Social Media Use in Chronic Disease: A Systematic Review and Novel Taxonomy

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ABSTRACT

PURPOSE: The purpose of this study is to evaluate clinical outcomes from applications of contemporary social media in chronic disease; to develop a conceptual taxonomy to categorize, summarize, and then analyze the current evidence base; and to suggest a framework for future studies on this topic.

METHODS: We performed a systematic review of MEDLINE via PubMed (January 2000 to January 2015) of studies reporting clinical outcomes on leading contemporary social media (ie, Facebook, Twitter, Wikipedia, YouTube) use in 10 chronic diseases. Two reviewers independently performed data extraction and quality assessment; characterization of study outcomes as positive, negative, neutral, or undefined impact; and inductive, thematic analysis to develop our taxonomy.

RESULTS: Of 378 citations identified, 42 studies examining the use of Facebook (n = 16), blogs (n = 13), Twitter (n = 8), wikis (n = 5), and YouTube (n = 4) on outcomes in cancer (n = 14), depression (n = 13), obesity (n = 9), diabetes (n = 4), heart disease (n = 3), stroke (n = 2), and chronic lower respiratory tract infection (n = 1) were included. Studies were classified as support (n = 16), patient education (n = 10), disease modification (n = 6), disease management (n = 5), and diagnosis (n = 5) within our taxonomy. The overall impact of social media on chronic disease was variable, with 48% of studies indicating benefit, 45% neutral or undefined, and 7% suggesting harm. Among studies that showed benefit, 85% used either Facebook or blogs, and 40% were based within the domain of support.

CONCLUSIONS: Using social media to provide social, emotional, or experiential support in chronic disease, especially with Facebook and blogs, appears most likely to improve patient care.

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KEYWORDS: Chronic disease; Social media; Social media taxonomy; Taxonomy

With well over 70% of all Internet users using some form of this technology, social media has become ubiquitous in America.[1,2] Such proliferation has provided patients a ne medium through which to exchange health-related information in innovative ways.[3,4] Consequently, social media has become increasingly prominent in health and health care; in a recent survey, 23% of social media users reported following a friend's personal health updates, 15% sought health information on the Web, 11% posted about health-related matters, and 9% joined health-related groups.[2]

These novel avenues of information acquisition and exchange have important implications for health and disease management. Rapid diffusion, low cost, and broad availability of social media make it an attractive platform for managing care, communication, and interventions in chronic disease. Yet, objective data to guide clinicians on how best to exchange information, measure progress, and intervene using social media is lacking. Existing narrative reviews on this topic highlight the complexity of evaluating this area of literature.[5,6] In addition, many such articles primarily have reviewed the predecessors of contemporary social media such as forums, bulletin/message boards, and chatrooms.[7,8] In

order to fully harness its promise, better understanding of the use and outcomes related to contemporary social media in chronic disease is needed.[5,6]

To address these gaps, we performed a systematic review of the literature and developed a taxonomy of contemporary social media use in highly morbid, common chronic diseases. Next, we assessed the impact of social media by taxonomy category. In doing so, we sought to develop a conceptual schema that would offer clinical insights into how best to use social media, while also creating a blueprint for future studies on this topic.

METHODS

We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations when performing this systematic review.[9] Contemporary social media sites were selected based on well-established definitions and global Web traffic rankings.[10,11] We selected chronic diseases listed on the Centers for Disease Control *Leading Causes of Death* list including heart disease (eg, hypertension, heart failure, coronary artery disease, valvular disease, and cardiac arrhythmias); cancer; chronic lower respiratory tract infection (CLRTI); stroke; Alzheimer's disease; and diabetes mellitus (see Appendix, online).[12,13] Depression was included as it is an antecedent condition to intentional self-harm (suicide); while obesity was included due to its established pathophysiologic association with many of the aforementioned diseases.[7,8]

Data Sources and Searches

With the assistance of a medical research librarian, we performed serial electronic literature searches of MEDLINE via PubMed for English-language studies published between January 2000 and January 2015. Search strings were constructed using Boolean operators, combining comprehensive terms for contemporary social media with terms for the diseases of interest (Appendix). Controlled vocabularies (ie, *MeSH* terms) and manual searches using relevant Cochrane reviews identified synonyms for all diseases of interest.[14-34] Additional studies also were identified by hand searches of bibliographies. No journal, study design, or subject filters were placed on the search; however, conference proceedings and abstracts were excluded. The search was last updated on January 3, 2015.

Study Selection

Two authors (RP and TC) independently assessed study eligibility; any difference of opinion was adjudicated by

a third author (VC). Studies were included if they: involved adults >18 years of age; represented primary investigations of contemporary social media technology; and reported outcomes regarding the effect of social media use in a chronic disease of interest. We excluded studies that: were not original research (eg, discussions, editorials); did not study the chronic diseases of interest; did not report clinical outcomes (eg, educational, research, or public policy); or described patterns of social media use rather than impact on a chronic disease state.

> ## CLINICAL SIGNIFICANCE
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> - Use of contemporary social media technology in chronic disease care can be categorized as: support, education, disease modification, disease diagnosis, or disease management.
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> - Based on the current literature, contemporary social media is most likely to improve chronic disease care when used to provide social, emotional, or experiential support.
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> - Few studies suggest any harm from the use of contemporary social media technology in chronic disease care.

Data Extraction and Quality Assessment

Three authors (RP, TC, and VC) independently abstracted data from all included studies to a template adapted from the Cochrane Collaboration.[35] For all studies, we extracted the following variables: study design, objectives, geographic location, setting, inclusion criteria, method of participant selection, sample size, participant age, study procedure, social media technology, chronic disease, primary outcomes, and secondary outcomes. In addition, for each study, reviewers independently assessed and categorized the impact of social media on the chronic disease of interest. We categorized studies as positive impact if social media use or content was reported by the authors as being beneficial in the chronic disease of interest; conversely, outcomes that suggested social media use was harmful were categorized as negative impact. Impact was classified as undefined if a study reported both positive and negative outcomes, or the overall benefits or harm of social media were unclear. The term "neutral" was used for studies when no change or difference in outcomes was reported. Abstraction accuracy and agreement regarding impact of social media on the chronic disease state was evaluated in triplicate (RP, TC, and VC). Inter-rater agreement of abstraction accuracy and impact of social media on disease states were assessed using Cohen's κ statistic. Study authors were contacted for additional data when needed.

Two authors (RP, VC) independently assessed study quality. Included studies were divided into quantitative or qualitative studies. We appraised risk of bias in quantitative studies using the Downs and Black tool as recommended by the Cochrane Collaboration.[35-37] The Downs and Black tool allows calculation of an overall score (max points = 28) for methodological quality in randomized and nonrandomized studies by asking 27 questions in 4 categories (reporting points = 11, external validity points = 3, internal validity − bias points = 7, and internal validity − confounding points = 6). Questions that we were unable to answer or did