, criticisms of the use of social media in health care have also arisen. The availability of misinformation is a risk, as health care providers are unable to control the content that is posted or discussed.[1,16,17] Inappropriate substitution of online information or advice for in-person visits to a health care provider can also potentially lead to harmful results, and this has been cited as a limitation of the use of social media and of the Internet generally.[1.18] Negative uses of social media have also been highlighted in the context of professionalism and confidentiality,[19] use by children and youth due to a limited capacity for self-regulation and vulnerability to peer influence,[20] and promotion of high-risk behaviours, such as suicide-related behaviours, drug use, and eating disordered behaviours.[21-24]

The objectives of this study were to map the existing literature examining the use of social media in patient and caregiver populations, to determine the extent and type of evidence available to inform more focused knowledge syntheses, and to identify gaps for future research. The specific questions guiding this scoping review were: 1) What social media tools are being used to improve health outcomes in patient populations? 2) For what purposes are social media tools being used in patient populations (e.g., to improve health literacy, to improve self-care)? 3) For what patient populations and disease conditions are social media tools being used? 4) What types of evidence and research designs (i.e., qualitative, quantitative) have been used to examine social media tools?

Methods

This scoping review on the use of social media in patient and caregiver populations was conducted in parallel with a review on the use of social media in health care professional and trainee populations;[25] therefore the literature search and screening for study eligibility were conducted concurrently. The review followed a protocol that we developed *a priori*.

Search strategy

A research librarian searched 11 databases in January 2012: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest. Dates were restricted to 2000 or later, corresponding to the advent of Web 2.0. No language or study design restrictions were applied. The search strategy for Medline is provided in the Appendix.

Study selection

Two reviewers independently screened titles and abstracts of studies for eligibility. The full text of studies assessed as "relevant" or "unclear" was then independently evaluated by two reviewers using a standard form. Discrepancies were resolved by consensus or adjudication by a third party.

Studies were included if they reported primary research (quantitative or qualitative), focused on health care issues related to patients or caregivers, and examined the use of a social media tool. Social media was defined according to Kaplan and Haenlein's classification scheme,[13] including: collaborative projects, blogs or microblogs, content communities, social networking sites, and virtual worlds. We excluded studies that examined mobile health (e.g., tracking or medical reference apps), one-way transmission of content (e.g., podcasts), and real-time exchanges mediated by technology (e.g., Skype, chat rooms). Electronic discussion forums and bulletin boards were included as they incorporate user-generated content and were judged to fall within the spectrum of social media. Outcomes were not defined *a priori* as they were to be incorporated into our description of the field. Likely categories for objectives and outcomes were adapted from those outlined in Coulter and Ellins' proposed framework for strategies to inform, educate, and involve patients.[26,27]

Data extraction

Data were extracted using standardized forms and entered into Microsoft Excel (Microsoft, Redmond, WA) by one reviewer and a 10% sample was checked for accuracy and completeness by another.[28] Reviewers resolved discrepancies through consensus. Extracted data included study and population characteristics, description of the social media tools used, objective of the tools, outcomes measured, and authors' conclusions.[29] Studies that examined social media as one component of a complex intervention were noted as such. Additional data were collected for randomized controlled trials (RCTs), including the primary outcome and its statistical significance.

Data synthesis

Data were synthesized descriptively in order to map different aspects of the literature as outlined in our key questions. Studies were grouped according to tool, audience, and study design, with data from RCTs examined in more detail. As discussion forums were not included in our original classification scheme, findings are presented both for all included studies and for studies that investigated tools other than discussion forums. Descriptive statistics were calculated using StataIC 11 (StataCorp, College Station, TX).

Results

Two hundred eighty four studies were included in the review. Figure 1 outlines the flow of studies through the inclusion process and Table 2 provides a description of included studies. Most studies (179/284; 63.0%) were conducted in North America, with more than half of the total sample (154/284; 54.2%) carried out in the United States and 8.8% (25/284) conducted in Canada. The median start date was in 2006 (range 1997 – 2011); when studies evaluating discussion forums were excluded, the start date was more recent (median 2008, range 2000 – 2011). Studies tended to be fairly short, with a median duration of 5 months (range 1 – 117 months). Nearly all included studies were published as journal articles (255/284; 89.8%); however, when studies of discussion forums were excluded, the proportion of dissertations written on the use of social media increased (14/284 to 12/95; 4.9% to 12.6%).

Social media tools used

The social media tools studied are outlined in Table 3. The use of discussion boards and online support groups (combined as discussion forums due to their common structure and intent) dominated the literature, encompassing 189 (66.6%) included studies. Social networking sites (42/284; 14.8%) and blogs or microblogs (40/284; 14.1%) were also commonly evaluated, followed by content communities (16/284; 5.6%), collaborative projects (6/284; 2.1%), and virtual worlds (6/284; 2.1%). In 116 (40.9%) included studies, the social media tool was included as part of a complex intervention. Where existing and publicly available social media applications were studied, Facebook (16/284; 5.6%), YouTube (12/284; 4.2%), and Twitter (10/284; 3.5%) were evaluated most frequently (Figure 2).

Purposes of social media use

The most common intended use of social media was for self-care, which was described as an objective of the tool in 219 (77.1%) studies (Table 3). This was particularly relevant to discussion forums, in which 166/189 (87.8%) studies were related to self-care. Other tools were often established with similar functions to discussion forums: they provided a platform on which users could post and share their experiences with peers. Collaborative projects were often used to address health literacy, and social networking sites were commonly used for patient safety purposes, largely for documentation of adverse events. While there were few studies that addressed clinical decision-making, these were almost exclusively conducted using discussion forums.

We categorized the outcomes measured in each of the studies under patients' knowledge, patients' experience, use of services and costs, health behaviour and status, and other (Table 4). Measures of patients' experience, specifically peer-to-peer communication (135/284; 47.5%), were most common and were often outcomes related to social support among members of an online community. Measures of psychological well-being (e.g., reports of anxiety levels) and changes in self-care activities (e.g., increases in physical activity) in relation to use of the tool were also commonly evaluated (78/284 and 63/284; or 27.5% and 22.2%, respectively).

Social media user groups

A wide range of conditions were covered in the included studies (Figure 3). The largest proportion fell under the lifestyle and weight loss category (36/284; 12.7%), followed by cancer (32/284; 11.3%), and studies in the general population (22/284; 7.8%). The general population studies tended to be surveys focused on usage, demographics, and user preferences relevant to social media use for health-related purposes. No strong trends emerged showing differences between user groups in the objective of the type of social media tool or the specific application used (data not shown). In nearly all conditions investigated, the social media tool studied was intended to facilitate self-care. One exception was seen in the case of infectious disease, where 7/12 (58.3%) relevant studies were focused on health literacy. This was mainly driven by large-scale strategies to provide updates on influenza or H1N1. For specific applications used, there were clusters of studies that examined condition-specific modalities. Social networking sites were common in studies of diabetes and metabolic syndrome due to the use of TuDiabetes, an online community targeted to those affected by diabetes. Similarly, Twitter was commonly used in the context of H1N1/influenza, and PatientsLikeMe was used for a group of chronic conditions including amyotrophic lateral sclerosis, fibromyalgia, human immunodeficiency virus, mood disorders, multiple sclerosis, and Parkinson’s disease. Aside from these small clusters, most studies across all conditions were conducted using discussion forums.

Evaluation of social media use

The majority of the included studies were descriptive: 63 (22.2%) were cross-sectional and 57 (20.1%) used content analysis to outline how social media is being applied (Table 2). Qualitative studies comprised 22.9% (65/284) of the total sample; mixed methods studies 11.6% (33/284);

observational studies 3.9% (11/284); and experimental studies 19.4% (55/284). Of the 33 mixed methods studies, 11 included a cross-sectional component and 20 included content analyses. Forty-eight RCTs were conducted, 45 of which were evaluating discussion forums as at least one component of the intervention. Of the remaining RCTs, one evaluated a blog, one evaluated Second Life, and one made use of Facebook and Twitter.

Overall, 186/284 (65.5%) studies concluded that there was evidence for the utility of social media, while only 15/284 (5.3%) concluded that there was not. The subset of RCTs was examined in more detail; while 35/48 (72.9%) studies presented positive conclusions, only 16/35 (45.7%) reported a statistically significant effect in relation to the primary outcome (Figure 4). All but one study with significant findings evaluated the use of a discussion forum; the other study evaluated a blog. Clusters of conditions appeared in the RCTs: 6 studies were related to lifestyle and weight loss, 3 were related to tobacco and substance use, 2 were in mental health, and 6 were in other conditions (diabetes, irritable bowel syndrome, multiple sclerosis, hearing loss, and breast cancer). The primary outcome in each of these studies was related to health behaviour and status, except two that evaluated patients' experience and one that measured website use. The social media tool was one component of a complex intervention in all studies, making it difficult to tease out any effect specific to its use. However, improvements were found in outcomes such as changes in body weight and activity levels, tobacco or substance use, and quality of life.

Discussion

There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations. While diversity exists in terms of the tools used, their intended purposes, and the conditions studied, the majority of studies evaluate discussion forums. This could point to the popularity of discussion forums among patients and caregivers in addressing their health care concerns; however, it may also be indicative of the behaviours or preferences of the site designers.

While general tools with broad applications (i.e., discussion forums) are commonly used, the promise of social media lies in its adaptability. Unique applications such as PatientsLikeMe and TuDiabetes have evolved out of the need to address the specific concerns of particular online communities, demonstrating the success that can be realized through tailoring a tool to the requirements of a chosen target audience. Conversely, a general tool such as Twitter has shown that it can be applied to a variety of different purposes, but has also found a specific niche in disseminating public health alerts. The ability of these platforms to be customized for different purposes is highly consistent with the principles underlying successful knowledge translation interventions.[30]

Most studies were descriptive, but our sample also included 48 RCTs. Nearly all of the trials evaluated the effectiveness of discussion forums, leaving a research gap in the evaluation of the performance of other social media tools. Given the rapid proliferation of social media, a plethora of platforms are being used and an investigation of their benefits and harms is a logical progression of the research agenda. Similarly, next steps in research could focus on isolating the effect of the social media tool, particularly as it relates to improved patient outcomes. All of the included RCTs evaluated a complex intervention, of which the social media tool was just one component. More focused efforts to determine whether social media has an impact on its own; or whether any observed effects are attributable to the intervention overall or to the non-social media components, would be a research priority. Similarly, more in-depth examination of how the social media interventions are implemented, and specifically how and to what extent health or other professionals are involved, would contribute to a better understanding of their use. Further, additional research is needed to clarify whether the use of social media truly confers an advantage, or if the novelty of the medium is solely responsible for its use.[31] The contrast between the statistical significance of the primary outcome in the RCTs and the positive conclusions reported suggests that issues such as selective outcome reporting (e.g., choice of groups to compare), misrepresentation of conclusions (e.g., focus on change over time within a group, rather than differences between groups), and spin in reporting (e.g., emphasis on a positive trend) may play a more substantial role in the promotion of social media use than actual effectiveness. The fact that most interventions were evaluated by their developers may have also influenced the positive conclusions reported.

Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing

supportive online communities and could have widespread applicability and utility within the health care setting.

Limitations

Social media is a relatively new concept and is continually undergoing transformations. As such, there is no universal definition, adding complexity to the process of determining study eligibility. The constantly changing nature of social media also proved challenging in defining the literature search, and the novelty of the topic made it difficult to keep the search updated due to a steady influx of new reports. However, as the focus of this scoping review was to identify broad categories of social media uses, the addition of studies published after the literature search would be unlikely to change the results.

While this scoping review focused on the peer-reviewed literature to identify how social media is being used by patient and caregiver populations, it may not encompass all of the work that has been done in the area, or cover the extent of the impact that social media has had on health care. Much of the driving force behind the use of social media has come from outside of the academic community; therefore certain constructs such as the role that Facebook plays in advocacy and community, and patient empowerment resulting from the use of Twitter have not been captured. Additionally, certain movements that have shaped social media use in health care, such as the ePatient movement[32] and Citizen Science,[33] were not included within the scope of our review. While we endeavored to be as comprehensive as possible in covering the published literature, our included patient population may not be representative of social media users as a whole.

As our inclusion criteria were intentionally broad, we included a number of different study designs, encompassing both quantitative and qualitative research. While this introduced challenges in addressing the nuances of each type of study, the end result is a comprehensive overview of the state of the literature. Further syntheses of the evidence in specific topics, clinical areas, and populations will be able to provide more focus on some of these details.

Conclusions

This scoping review provides a map of the existing literature evaluating the use of social media in patient and caregiver populations. The available evidence is extensive, and most studies to date have been descriptive in nature. Given such widespread use of social media, evaluations of effectiveness are also needed. While positive conclusions are commonly reported, these may not be reflective of the actual findings.

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Contributors: MPH, SDS, LMG, and LH designed the study. MPH coordinated the project and is guarantor. MPH, AC, and JS screened articles and performed data extraction. AM contributed to the conception of the study and conducted the literature search. MPH, AC, JS, and LH interpreted the data. MPH drafted and all authors critically reviewed the manuscript. All authors read and approved the manuscript.

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Table 1. Categorization of social media tools

Tool	Description	Examples
Collaborative projects	Enable the joint and simultaneous creation of content by many end-users.	Wikis (e.g., Wikipedia) Social bookmarking applications (e.g., Mendeley)
Blogs or microblogs	Websites that display date-stamped entries. They are usually managed by one person but provide the opportunity to interact with others through the addition of comments.	Wordpress Twitter (microblog)
Content communities	Allow for the sharing of media content between users, including text, photos, videos, and presentations.	BookCrossing Flickr YouTube Slideshare
Social networking sites	Enable users to connect by creating personal information profiles that can be accessed by friends and colleagues, and by sending emails and instant messages between each other.	Facebook MySpace LinkedIn
Virtual worlds	Platforms that replicate a 3D environment in which users can appear in the form of personalized avatars and interact with each other as they would in real life.	Second Life

Table 2. Description of included studies

Variable	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Continent of corresponding author		
Asia	12 (4.2)	5 (5.3)
Australia	14 (4.9)	3 (3.2)
Europe	78 (27.5)	19 (20.0)
North America	179 (63.0)	67 (70.5)
Not reported	1 (0.4)	1 (1.1)
Study start date – median (range)	2006 (1997 – 2011)	2008 (2000 – 2011)
Study duration – median (range)	5 months (1– 117)	3 months (1 – 117)
Sample size – median (range)	124 (1 – 16,703)*	130 (2 – 16,703)*
Publication type		
Journal article	255 (89.8)	75 (79.0)
Abstract	15 (5.3)	8 (8.4)
Dissertation	14 (4.9)	12 (12.6)
Study design		
Quantitative		
Randomized controlled trial	48 (16.9)	6 (6.3)
Non-randomized controlled trial	6 (2.1)	1 (1.1)
Controlled before-after	1 (0.4)	-
Observational	11 (3.9)	3 (3.2)
Cross-sectional	63 (22.2)	33 (34.7)
Qualitative		
Case study	1 (0.4)	-
Case series	3 (1.1)	2 (2.1)
Ethnography	3 (1.1)	2 (2.1)
Grounded theory	6 (2.1)	2 (2.1)
Phenomenology	6 (2.1)	1 (1.1)
Qualitative (other/not specified)	46 (16.2)	16 (16.8)
Mixed methods	33 (11.6)	9 (9.5)
Other		
Content analysis	57 (20.1)	20 (21.1)
Authors' conclusions		
Positive	186 (65.5)	56 (59.0)
Neutral	65 (22.9)	23 (24.2)
Negative	15 (5.3)	10 (10.5)
Indeterminate	18 (6.3)	6 (6.3)

*Excluding one study that examined >3,000,000 tweets.

Table 3. Description and objectives of social media tools used (N=284)

Tool	**Total – n (%)**	**Objective – n (%)**				
		Health Literacy	**Clinical Decision Making**	**Self-care**	**Patient Safety**	**Other**
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Collaborative project	6 (2.1)	5 (83.3)	-	-	-	1 (16.7)
Blog or microblog	40 (14.1)	11 (27.5)	-	24 (60.0)	4 (10.0)	9 (22.5)
Content community	16 (5.6)	8 (50.0)	-	5 (31.3)	2 (12.5)	4 (25.0)
Social networking site	42 (14.8)	10 (23.8)	1 (2.4)	24 (57.1)	8 (19.1)	9 (21.4)
Virtual world	6 (2.1)	3 (50.0)	-	3 (50.0)	1 (16.7)	1 (16.7)
Discussion forum	189 (66.6)	23 (12.2)	6 (3.2)	166 (87.8)	3 (1.6)	17 (9.0)
Component of a complex intervention	116 (40.9)	16 (13.8)	3 (2.6)	108 (93.1)	4 (3.5)	3 (2.6)

*Percentages do not add up to 100 due to the possibility of multiple tools and multiple objectives per study.

Table 4. Outcomes measured by social media tool

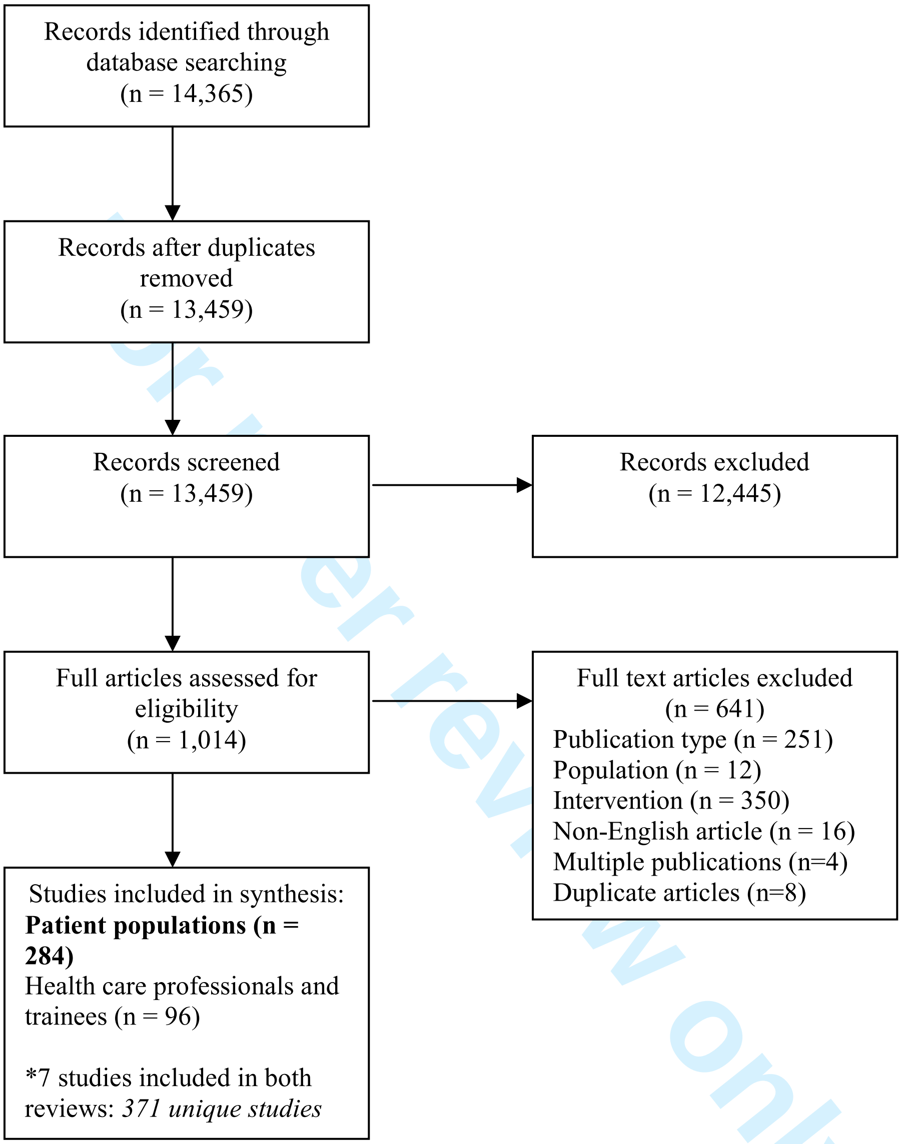
Outcomes	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Patients' knowledge		
Conditions and complications	54 (19.0)	22 (23.2)
Self-care	60 (21.1)	17 (17.9)
Treatment options	22 (7.8)	10 (10.5)
Comprehension	2 (0.7)	1 (1.1)
Patients' experience		
Satisfaction	69 (24.3)	21 (22.1)
Clinician-patient communication	39 (13.7)	16 (16.8)
Peer-to-peer communication	135 (47.5)	44 (46.3)
Quality of life	20 (7.0)	2 (2.1)
Psychological well-being	78 (27.5)	21 (22.1)
Self-efficacy	32 (11.3)	4 (4.2)
Involvement and empowerment	22 (7.8)	6 (6.3)
Use of services and costs		
Hospital admission rates	4 (1.4)	2 (2.1)
Emergency admission rates	2 (0.7)	-
Number of visits to general practitioners	7 (2.5)	2 (2.1)
Cost effectiveness	4 (1.4)	3 (3.2)
Health behaviour and status		
Self-care activities	63 (22.2)	15 (15.8)
Treatment adherence	13 (4.6)	1 (1.1)
Severity of disease or symptoms	17 (6.0)	4 (4.2)
Physical functioning	21 (7.4)	6 (6.3)
Mental functioning	25 (8.8)	8 (8.4)
Clinical indicators	23 (8.1)	3 (3.2)
Other		
Attitudes and preferences	14 (4.9)	7 (7.4)
Content and accuracy	33 (11.6)	21 (22.1)
Usability	9 (3.2)	2 (2.1)
Usage and demographics	106 (37.3)	34 (35.8)

*Percentages do not add up to 100 due to the possibility of multiple outcomes per study

Table 5. Social media objectives by authors' conclusions (N=284)

Conclusions	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Positive	186 (65.5)	28 (59.6)	6 (85.7)	149 (68.0)	14 (73.7)	21 (53.8)
Neutral	65 (22.9)	12 (25.5)	1 (14.3)	47 (21.5)	1 (5.3)	13 (33.3)
Negative	15 (5.3)	5 (10.6)	-	7 (3.2)	3 (15.8)	3 (7.7)
Indeterminate	18 (6.3)	2 (4.3)	-	16 (7.3)	1 (5.3)	2 (5.1)

Figure 1. Flow diagram of included studies



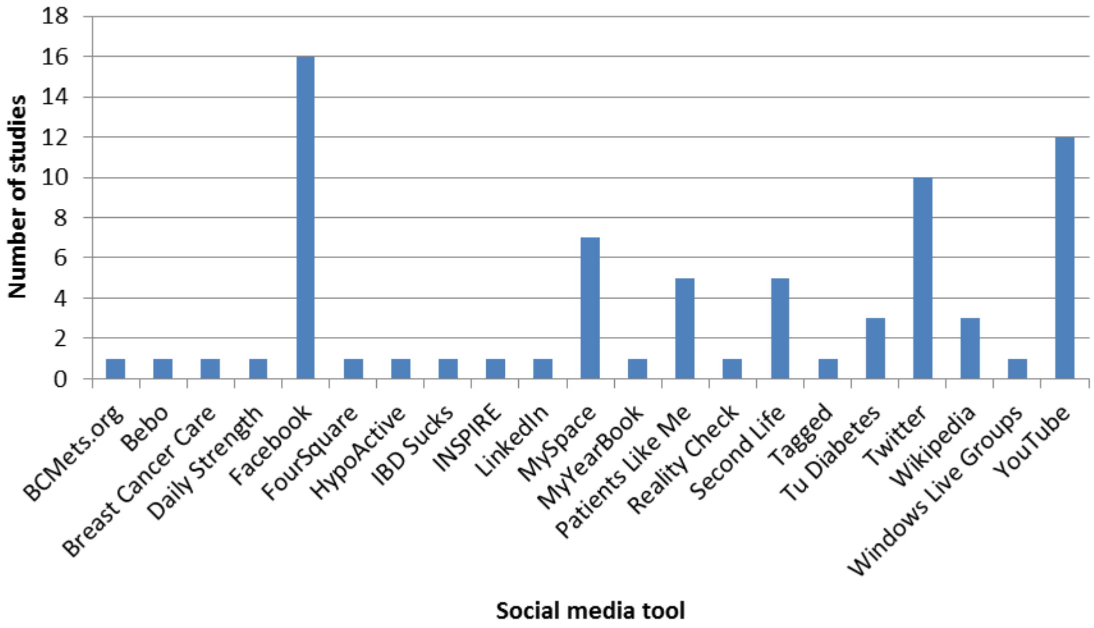


Figure 2. Specific social media tools described in included studies

Figure 3. Word cloud representing the conditions included in the study populations. The size of each term is proportional to its representation in the review.

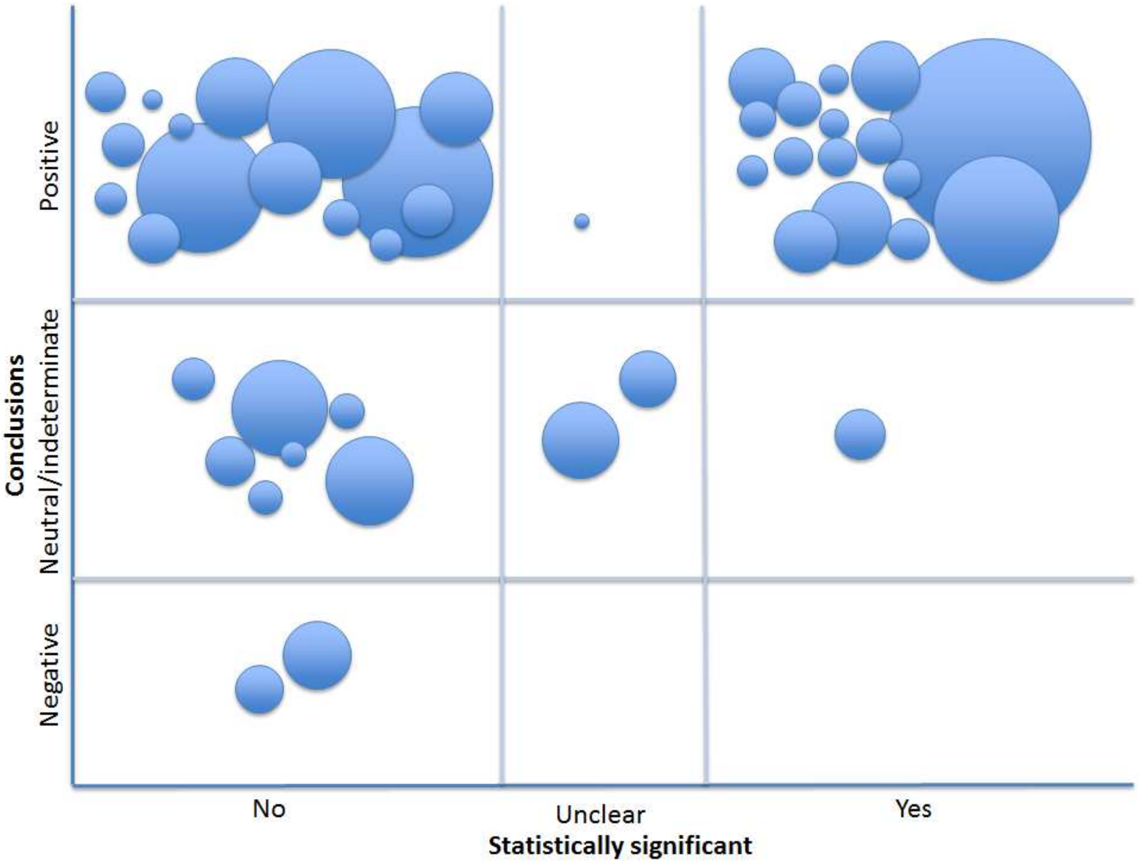


Figure 4. Authors' conclusions by statistical significance and sample size among randomized controlled trials. Each bubble represents one study and its size is proportional to the number of individuals evaluated.

Social media ~~to improve health outcomes~~use among patients and caregivers: a scoping review

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Abstract

Objective: To map the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Design: Scoping review.

Data sources: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest (2000-2012).

Study selection: Studies reporting primary research on the use of social media (collaborative projects, blogs/microblogs, content communities, social networking sites, virtual worlds) by patients or caregivers.

Data extraction: Two reviewers screened studies for eligibility; one reviewer extracted data from relevant studies and a second performed verification for accuracy and completeness on a 10% sample. Data were analyzed to describe which social media tools are being used, by whom, for what purpose, and how they are being evaluated.

Results: Two hundred eighty four studies were included. Discussion forums were highly prevalent and constitute 66.6% of the sample. Social networking sites (14.8%) and blogs/microblogs (14.1%) were the next most commonly used tools. The intended purpose of the tool was to facilitate self-care in 77.1% of studies. While there were clusters of studies that focused on similar conditions (e.g., lifestyle/weight loss (12.7%), cancer (11.3%)), there were no patterns in the objectives or tools used. A large proportion of the studies were descriptive (42.3%), however there were also 48 (16.9%) randomized controlled trials (RCTs). Among the RCTs, 35.4% reported statistically significant results favouring the social media intervention

being evaluated; however 72.9% presented positive conclusions regarding the use of social media.

Conclusions: There is an extensive body of literature examining the use of social media in patient and caregiver populations. Much of this work is descriptive; however with such widespread use, evaluations of effectiveness are ~~needed~~required. In studies that have examined effectiveness, ~~the~~ positive conclusions are often reported, despite non-significant findings. ~~not necessarily reflective of the findings.~~

Word count: ~~299~~297

Article summary

Article focus

- The use of social media in health care has been widely advocated, but there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations.

- We mapped the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Key messages

- There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations.

- Most studies have been descriptive; however with such widespread use, evaluations of effectiveness are needed.

- In studies that have examined effectiveness, ~~the~~ positive conclusions are often reported, despite non-significant findings ~~are not necessarily reflective of the actual findings~~.

Strengths and limitations of this study

- Our search was comprehensive and we included an extensive body of literature, across conditions, populations, and study designs.

- Social media is constantly evolving, leading to challenges in keeping the search updated.

- More in-depth analysis is needed on specific topics, conditions, and populations to guide the use and implementation of social media interventions.

Introduction

The use of social media in health care has been widely advocated;[1-8] however, there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations. It is clear, though, that in addition to seeking out traditional sources of health care information, patients are increasingly active online.[9] In 2011, looking for health care information was the third most common online activity;[10] in September 2012, 72% of adult Internet users sought support and medical information online,[11] and in December 2012, 67% of Internet users were using social media.[12] ~~As of 2010, the average Internet user spent nearly six hours per day on social media;[10] 61% of patients sought support and medical information online;[11] and looking for health care information became the third most common online activity.[12]~~ As social media continues to evolve, its momentum shows no sign of diminishing, instead finding new niches with unique applications.

Social media can be defined as a group of online applications that allow for the creation and exchange of user-generated content, and can be categorized into five groups: 1) collaborative projects (e.g., Wikipedia); 2) blogs or microblogs (e.g., Blogger, Twitter); 3) content communities (e.g., YouTube); 4) social networking sites (e.g., Facebook); and 5) virtual gaming or social worlds (e.g., ~~Second Life~~HumanSim®).[13] The collaborative environment to which social media belongs represents a shift in technology and functionality from “Web 1.0,” in which static online content and applications were created and published by individuals, to “Web 2.0,” in which there is continuous modification and participation by all users.[13] Table 1 provides an overview of the categories of social media tools.

Advocates of the use of social media in health care suggest that these tools allow for personalization, presentation, and participation – three key elements that make them highly effective.[14] The content can be tailored to the priorities of the users, the versatility of the different platforms creates numerous options for the presentation of information, and the collaborative nature of social media allows for a meaningful contribution from all user groups. The idea of a synergistic relationship between social media users is one of the main perceived advantages of using these platforms.[15] However, criticisms of the use of social media in health care have also arisen. The availability of misinformation is a risk, as health care providers are unable to control the content that is posted or discussed.[1,16,17] Inappropriate substitution of online information or advice for in-person visits to a health care provider can also potentially lead to harmful results, and this has been cited as a limitation of the use of social media and of the Internet generally.[1.18~~7~~] Negative uses of social media have also been highlighted in the context of professionalism and confidentiality,[19] use by children and youth due to a limited capacity for self-regulation and vulnerability to peer influence,[20] and promotion of high-risk behaviours, such as suicide-related behaviours, drug use, and eating disordered behaviours.[21-24]

The objectives of this study were to map the existing literature examining the use of social media in patient and caregiver populations, to determine the extent and type of evidence available to inform more focused knowledge syntheses, and to identify gaps for future research. The specific questions guiding this scoping review were: 1) What social media tools are being used to improve health outcomes in patient populations? 2) For what purposes are social media tools being used in patient populations (e.g., to improve health literacy, to improve self-care)? 3) For what patient populations and disease conditions are social media tools being used? 4) What types of evidence and research designs (i.e., qualitative, quantitative) have been used to examine social media tools?

Methods

This scoping review on the use of social media in patient and caregiver populations was conducted in parallel with a review on the use of social media in health care professional and trainee populations;[25~~18~~] therefore the literature search and screening for study eligibility were conducted concurrently. The review followed a protocol that we developed *a priori*.

Search strategy

A research librarian searched 11 databases in January 2012: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest. Dates were restricted to 2000 or later, corresponding to the advent of Web 2.0. No language or study design restrictions were applied. The search strategy for Medline is provided in the Appendix.

Study selection

Two reviewers independently screened titles and abstracts of studies for eligibility. The full text of studies assessed as “relevant” or “unclear” was then independently evaluated by two reviewers using a standard form. Discrepancies were resolved by consensus or adjudication by a third party.

Studies were included if they reported primary research (quantitative or qualitative), focused on health care issues related to patients or caregivers, and examined the use of a social media tool. Social media was defined according to Kaplan and Haenlein's classification scheme,[13] including: collaborative projects, blogs or microblogs, content communities, social networking sites, and virtual worlds. We excluded studies that examined mobile health (e.g., ~~non-social media~~tracking or medical reference apps), one-way transmission of content (e.g., podcasts), and real-time exchanges mediated by technology (e.g., Skype, chat rooms). Electronic discussion forums and bulletin boards were included as they incorporate user-generated content and were judged to fall within the spectrum of social media. Outcomes were not defined *a priori* as they were to be incorporated into our description of the field. Likely categories for objectives and outcomes were adapted from those outlined in Coulter and Ellins' proposed framework for strategies to inform, educate, and involve patients.[~~19,20~~26,27]

Data extraction

Data were extracted using standardized forms and entered into Microsoft Excel (Microsoft, Redmond, WA) by one reviewer and a 10% sample was checked for accuracy and completeness by another.[28~~1~~] Reviewers resolved discrepancies through consensus. Extracted data included study and population characteristics, description of the social media tools used, objective of the tools, outcomes measured, and authors' conclusions.[29~~2~~] Studies that examined social media as one component of a complex intervention were noted as such. Additional data were collected for randomized controlled trials (RCTs), including the primary outcome and its statistical significance.

Data synthesis

Data were synthesized descriptively in order to map different aspects of the literature as outlined in our key questions. Studies were grouped according to tool, audience, and study design, with data from RCTs examined in more detail. As discussion forums were not included in our original classification scheme, findings are presented both for all included studies and for studies that investigated tools other than discussion forums. Descriptive statistics were calculated using StataIC 11 (StataCorp, College Station, TX).

Results

Two hundred eighty four studies were included in the review. Figure 1 outlines the flow of studies through the inclusion process and Table 2 provides a description of included studies. Most studies (179/284; 63.0%) were conducted in North America, with more than half of the total sample (154/284; 54.2%) carried out in the United States and 8.8% (25/284) conducted in Canada. The median start date was in 2006 (range 1997 – 2011); when studies evaluating discussion forums were excluded, the start date was more recent (median 2008, range 2000 – 2011). Studies tended to be fairly short, with a median duration of 5 months (range 1 – 117 months). Nearly all included studies were published as journal articles (255/284; 89.8%); however, when studies of discussion forums were excluded, the proportion of dissertations written on the use of social media increased (14/284 to 12/95; 4.9% to 12.6%).

Social media tools used

The social media tools studied are outlined in Table 3. The use of discussion boards and online support groups (combined as discussion forums due to their common structure and intent) dominated the literature, encompassing 189 (66.6%) included studies. Social networking sites (42/284; 14.8%) and blogs or microblogs (40/284; 14.1%) were also commonly evaluated, followed by content communities (16/284; 5.6%), collaborative projects (6/284; 2.1%), and virtual worlds (6/284; 2.1%). In 116 (40.9%) included studies, the social media tool was included as part of a complex intervention. Where existing and publicly available social media applications were studied, Facebook (16/284; 5.6%), YouTube (12/284; 4.2%), and Twitter (10/284; 3.5%) were evaluated most frequently (Figure 2).

Purposes of social media use

The most common intended use of social media was for self-care, which was described as an objective of the tool in 219 (77.1%) studies (Table 3). This was particularly relevant to discussion forums, in which 166/189 (87.8%) studies were related to self-care. Other tools were often established with similar functions to discussion forums: they provided a platform on which users could post and share their experiences with peers. Collaborative projects were often used to address health literacy, and social networking sites were commonly used for patient safety purposes, largely for documentation of adverse events. While there were few studies that addressed clinical decision-making, these were almost exclusively conducted using discussion forums.

We categorized the outcomes measured in each of the studies under patients' knowledge, patients' experience, use of services and costs, health behaviour and status, and other (Table 4). Measures of patients' experience, specifically peer-to-peer communication (135/284; 47.5%), were most common and were often outcomes related to social support among members of an online community. Measures of psychological well-being (e.g., reports of anxiety levels) and changes in self-care activities (e.g., increases in physical activity) in relation to use of the tool were also commonly evaluated (78/284 and 63/284; or 27.5% and 22.2%, respectively).

Social media user groups

A wide range of conditions were covered in the included studies (Figure 3). The largest proportion fell under the lifestyle and weight loss category (36/284; 12.7%), followed by cancer (32/284; 11.3%), and studies in the general population (22/284; 7.8%). The general population studies tended to be surveys focused on usage, demographics, and user preferences relevant to social media use for health-related purposes. No strong trends emerged showing differences between user groups in the objective of the type of social media tool or the specific application used (data not shown). In nearly all conditions investigated, the social media tool studied was intended to facilitate self-care. One exception was seen in the case of infectious disease, where 7/12 (58.3%) relevant studies were focused on health literacy. This was mainly driven by large-scale strategies to provide updates on influenza or H1N1. For specific applications used, there were clusters of studies that examined condition-specific modalities. Social networking sites were common in studies of diabetes and metabolic syndrome due to the use of TuDiabetes, an online community targeted to those affected by diabetes. Similarly, Twitter was commonly used in the context of H1N1/influenza, and PatientsLikeMe was used for a group of chronic conditions including amyotrophic lateral sclerosis, fibromyalgia, human immunodeficiency virus, mood disorders, multiple sclerosis, and Parkinson’s disease. Aside from these small clusters, most studies across all conditions were conducted using discussion forums.

Evaluation of social media use

The majority of the included studies were descriptive: 63 (22.2%) were cross-sectional and 57 (20.1%) used content analysis to outline how social media is being applied (Table 2). Qualitative studies comprised 22.9% (65/284) of the total sample; mixed methods studies 11.6% (33/284); observational studies 3.9% (11/284); and experimental studies 19.4% (55/284). Of the 33 mixed methods studies, 11 included a cross-sectional component and 20 included content analyses. Forty-eight RCTs were conducted, 45 of which were evaluating discussion forums as at least one component of the intervention. Of the remaining RCTs, one evaluated a blog, one evaluated Second Life, and one made use of Facebook and Twitter.

Overall, 186/284 (65.5%) studies concluded that there was evidence for the utility of social media, while only 15/284 (5.3%) concluded that there was not. The subset of RCTs was examined in more detail; while 35/48 (72.9%) studies presented positive conclusions, only 16/35 (45.7%) reported a statistically significant effect in relation to the primary outcome (Figure 4). All but one study with significant findings evaluated the use of a discussion forum; the other study evaluated a blog. Clusters of conditions appeared in the RCTs: 6 studies were related to lifestyle and weight loss, 3 were related to tobacco and substance use, 2 were in mental health, and 6 were in other conditions (diabetes, irritable bowel syndrome, multiple sclerosis, hearing loss, and breast cancer). The primary outcome in each of these studies was related to health behaviour and status, except two that evaluated patients’ experience and one that measured website use. The social media tool was one component of a complex intervention in all studies, making it difficult to tease out any effect specific to its use. However, improvements were found in outcomes such as changes in body weight and activity levels, tobacco or substance use, and quality of life.

Discussion

There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations. While diversity exists in terms of the tools used, their intended purposes, and the conditions studied, the majority of studies evaluate discussion forums. This could point to the popularity of discussion forums among patients and caregivers in addressing their health care concerns; however, it may also be indicative of the behaviours or preferences of the site designers. ~~Given their role in facilitating support groups, the prevalence and popularity of discussion forums suggests that patients and caregivers are interested in seeking out "someone like me" in addressing their health care concerns.~~

While general tools with broad applications (i.e., discussion forums) are commonly used, the promise of social media lies in its adaptability. Unique applications such as PatientsLikeMe and TuDiabetes have evolved out of the need to address the specific concerns of particular online communities, demonstrating the success that can be realized through tailoring a tool to the requirements of a chosen target audience. Conversely, a general tool such as Twitter has shown that it can be applied to a variety of different purposes, but has also found a specific niche in disseminating public health alerts. The ability of these platforms to be customized for different purposes is highly consistent with the principles underlying successful knowledge translation interventions.[30~~23~~]

Most studies were descriptive, but our sample also included 48 RCTs. Nearly all of the trials evaluated the effectiveness of discussion forums, leaving a research gap in the evaluation of the performance of other social media tools. Given the rapid proliferation of social media, a plethora of platforms are being used and an investigation of their benefits and harms is a logical progression of the research agenda. Similarly, next steps in research could focus on isolating the effect of the social media tool, particularly as it relates to improved patient outcomes. All of the included RCTs evaluated a complex intervention, of which the social media tool was just one component. More focused efforts to determine whether social media has an impact on its own; or whether any observed effects are attributable to the intervention overall or to the non-social media components, would be a research priority. Similarly, more in-depth examination of how the social media interventions are implemented, and specifically how and to what extent health or other professionals are involved, would contribute to a better understanding of their use. Further, additional research is needed to clarify whether the use of social media truly confers an advantage, or if the novelty of the medium is solely responsible for its use.[24-31] The contrast between the statistical significance of the primary outcome in the RCTs and the positive conclusions reported suggests that issues such as selective outcome reporting (e.g., choice of groups to compare), misrepresentation of conclusions (e.g., focus on change over time within a group, rather than differences between groups), and spin in reporting (e.g., emphasis on a positive trend) may play a more substantial role in the promotion of social media use than actual effectiveness. The fact that most interventions were evaluated by their developers may have also influenced the positive conclusions reported.

Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing supportive online communities and could have widespread applicability and utility within the health care setting.

Limitations

Social media is a relatively new concept and is continually undergoing transformations. As such, there is no universal definition, adding complexity to the process of determining study eligibility. The constantly changing nature of social media also proved challenging in defining the literature search, and the novelty of the topic made it difficult to keep the search updated due to a steady influx of new reports. However, as the focus of this scoping review was to identify broad categories of social media uses, the addition of studies published after the literature search would be unlikely to change the results.

While this scoping review focused on the peer-reviewed literature to identify how social media is being used by patient and caregiver populations, it may not encompass all of the work that has been done in the area, or cover the extent of the impact that social media has had on health care. Much of the driving force behind the use of social media has come from outside of the academic community; therefore certain constructs such as the role that Facebook plays in advocacy and community, and patient empowerment resulting from the use of Twitter have not been captured. Additionally, certain movements that have shaped social media use in health care, such as the ePatient movement[32] and Citizen Science,[33] were not included within the scope of our review. While we endeavored to be as comprehensive as possible in covering the published literature, our included patient population may not be representative of social media users as a whole.

As our inclusion criteria were intentionally broad, we included a number of different study designs, encompassing both quantitative and qualitative research. While this introduced challenges in addressing the nuances of each type of study, the end result is a comprehensive overview of the state of the literature. Further syntheses of the evidence in specific topics, clinical areas, and populations will be able to provide more focus on some of these details.

Conclusions

This scoping review provides a map of the existing literature evaluating the use of social media in patient and caregiver populations. The available evidence is extensive, and most studies to date have been descriptive in nature. Given such widespread use of social media, evaluations of effectiveness are also needed. While positive conclusions are commonly reported, these may not be reflective of the actual findings.

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Contributors: MPH, SDS, LMG, and LH designed the study. MPH coordinated the project and is guarantor. MPH, AC, and JS screened articles and performed data extraction. AM contributed to the conception of the study and conducted the literature search. MPH, AC, JS, and LH interpreted the data. MPH drafted and all authors critically reviewed the manuscript. All authors read and approved the manuscript.

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Table 1. Categorization of social media tools

Tool	Description	Examples
Collaborative projects	Enable the joint and simultaneous creation of content by many end-users.	Wikis (e.g., Wikipedia) Social bookmarking applications (e.g., Mendeley)
Blogs or microblogs	Websites that display date-stamped entries. They are usually managed by one person but provide the opportunity to interact with others through the addition of comments.	Wordpress Twitter (microblog)
Content communities	Allow for the sharing of media content between users, including text, photos, videos, and presentations.	BookCrossing Flickr YouTube Slideshare
Social networking sites	Enable users to connect by creating personal information profiles that can be accessed by friends and colleagues, and by sending emails and instant messages between each other.	Facebook MySpace LinkedIn
Virtual worlds	Platforms that replicate a 3D environment in which users can appear in the form of personalized avatars and interact with each other as they would in real life.	Second Life

Table 2. Description of included studies

Variable	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Continent of corresponding author		
Asia	12 (4.2)	5 (5.3)
Australia	14 (4.9)	3 (3.2)
Europe	78 (27.5)	19 (20.0)
North America	179 (63.0)	67 (70.5)
Not reported	1 (0.4)	1 (1.1)
Study start date – median (range)	2006 (1997 – 2011)	2008 (2000 – 2011)
Study duration – median (range)	5 months (1– 117)	3 months (1 – 117)
Sample size – median (range)	124 (1 – 16,703)*	130 (2 – 16,703)*
Publication type		
Journal article	255 (89.8)	75 (79.0)
Abstract	15 (5.3)	8 (8.4)
Dissertation	14 (4.9)	12 (12.6)
Study design		
Quantitative		
Randomized controlled trial	48 (16.9)	6 (6.3)
Non-randomized controlled trial	6 (2.1)	1 (1.1)
Controlled before-after	1 (0.4)	-
Observational	11 (3.9)	3 (3.2)
Cross-sectional	63 (22.2)	33 (34.7)
Qualitative		
Case study	1 (0.4)	-
Case series	3 (1.1)	2 (2.1)
Ethnography	3 (1.1)	2 (2.1)
Grounded theory	6 (2.1)	2 (2.1)
Phenomenology	6 (2.1)	1 (1.1)
Qualitative (other/not specified)	46 (16.2)	16 (16.8)
Mixed methods	33 (11.6)	9 (9.5)
Other		
Content analysis	57 (20.1)	20 (21.1)
Authors' conclusions		
Positive	186 (65.5)	56 (59.0)
Neutral	65 (22.9)	23 (24.2)
Negative	15 (5.3)	10 (10.5)
Indeterminate	18 (6.3)	6 (6.3)

*Excluding one study that examined >3,000,000 tweets.

Table 3. Description and objectives of social media tools used (N=284)

Tool	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Collaborative project	6 (2.1)	5 (83.3)	-	-	-	1 (16.7)
Blog or microblog	40 (14.1)	11 (27.5)	-	24 (60.0)	4 (10.0)	9 (22.5)
Content community	16 (5.6)	8 (50.0)	-	5 (31.3)	2 (12.5)	4 (25.0)
Social networking site	42 (14.8)	10 (23.8)	1 (2.4)	24 (57.1)	8 (19.1)	9 (21.4)
Virtual world	6 (2.1)	3 (50.0)	-	3 (50.0)	1 (16.7)	1 (16.7)
Discussion forum	189 (66.6)	23 (12.2)	6 (3.2)	166 (87.8)	3 (1.6)	17 (9.0)
Component of a complex intervention	116 (40.9)	16 (13.8)	3 (2.6)	108 (93.1)	4 (3.5)	3 (2.6)

*Percentages do not add up to 100 due to the possibility of multiple tools and multiple objectives per study.

Table 4. Outcomes measured by social media tool

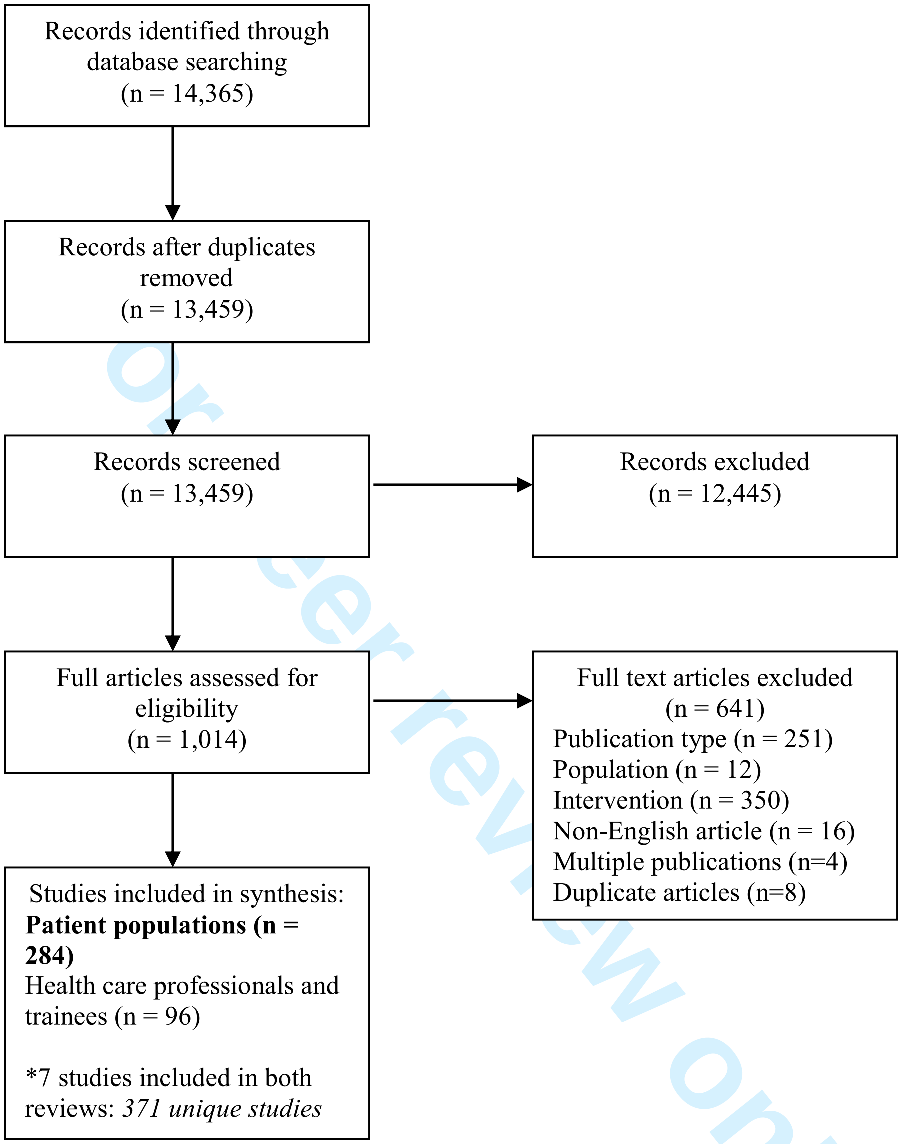
Outcomes	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Patients' knowledge		
Conditions and complications	54 (19.0)	22 (23.2)
Self-care	60 (21.1)	17 (17.9)
Treatment options	22 (7.8)	10 (10.5)
Comprehension	2 (0.7)	1 (1.1)
Patients' experience		
Satisfaction	69 (24.3)	21 (22.1)
Clinician-patient communication	39 (13.7)	16 (16.8)
Peer-to-peer communication	135 (47.5)	44 (46.3)
Quality of life	20 (7.0)	2 (2.1)
Psychological well-being	78 (27.5)	21 (22.1)
Self-efficacy	32 (11.3)	4 (4.2)
Involvement and empowerment	22 (7.8)	6 (6.3)
Use of services and costs		
Hospital admission rates	4 (1.4)	2 (2.1)
Emergency admission rates	2 (0.7)	-
Number of visits to general practitioners	7 (2.5)	2 (2.1)
Cost effectiveness	4 (1.4)	3 (3.2)
Health behaviour and status		
Self-care activities	63 (22.2)	15 (15.8)
Treatment adherence	13 (4.6)	1 (1.1)
Severity of disease or symptoms	17 (6.0)	4 (4.2)
Physical functioning	21 (7.4)	6 (6.3)
Mental functioning	25 (8.8)	8 (8.4)
Clinical indicators	23 (8.1)	3 (3.2)
Other		
Attitudes and preferences	14 (4.9)	7 (7.4)
Content and accuracy	33 (11.6)	21 (22.1)
Usability	9 (3.2)	2 (2.1)
Usage and demographics	106 (37.3)	34 (35.8)

*Percentages do not add up to 100 due to the possibility of multiple outcomes per study

Table 5. Social media objectives by authors' conclusions (N=284)

Conclusions	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Positive	186 (65.5)	28 (59.6)	6 (85.7)	149 (68.0)	14 (73.7)	21 (53.8)
Neutral	65 (22.9)	12 (25.5)	1 (14.3)	47 (21.5)	1 (5.3)	13 (33.3)
Negative	15 (5.3)	5 (10.6)	-	7 (3.2)	3 (15.8)	3 (7.7)
Indeterminate	18 (6.3)	2 (4.3)	-	16 (7.3)	1 (5.3)	2 (5.1)

Figure 1. Flow diagram of included studies



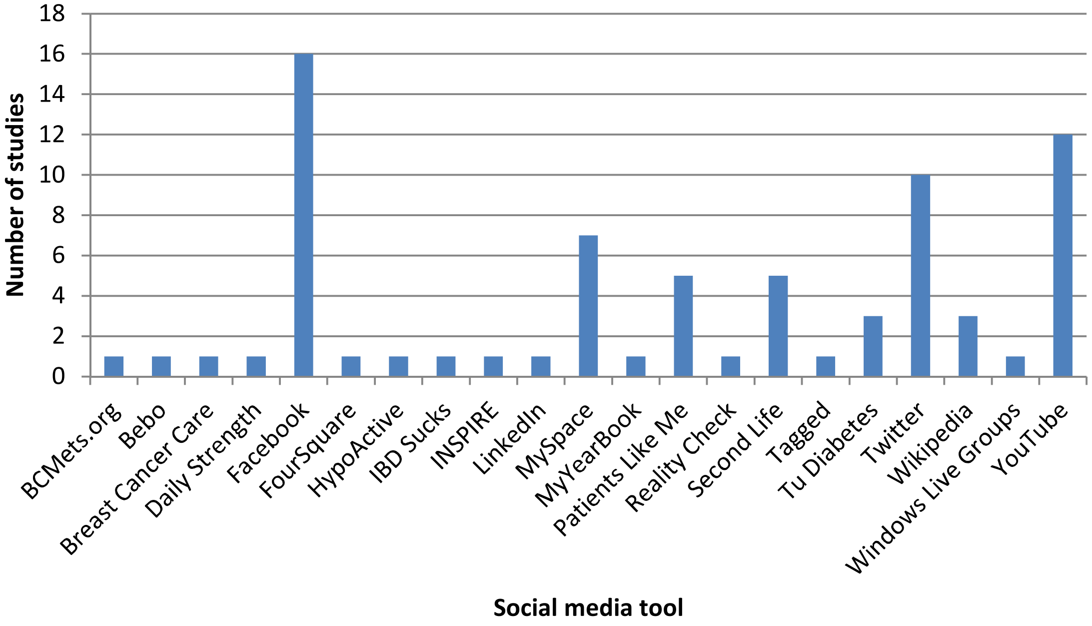
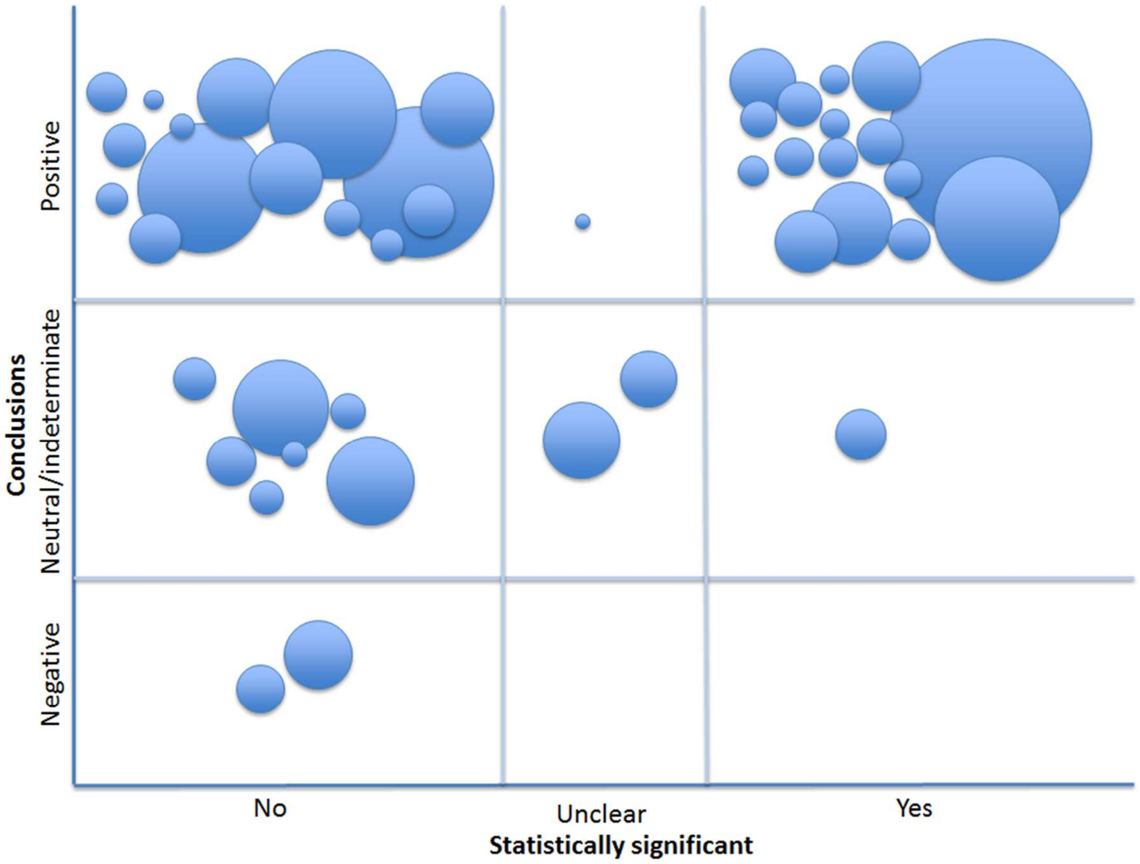


Figure 2. Specific social media tools described in included studies

Figure 3. Word cloud representing the conditions included in the study populations. The size of each term is proportional to its representation in the review.


Conclusions
Positive
Neutral/indeterminate
Negative
No
Unclear
Yes
Statistically significant

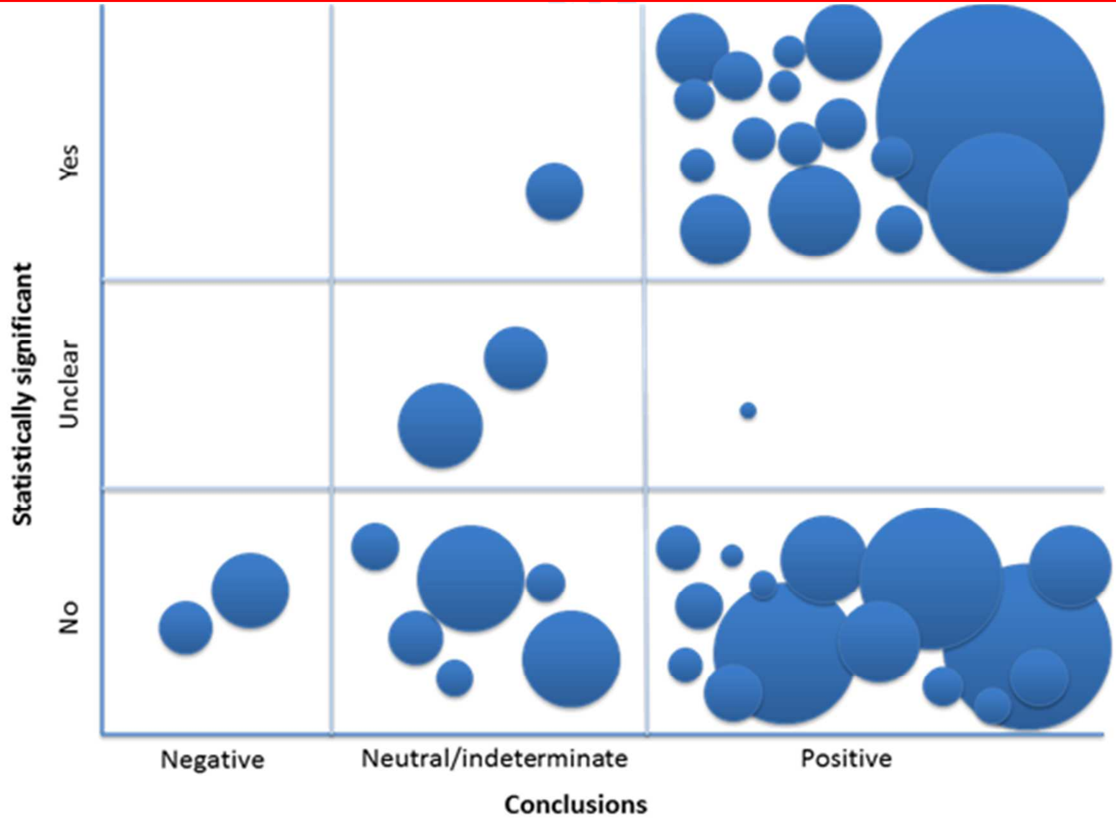

Statistically significant
Yes
Unclear
No
Negative
Neutral/indeterminate
Positive
Conclusions

Figure 4. Authors' conclusions by statistical significance and sample size among randomized controlled trials. Each bubble represents one study and its size is proportional to the number of individuals evaluated.

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Appendix. Search strategy for Medline

Database: Medline via Ovid <1946 to Present>

Search Title: Social Media Scoping Review 1.4 all SD filters | Medline – 15Dec2011 – AM

Date Searched: 13 January 2012

Limits: Year of publication ≥2000; RCT/CCT, SR, observational, qualitative study filters applied

Results: 5,468 (Ovid duplicate removal function applied)

Internet and social media related MeSH [Medical Subject Headings]
1. exp Internet/
2. Electronic Mail/
3. Mass Media/td, ut
4. Hypermedia/
5. Online Systems/td, ut
6. Medical Informatics/
7. User-Computer Interface/
8. Computer-Assisted Instruction/
9. Computers/td, ut
10. Search Engine/
11. Computer Communication Networks/
12. Information Dissemination/
13. Therapy, Computer-Assisted/
14. "Marketing of Health Services"/
15. Social Marketing/
16. exp Social Environment/
17. **Internet.mp. and (or/12-16)** [Internet combined with broader social network/computer terms]

Internet and social medial related keywords
18. (digital adj5 platform*).mp.
19. (website* or web site* or webpage* or web page*).mp.
20. Googl*.mp.
21. Facebook*.mp.
22. YouTube.mp.
23. Second Life.mp.
24. PatientsLikeMe.mp.
25. WebMD.mp.
26. elluminate.mp.
27. flickr.mp.
28. moodle.mp.
29. picsearch.mp.
30. skype.mp.
31. ustream.mp.
32. zotero.mp.
33. ((e or electronic) adj3 newsletter*).mp.
34. (viral adj5 market*).mp.
35. (banner adj5 ad*).mp.
36. ("Web 2.0" or "Web 2").mp.
37. "Health 2.0".mp.

38. "Medicine 2.0".mp.
39. (Social adj3 network*).mp.
40. linkedin.mp.
41. blog*.mp.
42. wiki*.mp.
43. podcast*.mp.
44. really simple syndicat*.mp.
45. (rss adj3 (reader* or feed*)).mp.
46. (forum* adj3 (internet or web* or chat*)).mp.
47. content communit*.mp.
48. user generated content.mp.
49. microblog*.mp.
50. (twitter or tweet*).mp.
51. (("peer to peer" adj5 network*) or P2P).mp.
52. (social adj3 media*).mp.
53. i-phone*.mp.
54. myspace.mp.
55. smartphone*.mp.

56. **or/1-11,17-55** [Internet/social media MeSH and keywords] (**92,578**)

Health care education/promotion terms

57. exp Health/
58. "Delivery of Health Care"/
59. health behavior/
60. exp Health Education/
61. exp Health Promotion/
62. Patient Care/
63. Patient Participation/
64. medical education/
65. ((patient* or physician* or nurse* or pharm* or "health care profession*") adj2 (teach* or train* or instruction* or intervention* or program* or inform* or educat* or outcome*)).mp.

66. **or/57-65** [Health promotion/health outcome terms] (**624,172**)

67. **and/56,66** [social media + health promotion/outcome terms] (**15,219**)

Search filters to stream out non-research papers

RCT Filter

68. randomized controlled trial.pt.
69. controlled clinical trial.pt.
70. randomized.ab.
71. placebo.ab.
72. exp Clinical Trials as Topic/
73. randomly.ab.
74. trial.ti.
75. or/68-74
76. exp animals/ not humans.sh.
77. **75 not 76** [Cochrane RCT filter to max sensitivity and precision] (**730,963**)

SR Filter

78. meta analysis.mp,pt.
79. review.pt.
80. search*.tw.
81. **or/78-80** [HIRU SR filter to balance sensitivity and specificity] (**1,779,109**)

Observational Study Filter

82. epidemiologic studies/
83. exp Case-Control Studies/
84. exp Cohort Studies/
85. case control.tw.
86. (cohort adj (study or studies)).tw.
87. cohort analy*.tw.
88. (follow up adj (study or studies)).tw.
89. (observational adj (study or studies)).tw.
90. longitudinal.tw.
91. retrospective.tw.
92. cross sectional.tw.
93. Cross-Sectional Studies/
94. **or/82-93** [SIGN observational study filter] (**1,508,983**)

Qualitative Research Filter

95. interview*.tw.
96. experience*.mp.
97. qualitative.tw.
98. **or/95-97** [HIRU qualitative study filter] (**756,921**)

99. or/77,81,94,98 [combination of all search filters] (**4,143,826**)

100. and/67,99 [combination of social media terms + health ed terms + SD filters] (**6,589**)

101. limit 100 to humans (**6,234**)
102. limit 101 to yr="2000 -Current" (**5,524**)
103. remove duplicates from 102 (**5,468**)

Social media use among patients and caregivers: a scoping review

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Manuscript ID:	bmjopen-2013-002819.R2
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Social media use among patients and caregivers: a scoping review

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Abstract

Objective: To map the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Design: Scoping review.

Data sources: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest (2000-2012).

Study selection: Studies reporting primary research on the use of social media (collaborative projects, blogs/microblogs, content communities, social networking sites, virtual worlds) by patients or caregivers.

Data extraction: Two reviewers screened studies for eligibility; one reviewer extracted data from relevant studies and a second performed verification for accuracy and completeness on a 10% sample. Data were analyzed to describe which social media tools are being used, by whom, for what purpose, and how they are being evaluated.

Results: Two hundred eighty four studies were included. Discussion forums were highly prevalent and constitute 66.6% of the sample. Social networking sites (14.8%) and blogs/microblogs (14.1%) were the next most commonly used tools. The intended purpose of the tool was to facilitate self-care in 77.1% of studies. While there were clusters of studies that focused on similar conditions (e.g., lifestyle/weight loss (12.7%), cancer (11.3%)), there were no patterns in the objectives or tools used. A large proportion of the studies were descriptive (42.3%), however there were also 48 (16.9%) randomized controlled trials (RCTs). Among the RCTs, 35.4% reported statistically significant results favouring the social media intervention

being evaluated; however 72.9% presented positive conclusions regarding the use of social media.

Conclusions: There is an extensive body of literature examining the use of social media in patient and caregiver populations. Much of this work is descriptive; however with such widespread use, evaluations of effectiveness are required. In studies that have examined effectiveness, positive conclusions are often reported, despite non-significant findings.

Word count: 297

Article summary

Article focus

- The use of social media in health care has been widely advocated, but there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations.

- We mapped the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Key messages

- There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations.

- Most studies have been descriptive; however with such widespread use, evaluations of effectiveness are needed.

- In studies that have examined effectiveness, positive conclusions are often reported, despite non-significant findings.

Strengths and limitations of this study

- Our search was comprehensive and we included an extensive body of literature, across conditions, populations, and study designs.

- Social media is constantly evolving, leading to challenges in keeping the search updated.

- More in-depth analysis is needed on specific topics, conditions, and populations to guide the use and implementation of social media interventions.

Introduction

The use of social media in health care has been widely advocated;[1-8] however, there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations. It is clear, though, that in addition to seeking out traditional sources of health care information, patients are increasingly active online.[9] In 2011, looking for health care information was the third most common online activity[10] and in September 2012, 72% of adult Internet users sought support and medical information online.[11] In 2012, 67% of Internet users were using social media for any purpose[12] and 26% were using it for health issues.[11] As social media continues to evolve, its momentum shows no sign of diminishing, instead finding new niches with unique applications.

Social media can be defined as a group of online applications that allow for the creation and exchange of user-generated content, and can be categorized into five groups: 1) collaborative projects (e.g., Wikipedia); 2) blogs or microblogs (e.g., Blogger, Twitter); 3) content communities (e.g., YouTube); 4) social networking sites (e.g., Facebook); and 5) virtual gaming or social worlds (e.g., HumanSim®).[13] The collaborative environment to which social media belongs represents a shift in technology and functionality from "Web 1.0," in which static online content and applications were created and published by individuals, to "Web 2.0," in which there is continuous modification and participation by all users.[13] Table 1 provides an overview of the categories of social media tools.

Advocates of the use of social media in health care suggest that these tools allow for personalization, presentation, and participation – three key elements that make them highly

effective.[14] The content can be tailored to the priorities of the users, the versatility of the different platforms creates numerous options for the presentation of information, and the collaborative nature of social media allows for a meaningful contribution from all user groups. The idea of a synergistic relationship between social media users is one of the main perceived advantages of using these platforms.[15] However, criticisms of the use of social media in health care have also arisen. The availability of misinformation is a risk, as health care providers are unable to control the content that is posted or discussed.[1,16,17] Inappropriate substitution of online information or advice for in-person visits to a health care provider can also potentially lead to harmful results, and this has been cited as a limitation of the use of social media and of the Internet generally.[1.18] Negative uses of social media have also been highlighted in the context of professionalism and confidentiality,[19] use by children and youth due to a limited capacity for self-regulation and vulnerability to peer influence,[20] and promotion of high-risk behaviours, such as suicide-related behaviours, drug use, and eating disordered behaviours.[21-24]

The objectives of this study were to map the existing literature examining the use of social media in patient and caregiver populations, to determine the extent and type of evidence available to inform more focused knowledge syntheses, and to identify gaps for future research. The specific questions guiding this scoping review were: 1) What social media tools are being used to improve health outcomes in patient populations? 2) For what purposes are social media tools being used in patient populations (e.g., to improve health literacy, to improve self-care)? 3) For what patient populations and disease conditions are social media tools being used? 4) What types of evidence and research designs (i.e., qualitative, quantitative) have been used to examine social media tools?

Methods

This scoping review on the use of social media in patient and caregiver populations was conducted in parallel with a review on the use of social media in health care professional and trainee populations;[25] therefore the literature search and screening for study eligibility were conducted concurrently. The review followed a protocol that we developed *a priori*.

Search strategy

A research librarian searched 11 databases in January 2012: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest. Dates were restricted to 2000 or later, corresponding to the advent of Web 2.0. No language or study design restrictions were applied. The search strategy for Medline is provided in the Appendix.

Study selection

Two reviewers independently screened titles and abstracts of studies for eligibility. The full text of studies assessed as "relevant" or "unclear" was then independently evaluated by two reviewers using a standard form. Discrepancies were resolved by consensus or adjudication by a third party.

Studies were included if they reported primary research (quantitative or qualitative), focused on health care issues related to patients or caregivers, and examined the use of a social media tool. Social media was defined according to Kaplan and Haenlein's classification scheme,[13] including:

collaborative projects, blogs or microblogs, content communities, social networking sites, and virtual worlds. We excluded studies that examined mobile health (e.g., tracking or medical reference apps), one-way transmission of content (e.g., podcasts), and real-time exchanges mediated by technology (e.g., Skype, chat rooms). Electronic discussion forums and bulletin boards were included as they incorporate user-generated content and were judged to fall within the spectrum of social media. Outcomes were not defined *a priori* as they were to be incorporated into our description of the field. Likely categories for objectives and outcomes were adapted from those outlined in Coulter and Ellins' proposed framework for strategies to inform, educate, and involve patients.[26,27]

Data extraction

Data were extracted using standardized forms and entered into Microsoft Excel (Microsoft, Redmond, WA) by one reviewer and a 10% sample was checked for accuracy and completeness by another.[28] Reviewers resolved discrepancies through consensus. Extracted data included study and population characteristics, description of the social media tools used, objective of the tools, outcomes measured, and authors' conclusions.[29] Studies that examined social media as one component of a complex intervention were noted as such. Additional data were collected for randomized controlled trials (RCTs), including the primary outcome and its statistical significance.

Data synthesis

Data were synthesized descriptively in order to map different aspects of the literature as outlined in our key questions. Studies were grouped according to tool, audience, and study design, with data from RCTs examined in more detail. As discussion forums were not included in our original classification scheme, findings are presented both for all included studies and for studies that investigated tools other than discussion forums. Descriptive statistics were calculated using StataIC 11 (StataCorp, College Station, TX).

Results

Two hundred eighty four studies were included in the review. Figure 1 outlines the flow of studies through the inclusion process and Table 2 provides a description of included studies. Most studies (179/284; 63.0%) were conducted in North America, with more than half of the total sample (154/284; 54.2%) carried out in the United States and 8.8% (25/284) conducted in Canada. The median start date was in 2006 (range 1997 – 2011); when studies evaluating discussion forums were excluded, the start date was more recent (median 2008, range 2000 – 2011). Studies tended to be fairly short, with a median duration of 5 months (range 1 – 117 months). Nearly all included studies were published as journal articles (255/284; 89.8%); however, when studies of discussion forums were excluded, the proportion of dissertations written on the use of social media increased (14/284 to 12/95; 4.9% to 12.6%).

Social media tools used

The social media tools studied are outlined in Table 3. The use of discussion boards and online support groups (combined as discussion forums due to their common structure and intent) dominated the literature, encompassing 189 (66.6%) included studies. Social networking sites (42/284; 14.8%) and blogs or microblogs (40/284; 14.1%) were also commonly evaluated, followed by content communities (16/284; 5.6%), collaborative projects (6/284; 2.1%), and virtual worlds (6/284; 2.1%). In 116 (40.9%) included studies, the social media tool was included as part of a complex intervention. Where existing and publicly available social media applications were studied, Facebook (16/284; 5.6%), YouTube (12/284; 4.2%), and Twitter (10/284; 3.5%) were evaluated most frequently (Figure 2).

Purposes of social media use

The most common intended use of social media was for self-care, which was described as an objective of the tool in 219 (77.1%) studies (Table 3). This was particularly relevant to discussion forums, in which 166/189 (87.8%) studies were related to self-care. Other tools were often established with similar functions to discussion forums: they provided a platform on which users could post and share their experiences with peers. Collaborative projects were often used to address health literacy, and social networking sites were commonly used for patient safety purposes, largely for documentation of adverse events. While there were few studies that addressed clinical decision-making, these were almost exclusively conducted using discussion forums.

We categorized the outcomes measured in each of the studies under patients' knowledge, patients' experience, use of services and costs, health behaviour and status, and other (Table 4). Measures of patients' experience, specifically peer-to-peer communication (135/284; 47.5%), were most common and were often outcomes related to social support among members of an online community. Measures of psychological well-being (e.g., reports of anxiety levels) and changes in self-care activities (e.g., increases in physical activity) in relation to use of the tool were also commonly evaluated (78/284 and 63/284; or 27.5% and 22.2%, respectively).

Social media user groups

A wide range of conditions were covered in the included studies (Figure 3). The largest proportion fell under the lifestyle and weight loss category (36/284; 12.7%), followed by cancer (32/284; 11.3%), and studies in the general population (22/284; 7.8%). The general population studies tended to be surveys focused on usage, demographics, and user preferences relevant to social media use for health-related purposes. No strong trends emerged showing differences between user groups in the objective of the type of social media tool or the specific application used (data not shown). In nearly all conditions investigated, the social media tool studied was intended to facilitate self-care. One exception was seen in the case of infectious disease, where 7/12 (58.3%) relevant studies were focused on health literacy. This was mainly driven by large-scale strategies to provide updates on influenza or H1N1. For specific applications used, there were clusters of studies that examined condition-specific modalities. Social networking sites were common in studies of diabetes and metabolic syndrome due to the use of TuDiabetes, an online community targeted to those affected by diabetes. Similarly, Twitter was commonly used in the context of H1N1/influenza, and PatientsLikeMe was used for a group of chronic conditions including amyotrophic lateral sclerosis, fibromyalgia, human immunodeficiency virus, mood disorders, multiple sclerosis, and Parkinson's disease. Aside from these small clusters, most studies across all conditions were conducted using discussion forums.

Evaluation of social media use

The majority of the included studies were descriptive: 63 (22.2%) were cross-sectional and 57 (20.1%) used content analysis to outline how social media is being applied (Table 2). Qualitative studies comprised 22.9% (65/284) of the total sample; mixed methods studies 11.6% (33/284); observational studies 3.9% (11/284); and experimental studies 19.4% (55/284). Of the 33 mixed methods studies, 11 included a cross-sectional component and 20 included content analyses. Forty-eight RCTs were conducted, 45 of which were evaluating discussion forums as at least one component of the intervention. Of the remaining RCTs, one evaluated a blog, one evaluated Second Life, and one made use of Facebook and Twitter.

Overall, 186/284 (65.5%) studies concluded that there was evidence for the utility of social media, while only 15/284 (5.3%) concluded that there was not. The subset of RCTs was examined in more detail; while 35/48 (72.9%) studies presented positive conclusions, only 16/35 (45.7%) reported a statistically significant effect in relation to the primary outcome (Figure 4). All but one study with significant findings evaluated the use of a discussion forum; the other study evaluated a blog. Clusters of conditions appeared in the RCTs: 6 studies were related to lifestyle and weight loss, 3 were related to tobacco and substance use, 2 were in mental health, and 6 were in other conditions (diabetes, irritable bowel syndrome, multiple sclerosis, hearing loss, and breast cancer). The primary outcome in each of these studies was related to health behaviour and status, except two that evaluated patients' experience and one that measured website use. The social media tool was one component of a complex intervention in all studies, making it difficult to tease out any effect specific to its use. However, improvements were found in outcomes such as changes in body weight and activity levels, tobacco or substance use, and quality of life.

Discussion

There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations. While diversity exists in terms of the tools used, their intended purposes, and the conditions studied, the majority of studies evaluate discussion forums. This could point to the popularity of discussion forums among patients and caregivers in addressing their health care concerns; however, it may also be indicative of the behaviours or preferences of the site designers.

While general tools with broad applications (i.e., discussion forums) are commonly used, the promise of social media lies in its adaptability. Unique applications such as PatientsLikeMe and TuDiabetes have evolved out of the need to address the specific concerns of particular online communities, demonstrating the success that can be realized through tailoring a tool to the requirements of a chosen target audience. Conversely, a general tool such as Twitter has shown that it can be applied to a variety of different purposes, but has also found a specific niche in disseminating public health alerts. The ability of these platforms to be customized for different purposes is highly consistent with the principles underlying successful knowledge translation interventions.[30]

Most studies were descriptive, but our sample also included 48 RCTs. Nearly all of the trials evaluated the effectiveness of discussion forums, leaving a research gap in the evaluation of the performance of other social media tools. Given the rapid proliferation of social media, a plethora of platforms are being used and an investigation of their benefits and harms is a logical progression of the research agenda. Similarly, next steps in research could focus on isolating the effect of the social media tool, particularly as it relates to improved patient outcomes. All of the included RCTs evaluated a complex intervention, of which the social media tool was just one component. More focused efforts to determine whether social media has an impact on its own; or whether any observed effects are attributable to the intervention overall or to the non-social media components, would be a research priority. Similarly, more in-depth examination of how the social media interventions are implemented, and specifically how and to what extent health or other professionals are involved, would contribute to a better understanding of their use. Further, additional research is needed to clarify whether the use of social media truly confers an advantage, or if the novelty of the medium is solely responsible for its use.[31] The contrast between the statistical significance of the primary outcome in the RCTs and the positive conclusions reported suggests that issues such as selective outcome reporting (e.g., choice of groups to compare), misrepresentation of conclusions (e.g., focus on change over time within a group, rather than differences between groups), and spin in reporting (e.g., emphasis on a positive trend) may play a more substantial role in the promotion of social media use than actual effectiveness. The fact that most interventions were evaluated by their developers may have also influenced the positive conclusions reported.

Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing

supportive online communities and could have widespread utility within the health care setting. However, these applications are dependent on further evidence of effectiveness.

Limitations

Social media is a relatively new concept and is continually undergoing transformations. As such, there is no universal definition, adding complexity to the process of determining study eligibility. The constantly changing nature of social media also proved challenging in defining the literature search, and the novelty of the topic made it difficult to keep the search updated due to a steady influx of new reports. However, as the focus of this scoping review was to identify broad categories of social media uses, the addition of studies published after the literature search would be unlikely to change the results.

While this scoping review focused on the peer-reviewed literature to identify how social media is being used by patient and caregiver populations, it may not encompass all of the work that has been done in the area, or cover the extent of the impact that social media has had on health care. Much of the driving force behind the use of social media has come from outside of the academic community; therefore certain constructs such as the role that Facebook plays in advocacy and community, and patient empowerment resulting from the use of Twitter have not been captured. Additionally, certain movements that have shaped social media use in health care, such as the ePatient movement[32] and Citizen Science,[33] were not included within the scope of our review. While we endeavored to be as comprehensive as possible in covering the published literature, our included patient population may not be representative of people who use social media for health generally.

As our inclusion criteria were intentionally broad, we included a number of different study designs, encompassing both quantitative and qualitative research. While this introduced challenges in addressing the nuances of each type of study, the end result is a comprehensive overview of the state of the literature. Further syntheses of the evidence in specific topics, clinical areas, and populations will be able to provide more focus on some of these details.

Conclusions

This scoping review provides a map of the existing literature evaluating the use of social media in patient and caregiver populations. The available evidence is extensive, and most studies to date have been descriptive in nature. Given such widespread use of social media, evaluations of effectiveness are also needed. While positive conclusions are commonly reported, these may not be reflective of the actual findings.

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Contributors: MPH, SDS, LMG, and LH designed the study. MPH coordinated the project and is guarantor. MPH, AC, and JS screened articles and performed data extraction. AM contributed to the conception of the study and conducted the literature search. MPH, AC, JS, and LH

interpreted the data. MPH drafted and all authors critically reviewed the manuscript. All authors read and approved the manuscript.

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Table 1. Categorization of social media tools

Tool	Description	Examples
Collaborative projects	Enable the joint and simultaneous creation of content by many end-users.	Wikis (e.g., Wikipedia) Social bookmarking applications (e.g., Mendeley)
Blogs or microblogs	Websites that display date-stamped entries. They are usually managed by one person but provide the opportunity to interact with others through the addition of comments.	Wordpress Twitter (microblog)
Content communities	Allow for the sharing of media content between users, including text, photos, videos, and presentations.	BookCrossing Flickr YouTube Slideshare
Social networking sites	Enable users to connect by creating personal information profiles that can be accessed by friends and colleagues, and by sending emails and instant messages between each other.	Facebook MySpace LinkedIn
Virtual worlds	Platforms that replicate a 3D environment in which users can appear in the form of personalized avatars and interact with each other as they would in real life.	Second Life

Table 2. Description of included studies

Variable	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Continent of corresponding author		
Asia	12 (4.2)	5 (5.3)
Australia	14 (4.9)	3 (3.2)
Europe	78 (27.5)	19 (20.0)
North America	179 (63.0)	67 (70.5)
Not reported	1 (0.4)	1 (1.1)
Study start date – median (range)	2006 (1997 – 2011)	2008 (2000 – 2011)
Study duration – median (range)	5 months (1– 117)	3 months (1 – 117)
Sample size – median (range)	124 (1 – 16,703)*	130 (2 – 16,703)*
Publication type		
Journal article	255 (89.8)	75 (79.0)
Abstract	15 (5.3)	8 (8.4)
Dissertation	14 (4.9)	12 (12.6)
Study design		
Quantitative		
Randomized controlled trial	48 (16.9)	6 (6.3)
Non-randomized controlled trial	6 (2.1)	1 (1.1)
Controlled before-after	1 (0.4)	-
Observational	11 (3.9)	3 (3.2)
Cross-sectional	63 (22.2)	33 (34.7)
Qualitative		
Case study	1 (0.4)	-
Case series	3 (1.1)	2 (2.1)
Ethnography	3 (1.1)	2 (2.1)
Grounded theory	6 (2.1)	2 (2.1)
Phenomenology	6 (2.1)	1 (1.1)
Qualitative (other/not specified)	46 (16.2)	16 (16.8)
Mixed methods	33 (11.6)	9 (9.5)
Other		
Content analysis	57 (20.1)	20 (21.1)
Authors' conclusions		
Positive	186 (65.5)	56 (59.0)
Neutral	65 (22.9)	23 (24.2)
Negative	15 (5.3)	10 (10.5)
Indeterminate	18 (6.3)	6 (6.3)

*Excluding one study that examined >3,000,000 tweets.

Table 3. Description and objectives of social media tools used (N=284)

Tool	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Collaborative project	6 (2.1)	5 (83.3)	-	-	-	1 (16.7)
Blog or microblog	40 (14.1)	11 (27.5)	-	24 (60.0)	4 (10.0)	9 (22.5)
Content community	16 (5.6)	8 (50.0)	-	5 (31.3)	2 (12.5)	4 (25.0)
Social networking site	42 (14.8)	10 (23.8)	1 (2.4)	24 (57.1)	8 (19.1)	9 (21.4)
Virtual world	6 (2.1)	3 (50.0)	-	3 (50.0)	1 (16.7)	1 (16.7)
Discussion forum	189 (66.6)	23 (12.2)	6 (3.2)	166 (87.8)	3 (1.6)	17 (9.0)
Component of a complex intervention	116 (40.9)	16 (13.8)	3 (2.6)	108 (93.1)	4 (3.5)	3 (2.6)

*Percentages do not add up to 100 due to the possibility of multiple tools and multiple objectives per study.

Table 4. Outcomes measured by social media tool

Outcomes	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Patients' knowledge		
Conditions and complications	54 (19.0)	22 (23.2)
Self-care	60 (21.1)	17 (17.9)
Treatment options	22 (7.8)	10 (10.5)
Comprehension	2 (0.7)	1 (1.1)
Patients' experience		
Satisfaction	69 (24.3)	21 (22.1)
Clinician-patient communication	39 (13.7)	16 (16.8)
Peer-to-peer communication	135 (47.5)	44 (46.3)
Quality of life	20 (7.0)	2 (2.1)
Psychological well-being	78 (27.5)	21 (22.1)
Self-efficacy	32 (11.3)	4 (4.2)
Involvement and empowerment	22 (7.8)	6 (6.3)
Use of services and costs		
Hospital admission rates	4 (1.4)	2 (2.1)
Emergency admission rates	2 (0.7)	-
Number of visits to general practitioners	7 (2.5)	2 (2.1)
Cost effectiveness	4 (1.4)	3 (3.2)
Health behaviour and status		
Self-care activities	63 (22.2)	15 (15.8)
Treatment adherence	13 (4.6)	1 (1.1)
Severity of disease or symptoms	17 (6.0)	4 (4.2)
Physical functioning	21 (7.4)	6 (6.3)
Mental functioning	25 (8.8)	8 (8.4)
Clinical indicators	23 (8.1)	3 (3.2)
Other		
Attitudes and preferences	14 (4.9)	7 (7.4)
Content and accuracy	33 (11.6)	21 (22.1)
Usability	9 (3.2)	2 (2.1)
Usage and demographics	106 (37.3)	34 (35.8)

*Percentages do not add up to 100 due to the possibility of multiple outcomes per study

Table 5. Social media objectives by authors' conclusions (N=284)

Conclusions	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Positive	186 (65.5)	28 (59.6)	6 (85.7)	149 (68.0)	14 (73.7)	21 (53.8)
Neutral	65 (22.9)	12 (25.5)	1 (14.3)	47 (21.5)	1 (5.3)	13 (33.3)
Negative	15 (5.3)	5 (10.6)	-	7 (3.2)	3 (15.8)	3 (7.7)
Indeterminate	18 (6.3)	2 (4.3)	-	16 (7.3)	1 (5.3)	2 (5.1)

Figure legends:

Figure 1. Flow diagram of included studies
Figure 2. Specific social media tools described in included studies
Figure 3. Word cloud representing the conditions included in the study populations. The size of each term is proportional to its representation in the review.
Figure 4. Authors' conclusions by statistical significance and sample size among randomized controlled trials. Each bubble represents one study and its size is proportional to the number of individuals evaluated.

Social media use among patients and caregivers: a scoping review

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Abstract

Objective: To map the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Design: Scoping review.

Data sources: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest (2000-2012).

Study selection: Studies reporting primary research on the use of social media (collaborative projects, blogs/microblogs, content communities, social networking sites, virtual worlds) by patients or caregivers.

Data extraction: Two reviewers screened studies for eligibility; one reviewer extracted data from relevant studies and a second performed verification for accuracy and completeness on a 10% sample. Data were analyzed to describe which social media tools are being used, by whom, for what purpose, and how they are being evaluated.

Results: Two hundred eighty four studies were included. Discussion forums were highly prevalent and constitute 66.6% of the sample. Social networking sites (14.8%) and blogs/microblogs (14.1%) were the next most commonly used tools. The intended purpose of the tool was to facilitate self-care in 77.1% of studies. While there were clusters of studies that focused on similar conditions (e.g., lifestyle/weight loss (12.7%), cancer (11.3%)), there were no patterns in the objectives or tools used. A large proportion of the studies were descriptive (42.3%), however there were also 48 (16.9%) randomized controlled trials (RCTs). Among the RCTs, 35.4% reported statistically significant results favouring the social media intervention

being evaluated; however 72.9% presented positive conclusions regarding the use of social media.

Conclusions: There is an extensive body of literature examining the use of social media in patient and caregiver populations. Much of this work is descriptive; however with such widespread use, evaluations of effectiveness are required. In studies that have examined effectiveness, positive conclusions are often reported, despite non-significant findings.

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Article summary

Article focus

- The use of social media in health care has been widely advocated, but there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations.

- We mapped the state of the existing literature evaluating the use of social media in patient and caregiver populations.

Key messages

- There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations.

- Most studies have been descriptive; however with such widespread use, evaluations of effectiveness are needed.

- In studies that have examined effectiveness, positive conclusions are often reported, despite non-significant findings.

Strengths and limitations of this study

- Our search was comprehensive and we included an extensive body of literature, across conditions, populations, and study designs.

- Social media is constantly evolving, leading to challenges in keeping the search updated.

- More in-depth analysis is needed on specific topics, conditions, and populations to guide the use and implementation of social media interventions.

Introduction

The use of social media in health care has been widely advocated;[1-8] however, there is little evidence describing the current state of the science and whether or not these tools can be used to benefit patient populations. It is clear, though, that in addition to seeking out traditional sources of health care information, patients are increasingly active online.[9] In 2011, looking for health care information was the third most common online activity~~;~~[10] and in September 2012, 72% of adult Internet users sought support and medical information online.~~,~~[11] ~~and in December~~ In 2012, 67% of Internet users were using social media for any purpose~~.~~[12] and 26% were using it for health issues.[11] As social media continues to evolve, its momentum shows no sign of diminishing, instead finding new niches with unique applications.

Social media can be defined as a group of online applications that allow for the creation and exchange of user-generated content, and can be categorized into five groups: 1) collaborative projects (e.g., Wikipedia); 2) blogs or microblogs (e.g., Blogger, Twitter); 3) content communities (e.g., YouTube); 4) social networking sites (e.g., Facebook); and 5) virtual gaming or social worlds (e.g., HumanSim®).[13] The collaborative environment to which social media belongs represents a shift in technology and functionality from "Web 1.0," in which static online content and applications were created and published by individuals, to "Web 2.0," in which there is continuous modification and participation by all users.[13] Table 1 provides an overview of the categories of social media tools.

Advocates of the use of social media in health care suggest that these tools allow for personalization, presentation, and participation – three key elements that make them highly

effective.[14] The content can be tailored to the priorities of the users, the versatility of the different platforms creates numerous options for the presentation of information, and the collaborative nature of social media allows for a meaningful contribution from all user groups. The idea of a synergistic relationship between social media users is one of the main perceived advantages of using these platforms.[15] However, criticisms of the use of social media in health care have also arisen. The availability of misinformation is a risk, as health care providers are unable to control the content that is posted or discussed.[1,16,17] Inappropriate substitution of online information or advice for in-person visits to a health care provider can also potentially lead to harmful results, and this has been cited as a limitation of the use of social media and of the Internet generally.[1.18] Negative uses of social media have also been highlighted in the context of professionalism and confidentiality,[19] use by children and youth due to a limited capacity for self-regulation and vulnerability to peer influence,[20] and promotion of high-risk behaviours, such as suicide-related behaviours, drug use, and eating disordered behaviours.[21-24]

The objectives of this study were to map the existing literature examining the use of social media in patient and caregiver populations, to determine the extent and type of evidence available to inform more focused knowledge syntheses, and to identify gaps for future research. The specific questions guiding this scoping review were: 1) What social media tools are being used to improve health outcomes in patient populations? 2) For what purposes are social media tools being used in patient populations (e.g., to improve health literacy, to improve self-care)? 3) For what patient populations and disease conditions are social media tools being used? 4) What types of evidence and research designs (i.e., qualitative, quantitative) have been used to examine social media tools?

Methods

This scoping review on the use of social media in patient and caregiver populations was conducted in parallel with a review on the use of social media in health care professional and trainee populations;[25] therefore the literature search and screening for study eligibility were conducted concurrently. The review followed a protocol that we developed *a priori*.

Search strategy

A research librarian searched 11 databases in January 2012: Medline, CENTRAL, ERIC, PubMed, CINAHL Plus Full Text, Academic Search Complete, Alt Health Watch, Health Source, Communication and Mass Media Complete, Web of Knowledge, and ProQuest. Dates were restricted to 2000 or later, corresponding to the advent of Web 2.0. No language or study design restrictions were applied. The search strategy for Medline is provided in the Appendix.

Study selection

Two reviewers independently screened titles and abstracts of studies for eligibility. The full text of studies assessed as “relevant” or “unclear” was then independently evaluated by two reviewers using a standard form. Discrepancies were resolved by consensus or adjudication by a third party.

Studies were included if they reported primary research (quantitative or qualitative), focused on health care issues related to patients or caregivers, and examined the use of a social media tool. Social media was defined according to Kaplan and Haenlein’s classification scheme,[13] including:

collaborative projects, blogs or microblogs, content communities, social networking sites, and virtual worlds. We excluded studies that examined mobile health (e.g., tracking or medical reference apps), one-way transmission of content (e.g., podcasts), and real-time exchanges mediated by technology (e.g., Skype, chat rooms). Electronic discussion forums and bulletin boards were included as they incorporate user-generated content and were judged to fall within the spectrum of social media. Outcomes were not defined *a priori* as they were to be incorporated into our description of the field. Likely categories for objectives and outcomes were adapted from those outlined in Coulter and Ellins' proposed framework for strategies to inform, educate, and involve patients.[26,27]

Data extraction

Data were extracted using standardized forms and entered into Microsoft Excel (Microsoft, Redmond, WA) by one reviewer and a 10% sample was checked for accuracy and completeness by another.[28] Reviewers resolved discrepancies through consensus. Extracted data included study and population characteristics, description of the social media tools used, objective of the tools, outcomes measured, and authors' conclusions.[29] Studies that examined social media as one component of a complex intervention were noted as such. Additional data were collected for randomized controlled trials (RCTs), including the primary outcome and its statistical significance.

Data synthesis

Data were synthesized descriptively in order to map different aspects of the literature as outlined in our key questions. Studies were grouped according to tool, audience, and study design, with data from RCTs examined in more detail. As discussion forums were not included in our original classification scheme, findings are presented both for all included studies and for studies that investigated tools other than discussion forums. Descriptive statistics were calculated using StataIC 11 (StataCorp, College Station, TX).

Results

Two hundred eighty four studies were included in the review. Figure 1 outlines the flow of studies through the inclusion process and Table 2 provides a description of included studies. Most studies (179/284; 63.0%) were conducted in North America, with more than half of the total sample (154/284; 54.2%) carried out in the United States and 8.8% (25/284) conducted in Canada. The median start date was in 2006 (range 1997 – 2011); when studies evaluating discussion forums were excluded, the start date was more recent (median 2008, range 2000 – 2011). Studies tended to be fairly short, with a median duration of 5 months (range 1 – 117 months). Nearly all included studies were published as journal articles (255/284; 89.8%); however, when studies of discussion forums were excluded, the proportion of dissertations written on the use of social media increased (14/284 to 12/95; 4.9% to 12.6%).

Social media tools used

The social media tools studied are outlined in Table 3. The use of discussion boards and online support groups (combined as discussion forums due to their common structure and intent) dominated the literature, encompassing 189 (66.6%) included studies. Social networking sites (42/284; 14.8%) and blogs or microblogs (40/284; 14.1%) were also commonly evaluated, followed by content communities (16/284; 5.6%), collaborative projects (6/284; 2.1%), and virtual worlds (6/284; 2.1%). In 116 (40.9%) included studies, the social media tool was included as part of a complex intervention. Where existing and publicly available social media applications were studied, Facebook (16/284; 5.6%), YouTube (12/284; 4.2%), and Twitter (10/284; 3.5%) were evaluated most frequently (Figure 2).

Purposes of social media use

The most common intended use of social media was for self-care, which was described as an objective of the tool in 219 (77.1%) studies (Table 3). This was particularly relevant to discussion forums, in which 166/189 (87.8%) studies were related to self-care. Other tools were often established with similar functions to discussion forums: they provided a platform on which users could post and share their experiences with peers. Collaborative projects were often used to address health literacy, and social networking sites were commonly used for patient safety purposes, largely for documentation of adverse events. While there were few studies that addressed clinical decision-making, these were almost exclusively conducted using discussion forums.

We categorized the outcomes measured in each of the studies under patients' knowledge, patients' experience, use of services and costs, health behaviour and status, and other (Table 4). Measures of patients' experience, specifically peer-to-peer communication (135/284; 47.5%), were most common and were often outcomes related to social support among members of an online community. Measures of psychological well-being (e.g., reports of anxiety levels) and changes in self-care activities (e.g., increases in physical activity) in relation to use of the tool were also commonly evaluated (78/284 and 63/284; or 27.5% and 22.2%, respectively).

Social media user groups

A wide range of conditions were covered in the included studies (Figure 3). The largest proportion fell under the lifestyle and weight loss category (36/284; 12.7%), followed by cancer (32/284; 11.3%), and studies in the general population (22/284; 7.8%). The general population studies tended to be surveys focused on usage, demographics, and user preferences relevant to social media use for health-related purposes. No strong trends emerged showing differences between user groups in the objective of the type of social media tool or the specific application used (data not shown). In nearly all conditions investigated, the social media tool studied was intended to facilitate self-care. One exception was seen in the case of infectious disease, where 7/12 (58.3%) relevant studies were focused on health literacy. This was mainly driven by large-scale strategies to provide updates on influenza or H1N1. For specific applications used, there were clusters of studies that examined condition-specific modalities. Social networking sites were common in studies of diabetes and metabolic syndrome due to the use of TuDiabetes, an online community targeted to those affected by diabetes. Similarly, Twitter was commonly used in the context of H1N1/influenza, and PatientsLikeMe was used for a group of chronic conditions including amyotrophic lateral sclerosis, fibromyalgia, human immunodeficiency virus, mood disorders, multiple sclerosis, and Parkinson's disease. Aside from these small clusters, most studies across all conditions were conducted using discussion forums.

Evaluation of social media use

The majority of the included studies were descriptive: 63 (22.2%) were cross-sectional and 57 (20.1%) used content analysis to outline how social media is being applied (Table 2). Qualitative studies comprised 22.9% (65/284) of the total sample; mixed methods studies 11.6% (33/284); observational studies 3.9% (11/284); and experimental studies 19.4% (55/284). Of the 33 mixed methods studies, 11 included a cross-sectional component and 20 included content analyses. Forty-eight RCTs were conducted, 45 of which were evaluating discussion forums as at least one component of the intervention. Of the remaining RCTs, one evaluated a blog, one evaluated Second Life, and one made use of Facebook and Twitter.

Overall, 186/284 (65.5%) studies concluded that there was evidence for the utility of social media, while only 15/284 (5.3%) concluded that there was not. The subset of RCTs was examined in more detail; while 35/48 (72.9%) studies presented positive conclusions, only 16/35 (45.7%) reported a statistically significant effect in relation to the primary outcome (Figure 4). All but one study with significant findings evaluated the use of a discussion forum; the other study evaluated a blog. Clusters of conditions appeared in the RCTs: 6 studies were related to lifestyle and weight loss, 3 were related to tobacco and substance use, 2 were in mental health, and 6 were in other conditions (diabetes, irritable bowel syndrome, multiple sclerosis, hearing loss, and breast cancer). The primary outcome in each of these studies was related to health behaviour and status, except two that evaluated patients' experience and one that measured website use. The social media tool was one component of a complex intervention in all studies, making it difficult to tease out any effect specific to its use. However, improvements were found in outcomes such as changes in body weight and activity levels, tobacco or substance use, and quality of life.

Discussion

There is an extensive and rapidly growing body of literature available investigating the use of social media in patient and caregiver populations. While diversity exists in terms of the tools used, their intended purposes, and the conditions studied, the majority of studies evaluate discussion forums. This could point to the popularity of discussion forums among patients and caregivers in addressing their health care concerns; however, it may also be indicative of the behaviours or preferences of the site designers.

While general tools with broad applications (i.e., discussion forums) are commonly used, the promise of social media lies in its adaptability. Unique applications such as PatientsLikeMe and TuDiabetes have evolved out of the need to address the specific concerns of particular online communities, demonstrating the success that can be realized through tailoring a tool to the requirements of a chosen target audience. Conversely, a general tool such as Twitter has shown that it can be applied to a variety of different purposes, but has also found a specific niche in disseminating public health alerts. The ability of these platforms to be customized for different purposes is highly consistent with the principles underlying successful knowledge translation interventions.[30]

Most studies were descriptive, but our sample also included 48 RCTs. Nearly all of the trials evaluated the effectiveness of discussion forums, leaving a research gap in the evaluation of the performance of other social media tools. Given the rapid proliferation of social media, a plethora of platforms are being used and an investigation of their benefits and harms is a logical progression of the research agenda. Similarly, next steps in research could focus on isolating the effect of the social media tool, particularly as it relates to improved patient outcomes. All of the included RCTs evaluated a complex intervention, of which the social media tool was just one component. More focused efforts to determine whether social media has an impact on its own; or whether any observed effects are attributable to the intervention overall or to the non-social media components, would be a research priority. Similarly, more in-depth examination of how the social media interventions are implemented, and specifically how and to what extent health or other professionals are involved, would contribute to a better understanding of their use. Further, additional research is needed to clarify whether the use of social media truly confers an advantage, or if the novelty of the medium is solely responsible for its use.[31] The contrast between the statistical significance of the primary outcome in the RCTs and the positive conclusions reported suggests that issues such as selective outcome reporting (e.g., choice of groups to compare), misrepresentation of conclusions (e.g., focus on change over time within a group, rather than differences between groups), and spin in reporting (e.g., emphasis on a positive trend) may play a more substantial role in the promotion of social media use than actual effectiveness. The fact that most interventions were evaluated by their developers may have also influenced the positive conclusions reported.

Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing

supportive online communities and could have widespread ~~applicability and~~ utility within the health care setting. However, these applications are dependent on further evidence of effectiveness.

Limitations

Social media is a relatively new concept and is continually undergoing transformations. As such, there is no universal definition, adding complexity to the process of determining study eligibility. The constantly changing nature of social media also proved challenging in defining the literature search, and the novelty of the topic made it difficult to keep the search updated due to a steady influx of new reports. However, as the focus of this scoping review was to identify broad categories of social media uses, the addition of studies published after the literature search would be unlikely to change the results.

While this scoping review focused on the peer-reviewed literature to identify how social media is being used by patient and caregiver populations, it may not encompass all of the work that has been done in the area, or cover the extent of the impact that social media has had on health care. Much of the driving force behind the use of social media has come from outside of the academic community; therefore certain constructs such as the role that Facebook plays in advocacy and community, and patient empowerment resulting from the use of Twitter have not been captured. Additionally, certain movements that have shaped social media use in health care, such as the ePatient movement[32] and Citizen Science,[33] were not included within the scope of our review. While we endeavored to be as comprehensive as possible in covering the published literature, our included patient population may not be representative of people who use social media for health generally. ~~users as a whole.~~

As our inclusion criteria were intentionally broad, we included a number of different study designs, encompassing both quantitative and qualitative research. While this introduced challenges in addressing the nuances of each type of study, the end result is a comprehensive overview of the state of the literature. Further syntheses of the evidence in specific topics, clinical areas, and populations will be able to provide more focus on some of these details.

Conclusions

This scoping review provides a map of the existing literature evaluating the use of social media in patient and caregiver populations. The available evidence is extensive, and most studies to date have been descriptive in nature. Given such widespread use of social media, evaluations of effectiveness are also needed. While positive conclusions are commonly reported, these may not be reflective of the actual findings.

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Contributors: MPH, SDS, LMG, and LH designed the study. MPH coordinated the project and is guarantor. MPH, AC, and JS screened articles and performed data extraction. AM contributed

to the conception of the study and conducted the literature search. MPH, AC, JS, and LH interpreted the data. MPH drafted and all authors critically reviewed the manuscript. All authors read and approved the manuscript.

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Table 1. Categorization of social media tools

Tool	Description	Examples
Collaborative projects	Enable the joint and simultaneous creation of content by many end-users.	Wikis (e.g., Wikipedia) Social bookmarking applications (e.g., Mendeley)
Blogs or microblogs	Websites that display date-stamped entries. They are usually managed by one person but provide the opportunity to interact with others through the addition of comments.	Wordpress Twitter (microblog)
Content communities	Allow for the sharing of media content between users, including text, photos, videos, and presentations.	BookCrossing Flickr YouTube Slideshare
Social networking sites	Enable users to connect by creating personal information profiles that can be accessed by friends and colleagues, and by sending emails and instant messages between each other.	Facebook MySpace LinkedIn
Virtual worlds	Platforms that replicate a 3D environment in which users can appear in the form of personalized avatars and interact with each other as they would in real life.	Second Life

Table 2. Description of included studies

Variable	Total – n (%)	Excluding discussion forums – n (%)
Total – N	***284***	***95***
Continent of corresponding author		
Asia	12 (4.2)	5 (5.3)
Australia	14 (4.9)	3 (3.2)
Europe	78 (27.5)	19 (20.0)
North America	179 (63.0)	67 (70.5)
Not reported	1 (0.4)	1 (1.1)
Study start date – median (range)	2006 (1997 – 2011)	2008 (2000 – 2011)
Study duration – median (range)	5 months (1– 117)	3 months (1 – 117)
Sample size – median (range)	124 (1 – 16,703)*	130 (2 – 16,703)*
Publication type		
Journal article	255 (89.8)	75 (79.0)
Abstract	15 (5.3)	8 (8.4)
Dissertation	14 (4.9)	12 (12.6)
Study design		
Quantitative		
Randomized controlled trial	48 (16.9)	6 (6.3)
Non-randomized controlled trial	6 (2.1)	1 (1.1)
Controlled before-after	1 (0.4)	-
Observational	11 (3.9)	3 (3.2)
Cross-sectional	63 (22.2)	33 (34.7)
Qualitative		
Case study	1 (0.4)	-
Case series	3 (1.1)	2 (2.1)
Ethnography	3 (1.1)	2 (2.1)
Grounded theory	6 (2.1)	2 (2.1)
Phenomenology	6 (2.1)	1 (1.1)
Qualitative (other/not specified)	46 (16.2)	16 (16.8)
Mixed methods	33 (11.6)	9 (9.5)
Other		
Content analysis	57 (20.1)	20 (21.1)
Authors' conclusions		
Positive	186 (65.5)	56 (59.0)
Neutral	65 (22.9)	23 (24.2)
Negative	15 (5.3)	10 (10.5)
Indeterminate	18 (6.3)	6 (6.3)

*Excluding one study that examined >3,000,000 tweets.

Table 3. Description and objectives of social media tools used (N=284)

Tool	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Collaborative project	6 (2.1)	5 (83.3)	-	-	-	1 (16.7)
Blog or microblog	40 (14.1)	11 (27.5)	-	24 (60.0)	4 (10.0)	9 (22.5)
Content community	16 (5.6)	8 (50.0)	-	5 (31.3)	2 (12.5)	4 (25.0)
Social networking site	42 (14.8)	10 (23.8)	1 (2.4)	24 (57.1)	8 (19.1)	9 (21.4)
Virtual world	6 (2.1)	3 (50.0)	-	3 (50.0)	1 (16.7)	1 (16.7)
Discussion forum	189 (66.6)	23 (12.2)	6 (3.2)	166 (87.8)	3 (1.6)	17 (9.0)
Component of a complex intervention	116 (40.9)	16 (13.8)	3 (2.6)	108 (93.1)	4 (3.5)	3 (2.6)

*Percentages do not add up to 100 due to the possibility of multiple tools and multiple objectives per study.

Table 4. Outcomes measured by social media tool

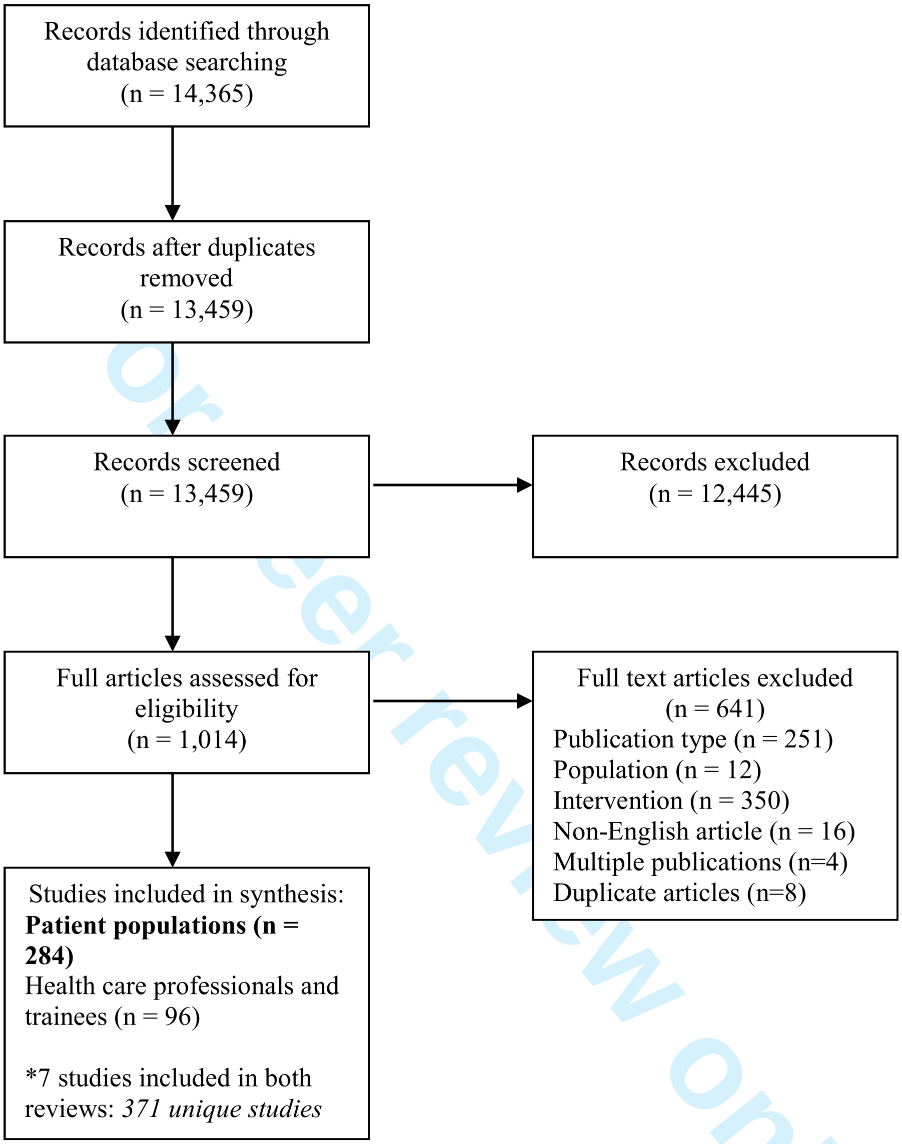
Outcomes	**Total – n (%)**	**Excluding discussion forums – n (%)**
Total – N	***284***	***95***
Patients' knowledge		
Conditions and complications	54 (19.0)	22 (23.2)
Self-care	60 (21.1)	17 (17.9)
Treatment options	22 (7.8)	10 (10.5)
Comprehension	2 (0.7)	1 (1.1)
Patients' experience		
Satisfaction	69 (24.3)	21 (22.1)
Clinician-patient communication	39 (13.7)	16 (16.8)
Peer-to-peer communication	135 (47.5)	44 (46.3)
Quality of life	20 (7.0)	2 (2.1)
Psychological well-being	78 (27.5)	21 (22.1)
Self-efficacy	32 (11.3)	4 (4.2)
Involvement and empowerment	22 (7.8)	6 (6.3)
Use of services and costs		
Hospital admission rates	4 (1.4)	2 (2.1)
Emergency admission rates	2 (0.7)	-
Number of visits to general practitioners	7 (2.5)	2 (2.1)
Cost effectiveness	4 (1.4)	3 (3.2)
Health behaviour and status		
Self-care activities	63 (22.2)	15 (15.8)
Treatment adherence	13 (4.6)	1 (1.1)
Severity of disease or symptoms	17 (6.0)	4 (4.2)
Physical functioning	21 (7.4)	6 (6.3)
Mental functioning	25 (8.8)	8 (8.4)
Clinical indicators	23 (8.1)	3 (3.2)
Other		
Attitudes and preferences	14 (4.9)	7 (7.4)
Content and accuracy	33 (11.6)	21 (22.1)
Usability	9 (3.2)	2 (2.1)
Usage and demographics	106 (37.3)	34 (35.8)

*Percentages do not add up to 100 due to the possibility of multiple outcomes per study

Table 5. Social media objectives by authors' conclusions (N=284)

Conclusions	Total – n (%)	Objective – n (%)				
		Health Literacy	Clinical Decision Making	Self-care	Patient Safety	Other
Total – n (%)		47 (16.6)	7 (2.5)	219 (77.1)	19 (6.7)	39 (13.7)
Positive	186 (65.5)	28 (59.6)	6 (85.7)	149 (68.0)	14 (73.7)	21 (53.8)
Neutral	65 (22.9)	12 (25.5)	1 (14.3)	47 (21.5)	1 (5.3)	13 (33.3)
Negative	15 (5.3)	5 (10.6)	-	7 (3.2)	3 (15.8)	3 (7.7)
Indeterminate	18 (6.3)	2 (4.3)	-	16 (7.3)	1 (5.3)	2 (5.1)

Figure 1. Flow diagram of included studies



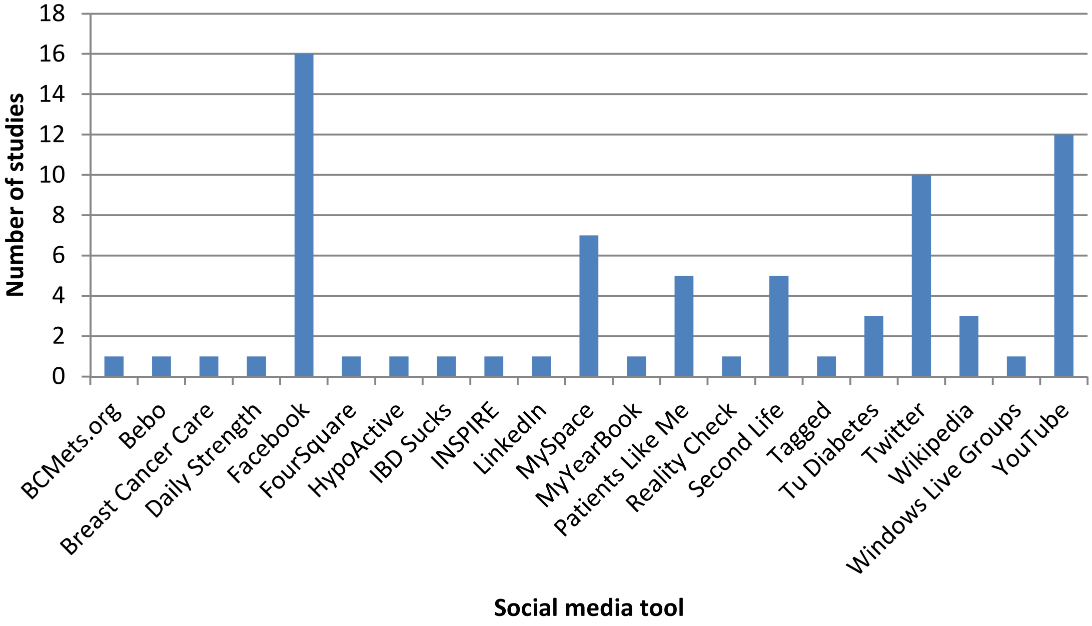


Figure 2. Specific social media tools described in included studies

Figure 3. Word cloud representing the conditions included in the study populations. The size of each term is proportional to its representation in the review.

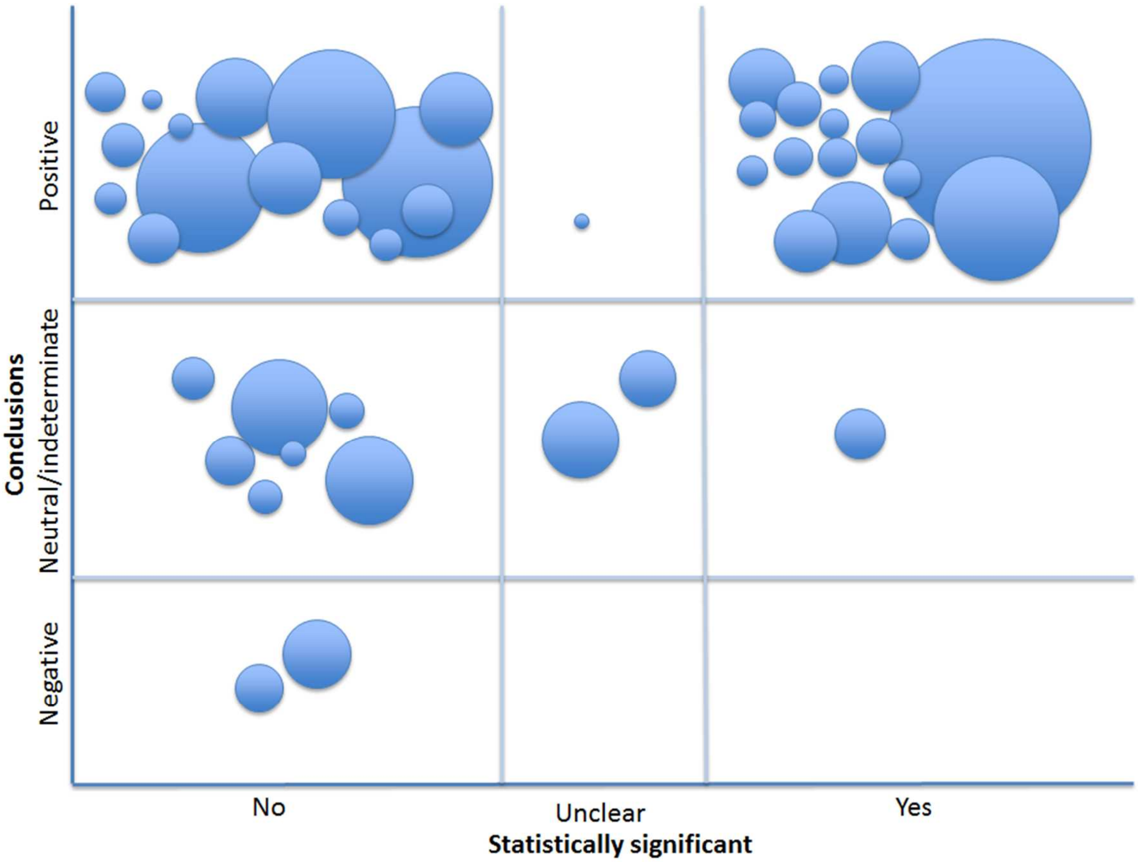


Figure 4. Authors' conclusions by statistical significance and sample size among randomized controlled trials. Each bubble represents one study and its size is proportional to the number of individuals evaluated.

Included Studies

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Appendix. Search strategy for Medline

Database: Medline via Ovid <1946 to Present>

Search Title: Social Media Scoping Review 1.4 all SD filters | Medline – 15Dec2011 – AM

Date Searched: 13 January 2012

Limits: Year of publication ≥2000; RCT/CCT, SR, observational, qualitative study filters applied

Results: 5,468 (Ovid duplicate removal function applied)

Internet and social media related MeSH [Medical Subject Headings]
1. exp Internet/
2. Electronic Mail/
3. Mass Media/td, ut
4. Hypermedia/
5. Online Systems/td, ut
6. Medical Informatics/
7. User-Computer Interface/
8. Computer-Assisted Instruction/
9. Computers/td, ut
10. Search Engine/
11. Computer Communication Networks/
12. Information Dissemination/
13. Therapy, Computer-Assisted/
14. "Marketing of Health Services"/
15. Social Marketing/
16. exp Social Environment/
17. **Internet.mp. and (or/12-16)** [Internet combined with broader social network/computer terms]

Internet and social medial related keywords
18. (digital adj5 platform*).mp.
19. (website* or web site* or webpage* or web page*).mp.
20. Googl*.mp.
21. Facebook*.mp.
22. YouTube.mp.
23. Second Life.mp.
24. PatientsLikeMe.mp.
25. WebMD.mp.
26. elluminate.mp.
27. flickr.mp.
28. moodle.mp.
29. picsearch.mp.
30. skype.mp.
31. ustream.mp.
32. zotero.mp.
33. ((e or electronic) adj3 newsletter*).mp.
34. (viral adj5 market*).mp.
35. (banner adj5 ad*).mp.
36. ("Web 2.0" or "Web 2").mp.
37. "Health 2.0".mp.

38. "Medicine 2.0".mp.
39. (Social adj3 network*).mp.
40. linkedin.mp.
41. blog*.mp.
42. wiki*.mp.
43. podcast*.mp.
44. really simple syndicat*.mp.
45. (rss adj3 (reader* or feed*)).mp.
46. (forum* adj3 (internet or web* or chat*)).mp.
47. content communit*.mp.
48. user generated content.mp.
49. microblog*.mp.
50. (twitter or tweet*).mp.
51. (("peer to peer" adj5 network*) or P2P).mp.
52. (social adj3 media*).mp.
53. i-phone*.mp.
54. myspace.mp.
55. smartphone*.mp.

56. **or/1-11,17-55** [Internet/social media MeSH and keywords] (**92,578**)

Health care education/promotion terms

57. exp Health/
58. "Delivery of Health Care"/
59. health behavior/
60. exp Health Education/
61. exp Health Promotion/
62. Patient Care/
63. Patient Participation/
64. medical education/
65. ((patient* or physician* or nurse* or pharm* or "health care profession*") adj2 (teach* or train* or instruction* or intervention* or program* or inform* or educat* or outcome*)).mp.

66. **or/57-65** [Health promotion/health outcome terms] (**624,172**)

67. **and/56,66** [social media + health promotion/outcome terms] (**15,219**)

Search filters to stream out non-research papers

RCT Filter

68. randomized controlled trial.pt.
69. controlled clinical trial.pt.
70. randomized.ab.
71. placebo.ab.
72. exp Clinical Trials as Topic/
73. randomly.ab.
74. trial.ti.
75. or/68-74
76. exp animals/ not humans.sh.
77. **75 not 76** [Cochrane RCT filter to max sensitivity and precision] (**730,963**)

SR Filter

78. meta analysis.mp,pt.
79. review.pt.
80. search*.tw.
81. **or/78-80** [HIRU SR filter to balance sensitivity and specificity] (**1,779,109**)

Observational Study Filter

82. epidemiologic studies/
83. exp Case-Control Studies/
84. exp Cohort Studies/
85. case control.tw.
86. (cohort adj (study or studies)).tw.
87. cohort analy*.tw.
88. (follow up adj (study or studies)).tw.
89. (observational adj (study or studies)).tw.
90. longitudinal.tw.
91. retrospective.tw.
92. cross sectional.tw.
93. Cross-Sectional Studies/
94. **or/82-93** [SIGN observational study filter] (**1,508,983**)

Qualitative Research Filter

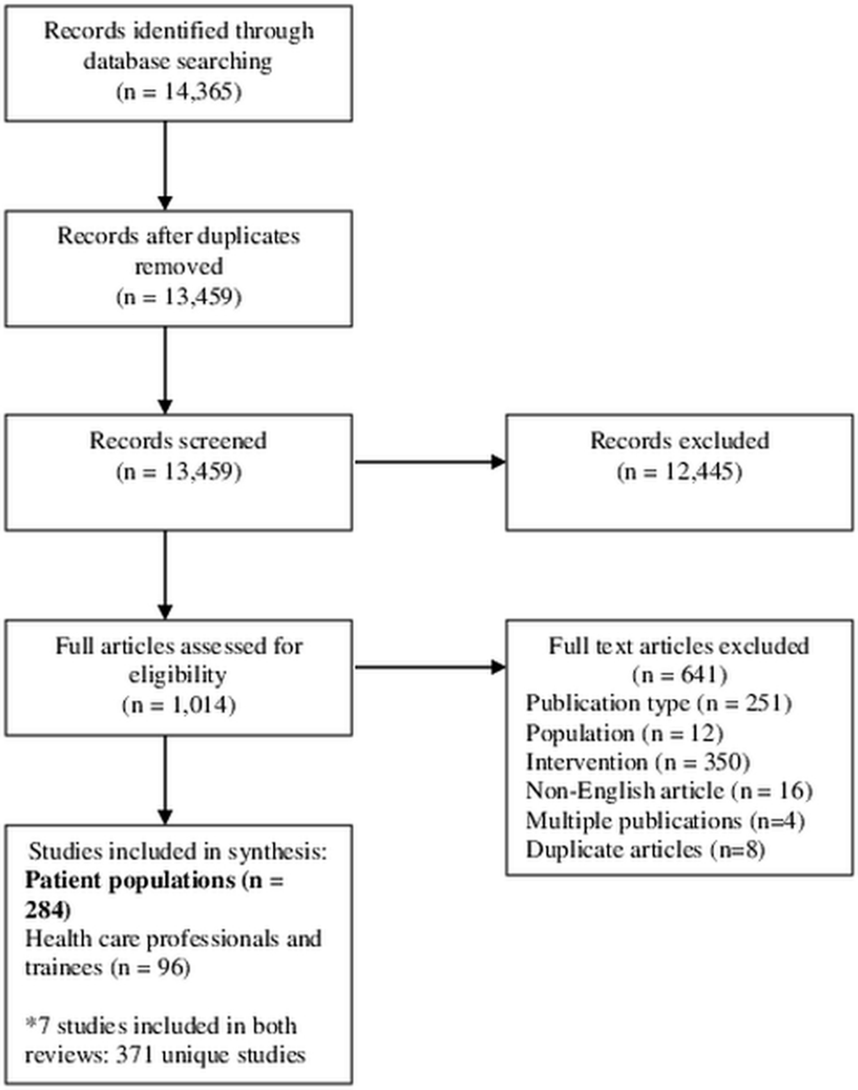
95. interview*.tw.
96. experience*.mp.
97. qualitative.tw.
98. **or/95-97** [HIRU qualitative study filter] (**756,921**)

99. or/77,81,94,98 [combination of all search filters] (**4,143,826**)

100. and/67,99 [combination of social media terms + health ed terms + SD filters] (**6,589**)

101. limit 100 to humans (**6,234**)
102. limit 101 to yr="2000 -Current" (**5,524**)
103. remove duplicates from 102 (**5,468**)

Figure 1. Flow diagram of included studies



90x107mm (300 x 300 DPI)

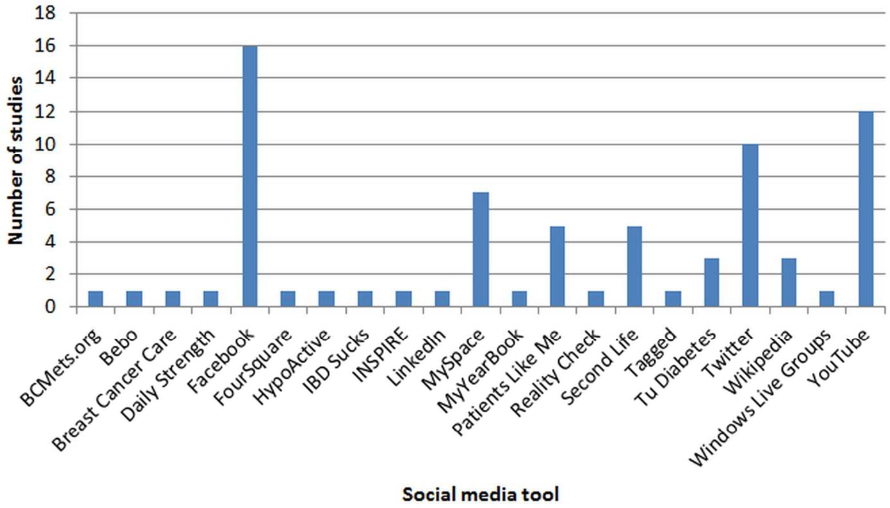


Figure 2. Specific social media tools described in included studies

139x90mm (300 x 300 DPI)

Figure 3. Word cloud representing the conditions included in the study populations. The size of each term is proportional to its representation in the review.

160x90mm (300 x 300 DPI)

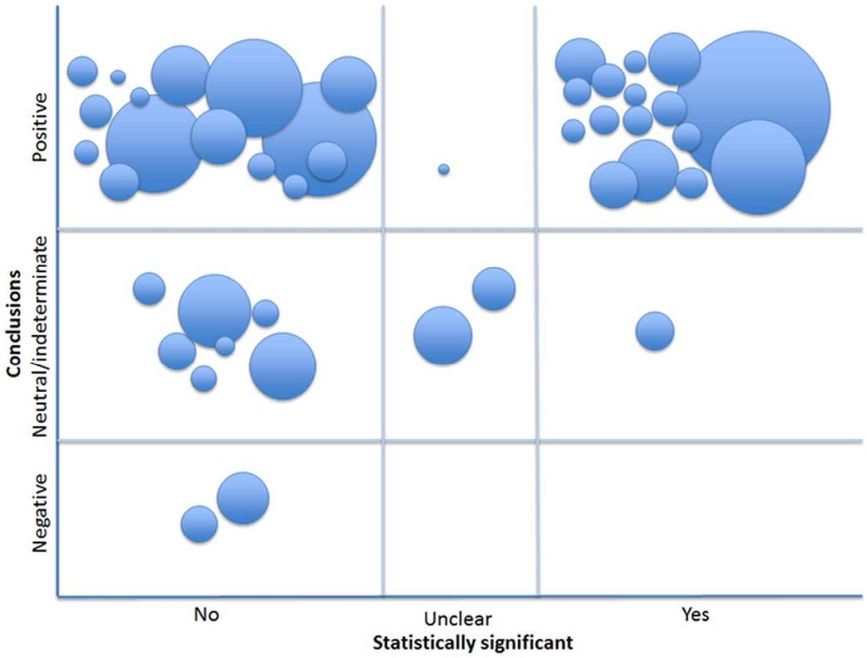


Figure 4. Authors' conclusions by statistical significance and sample size among randomized controlled trials. Each bubble represents one study and its size is proportional to the number of individuals evaluated.

103x90mm (300 x 300 DPI)