Journal of Biomedical Informatics 46 (2013) 957–969

Contents lists available at SciVerse ScienceDirect

Journal of Biomedical Informatics

journal homepage: www.elsevier.com/locate/yjbin

Methodological Review

Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances

Mark Merolli [a,*], Kathleen Gray [a,b], Fernando Martin-Sanchez [a]

[a] Health and Biomedical Informatics Centre, The University of Melbourne, Level 1/202 Berkeley St., Parkville, Victoria 3010, Australia
[b] Department of Computing and Information Systems, The University of Melbourne, Level 1/202 Berkeley St., Parkville, Victoria 3010, Australia

ARTICLE INFO

Article history:
Received 30 September 2012
Accepted 26 April 2013
Available online 20 May 2013

Keywords:
Chronic disease
Social media
Web 2.0
Health outcomes
Affordances

ABSTRACT

Whilst the future for social media in chronic disease management appears to be optimistic, there is limited concrete evidence indicating whether and how social media use significantly improves patient outcomes. This review examines the health outcomes and related effects of using social media, while also exploring the unique affordances underpinning these effects. Few studies have investigated social media's potential in chronic disease, but those we found indicate impact on health status and other effects are positive, with none indicating adverse events. Benefits have been reported for psychosocial management via the ability to foster support and share information; however, there is less evidence of benefits for physical condition management. We found that studies covered a very limited range of social media platforms and that there is an ongoing propensity towards reporting investigations of earlier social platforms, such as online support groups (OSG), discussion forums and message boards. Finally, it is hypothesized that for social media to form a more meaningful part of effective chronic disease management, interventions need to be tailored to the individualized needs of sufferers. The particular affordances of social media that appear salient in this regard from analysis of the literature include: identity, flexibility, structure, narration and adaptation. This review suggests further research of high methodological quality is required to investigate the affordances of social media and how these can best serve chronic disease sufferers. Evidence-based practice (EBP) using social media may then be considered.

Contents

Abbreviations: OSG, Online Support Group(s); SNS, Social Network Site(s); RCT, randomized controlled trial; QOL, quality of life.

* Corresponding author. Fax: +61 39035 8873.
E-mail addresses: mmerolli@student.unimelb.edu.au (M. Merolli), kgray@unimelb.edu.au (K. Gray), fjms@unimelb.edu.au (F. Martin-Sanchez).

1532-0464/$ - see front matter © 2013 Elsevier Inc. All rights reserved.
http://dx.doi.org/10.1016/j.jbi.2013.04.010

1. Introduction

1.1. Background

The age of web 2.0 has created new opportunities not only for the way in which chronic disease sufferers manage their condition but also for clinicians who provide their healthcare [1]. Reports highlight that healthcare consumers turn to the Internet for a variety of health information and that if Internet access is available to them, chronic disease sufferers are likely to take advantage of social media for sourcing health information to aid with managing their condition [2]. The phenomenon of social media has become part of Internet culture and published literature describing social media interventions for chronic disease management are becoming more prevalent. This comes alongside the suggestion that social media may allow for communication processes that are different from those allowed by other information technologies [2,3]. Inherently this represents a shift in the paradigm of online health information seeking, shifting from traditional Internet search to a more user-centric, engaged and collaborative experience [4]. Patient-centeredness and tailored information are the key aspects, whereby the sharing of online health information is the focus, not the information itself [5–7]. Chronic disease sufferers have continued to lead the way as a user group, with poorer health status, stigmatization, isolation and disconnection suggested as major reasons [1,8].

1.1.1. What is the theory behind web 2.0?

While the number of published studies on the use of web 2.0 and social media in healthcare is rising, it is difficult to form a definitive picture of social media usage in chronic disease management. Foundations for understanding web 2.0 and theory behind the term may be one of the reasons feeding confusion and creating obscurity when exploring health effects of using 2.0 platforms. Often this confusion comes from how they differ from their web 1.0 predecessors. The lines are blurred [9]. Exploring the background of web 2.0 provides a sounder basis for designing research, framing arguments and interpreting study results.

Definitive attempts to clarify the complexities of web 2.0 remain elusive. We know that the term was popularized commercially in 2004 [9,10], to describe a new generation of the Internet, modelled on a set of technologic, economic and social trends. What can be agreed upon is that the underlying principles are participation, communication, user-centeredness, collaboration and openness [11,12], which were rapidly taken up to describe a set of web 2.0 services, specifically for the provision of healthcare [12]. 'Social media' are essentially the services that allow for the principles of web 2.0 to be realized and examples include: Social Network Sites (SNS), blogs, wikis, photo/video sharing services, bookmarking tools and virtual worlds [4,6,13]. Deciding whether a given platform is web 2.0 or an earlier 1.0 technology is where the difficulty lies and is worthy of further examination.

1.1.2. How does web 2.0 differ from web 1.0?

Web 2.0 may be seen as an evolutionary extension of web and Internet 1.0 [10]. Compared to the core principles of web 2.0, 1.0 technologies such as email and simple websites emphasised consumption of information, with content creators being few [10]. 1.0 technologies predate the institution of web 2.0 into mainstream Internet culture, and have changed little in their structure and functionality, which is yet another reason they are not considered social media.

Social media inherently display distinguishing features missing in their 1.0 predecessors, namely large social components that offer users a wide variety of interactive tasks and roles [10]. Social Network Sites (SNS) are a good example of this: user profiles, connections to others, encouragement of user-generated content, posting of various forms of content (including text, photo and video), commenting, tagging, rating and reviewing [7,10].

However, there are grey areas when considering whether certain applications are social media, or whether they should be categorized as 1.0. For example, while online communities/support groups, discussion forums and message boards do present limited user profiles and allow for collaborative dialogue and/or connection to other users, their interfaces and architecture go back to the early days of the Internet [10]. For this reason it is difficult to label them social media. On the other hand, they warrant recognition because they persist in supporting basic online social interactions, even though they do not have the advanced features that have evolved in social media [7].

Consequently, in scoping this review it became apparent that many of the studies investigating social media and their impact on health outcomes add to the confusion of what typically constitutes social media and how they may impact chronic disease sufferers. For example, we found studies that described a social media intervention without considering what social media and web 2.0 actually are or do. Much of the published literature focuses on the features and functionality of the platform (e.g. walls for posting, virtual environment design, etc.), rather than interactions occurring, and thus gives limited insight into the relationship between social media use and impact on sufferers [14]. For this reason, in order to progress a theory of social media effects in healthcare and chronic disease, this literature review approaches social media use from the point of view of 'how' social media impacts sufferers. Are there interactions enabled by social media that may explain different usage behaviours? Essentially, what do social media 'afford' chronic disease sufferers? [10,14]. This concept is far from evolved in health and chronic disease management.

1.1.3. What are affordances and how might they be applied to social media?

The application of affordance theory continues to evolve and adapt in the area of human–computer interaction, but has firm origins in perceptual and cognitive psychology. It suggests that individuals have differing perceptions about the objects in their environment, including not merely what an object is, but what potential uses it affords, thus the origin of the word 'affordance' [15]. Psychologist James Gibson's suggestion was that individuals do not interact with an object until they perceive what can be done with it. In this sense, although an object's physical features are generally the same to different people, its affordances are not. They are unique to the individual way people perceive them and thus use an object. The relationship between the actual material features of an object and its affordances can be conceived thus – when we interact with something we think more about the uses it affords rather than thinking about its qualities per se [15].

Psychologist Donald Norman further appropriated the concept in an attempt to explain how the design of emerging technologies could be refined [16]. In line with Gibson's original theory, the concept continues to rely on the individual's ability to perceive an object's actionable possibilities. However, emphasis is placed on the relationship between the user and the features of the object they are interacting with. In this sense, it takes into consideration one's own experiences, beliefs, goals, plans and values. Different goals lead to different perceived affordances for possible action depending on the context [14,16].

The idea behind how certain affordances of social media can stimulate different interactions and thus different effects among chronic disease sufferers may be useful in several ways: It may assist researchers to investigate how sufferers use different social media in relation to their individualized needs, rather than focus solely on the features of the platforms being used. It may help to explain consistency or disparity between different patient outcomes when using particular platforms. Also, it may provide an avenue to include the patient in the data collection process as patient perceptions and preferences are given more weighting (i.e. more patient-centred research) [14].

1.2. Rationale for the review

Social media may offer scope to help ease the burden of self-management for chronic disease sufferers and may be a suitable means to provide clinical care and meet patient needs otherwise not being met in face-to-face environments. Good practice in chronic disease management relies on using the most effective and efficient methods for which there are evidence to deliver solutions best suited to the needs of patients. Although therapeutic interest in using web-based interventions in chronic disease management is increasing, the evidence base is not well established. This review is needed to fill gaps in clinician and patient knowledge about promising directions for social media use leading to improved health outcomes and other beneficial effects. Whilst there are an abundance of clinical guidelines informing management for a variety of chronic diseases, there are presently no evidence-based frameworks available informing chronic disease management using social media, nor any robust recommendations that intimately link the premise of what social media can afford the individualized needs of different groups of chronic disease sufferers. This review is part of a larger project, whose purpose is to develop such a framework for generating evidence of health outcomes from social media use in chronic disease management.

1.3. Objectives of the review

The key objective of this literature review is to examine how social media are utilized in chronic disease management and to explore affordances underlying use. Of particular interest is the effect they have on patients and what impact they have on health outcomes. Given the breadth of chronic diseases, and specific focus of this research to chronic disease and social media, a broad approach was adopted and several, often interrelated chronic diseases were studied in order to obtain a robust cross-section of the current landscape of social media utilization. Examples of chronic diseases represented in this review include: chronic pain, arthritis, diabetes, cancer and depression.

The specific objectives include appraising the evidence about:

- Which social media have been used in chronic disease management.
- In which chronic diseases (and demographics) social media have been used.
- How social media have been used.
- What health outcomes and other effects have been linked to social media use.
- What research methods have been used to determine these links.
- How particular affordances of social media have been linked to these health outcomes and effects.

1.4. Structure of the review

The methodology used to perform this review is explained with reference to inclusion and exclusion criteria, and the search strategy. The results of the review are then broken down. Structure:

- Research methods of included studies.
- Categorization of studies.
- Chronic diseases utilizing.
- Participants utilizing.
- Forms of social media utilization.
- Reported effects/outcomes.
- Evidence of the role of affordances.

2. Research method

2.1. Search strategy/search terms

A number of databases were searched systematically for relevant academically published articles. These included MEDLINE, Web of Science, Scopus and Computers & Applied Sciences. They were chosen for their coverage of a range of relevant disciplines or wide clinician audience. The studies sourced and final studies included represent the best available specimens from the literature. Search terms were consistent across all databases and these are shown in Appendix A. The search focus was for articles that encompassed the interaction of social media with known chronic diseases (e.g. "social media" AND "chronic disease"). This was further refined to those reporting effects on patients and impact on health outcomes (i.e. AND "patient management"). For full search strategy refer to Fig. 1.

Pertinent to this review, it was observed that terms describing social media vary immensely. Terms that featured commonly included 'web 2.0', 'social networking sites', 'online support groups' or 'OSG' and 'electronic support groups' or 'ESG'. These were all therefore included. It was also apparent that the scope of chronic diseases and conditions that come under this umbrella varies widely too. 'Cancer' was the most commonly encountered condition when searching for chronic disease (increasingly classified as a chronic disease [17]) and for this reason it had to be included. 'Chronic pain', 'arthritis', 'diabetes', 'depression' and 'anxiety' were also some of the others present.

Given the relative infancy of social media and web 2.0, the same searches were initially run including general terms such as 'online',' Internet' and '1.0'. This approach was taken because in order to fill the gaps in research for the utilization of social media, a broader view must first be taken of more standard web-based interventions that have paved the way for current research into social media. This search was not without its challenges. At first, this more open search strategy yielded an abundance of highly irrelevant articles. The main problem appeared to be that the inclusion of general terms, for example, 'email' (originally included because of the 'social' nature of emails) was being recognized in any article that contained the author's email address in the title. Therefore, omitting 'email' and recombining search terms better filtered relevant studies.

The search process yielded nineteen included studies for formal analysis that satisfied the criteria. These studies were imported into reference software EndNote. Each of the included studies was written up as a brief description of the article, platform investigated, study type, major findings discussed and implications drawn for further research.

2.2. Inclusion/exclusion criteria

Inclusion/exclusion criteria are listed in Table 1. Due to the breadth of academic literature on web-based interventions in the health discipline (with or without social media components), it was necessary to narrow the focus to chronic disease and concentrate on a specific cohort of literature in this field. It is for this reason that the inclusion/exclusion criteria were applied. Studies that

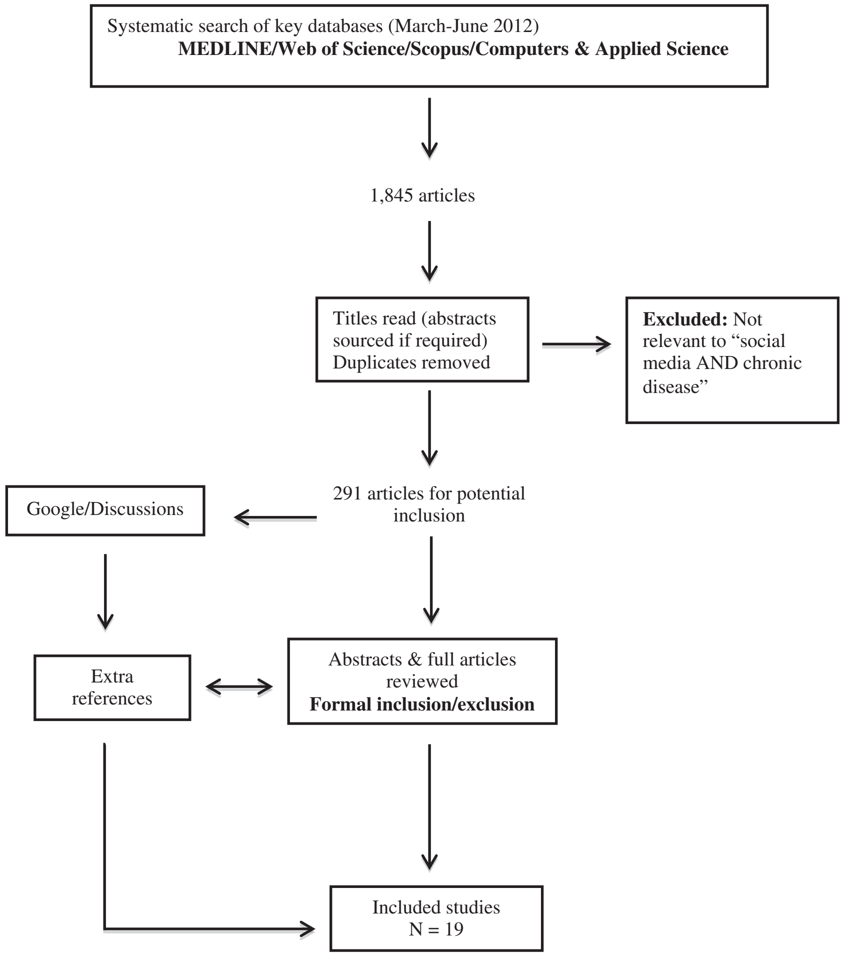

Fig. 1. Search strategy and refinement.

Table 1
Inclusion versus exclusion criteria.

Inclusion	Exclusion
Use of social media	Not focused on social media
Interventions using web 2.0 (also, predecessors such as OSG and discussion forums included)	Simple, non-social Internet-based interventions (i.e. web 1.0)
Make reference to the effects or improved health outcomes for sufferers – i.e. describes change	Neither discussed value to the participants, nor described effects or changes to health outcomes
A chronic disease is the focus or inferred focus	Not chronic disease management focused (i.e. health promotion or health communications)
Articles from 2004 and beyond	Studies earlier than 2004
Patients are adult sufferers surviving their illness	Child, carer or facilitator focused

described face-to-face interventions simply transcribed for online use were excluded. Also, those that described Internet-based management of chronic disease were excluded if the intervention described was a non-social or 1.0 use of the Internet. For example, websites without social components and simple email interventions [18]. However, studies of OSG and discussion forums were not excluded on this basis, as it was deemed that despite not satisfying classification as actual social media, these applications do offer limited social interaction and precede social media platforms that have evolved since 2004, thus forming an important part in social media's foundations. Finally, studies were excluded if the focus was on children and/or their carers [19].

Studies were deemed appropriate for inclusion if they were chronic disease focused, described a social media platform or one of the above predecessors (i.e. OSG, discussion forums, etc.) as the focus, discussed how the use of the reported platform impacted the patient group or how it affected health outcomes. Both peer to peer interventions and professionally led/facilitated interventions were included. Participants in the studies had to be of 18 years or older, given the legal ramifications of social media usage (which is beyond the scope of this review) and studies focused on carers were excluded given the focus of this review on the sufferer or patient. Literature that reported patient–clinician relationships was included, given the relevance to clinical practice for clinicians reading this review.

When attempting to decide on what typically constituted 'social media', therefore placing a time stamp on the retrieved literature, it was useful to revisit the rise of social media and the commercialization of 'web 2.0' in 2004 [11]. Due to this timeframe and that social media are essentially defined as the tools that build on the foundations of web 2.0, 2004 studies and beyond have been selected [6]. Unfortunately, the relative infancy of this field has still led to a bias in published literature reporting on earlier social platforms such OSG, discussion forums and bulletin boards over social media such as SNS, blogs and wikis.

2.3. Coding/analysis

2.3.1. Coding

The nineteen included studies were coded and reviewed several times. Each individual study was coded for the type of social media being utilized, study characteristics (including participant demographic data) and main research findings. The interactions that were of particular interest included the identification of any affordances of social media. SNS were further broken down where applicable into: profiles, wall/forums, groups, photo/video, chat and messaging). Participant characteristics recorded included chronic disease suffered, mean age, sex, ethnicity, level of education, work status and relationship status. Study design characteristics were also coded, including sample size and study design type. The intervention/ platform characteristics recorded included the specific platform (e.g. Facebook, Second Life, DailyStrength, RA-Help) and for others such as OSG and/or custom designed platforms the communication channel was listed (i.e. discussion forum, bulletin board). Intervention characteristics recorded included duration of study/intervention and length of follow-up if this occurred. Finally, in the case of each study, the main effects and/or outcomes realized were recorded.

2.3.2. Analysis

Formal systematic review was difficult due to the large variation in study types and methodologies employed by the included studies. The variability in study types was thus explored by comparing the social media platforms with their reported effects on the participant groups and then further correlating this with information about the samples. Research methods were mixed. Some studies reported using descriptive statistical analysis. However, the majority used qualitative methods, especially thematic content analysis. Similar qualitative methods were employed in conducting the present review. When the included studies were reviewed, the following questions were kept in mind: (a) What health outcomes and other effects were reported in the study? (b) Was their any discussion of the underlying mechanisms behind reported outcomes? Namely, what did the social media afford sufferers? (c) What effect did these affordances have? In terms of the health outcomes and other non-health effects seen, this involved examining each paper to determine what the reported effects/outcomes were. These were thematically coded as they appeared and as new health outcomes and effects were noted they too were added to the list. We then sought to examine whether authors discussed how the social media use may have influenced outcomes. This process followed that of affordance theory and much like the authors in [14], considered instances where questions of 'how' and 'why' the social media may have influenced sufferers were discussed. Common themes in the affordances of social media in a chronic disease management context were refined and coded. Given that coding of social media affordances in a chronic disease context is novel, the labels given to the unique affordances have been created for the purposes of this review and will be subject to ongoing revision and refinement. Five distinct affordances emerged at this stage of investigation: identity, flexibility, structure, narration and adaptation. With these affordances postulated, investigation centred on how they featured and were described in the representative studies.

3. Results

3.1. Research methods of included studies

The most salient finding of this literature review was the paucity of rigorous studies in this domain, as well as variability of study methodologies. Of the nineteen included studies, seven examined discourse or the content of communication occurring on specific social platforms via thematic content analysis techniques [20–26], three studies were randomized controlled trials (RCT) [27–29] and one was a randomized longitudinal design [30], while only one conducted a systematic review investigating the role of internet support groups on decreasing depressive symptoms [31]. The remaining studies tended to employ mixed methods designs either via descriptive statistical analysis or statistical correlation coupled with thematic content analysis [32–38].

3.2. Categorization of studies

Upon closer examination of the nineteen included studies, we discerned two categories of social web technology, which we have labelled ‘Predecessors’ and ‘Social Media’. Within these categories the specific platforms are then outlined.

PREDECESSORS ($N = 12$) included those studies that reported social interactions on earlier social platforms such as discussion forums, bulletin boards and chat tools. This is the process that commonly occurs in ‘online support groups’ (OSG) [22–25,28–31,35–38].

SOCIAL MEDIA ($N = 7$) included those studies that satisfied the criteria re: ‘social media/web 2.0’ platforms. They included interventions using:

- Social Network Sites (SNS) ($N = 5$) – either custom (i.e. the Chronic Pain Management System, LIFECommunity, RAHelp) or existing (i.e. Facebook, Daily Strength) or [20,21,26,27,32] Blogs ($N = 1$) nb. Various platforms [33].
- Virtual Worlds ($N = 1$) i.e. Second Life [34].

3.3. Chronic diseases utilizing

Of the included studies focussing solely on a single chronic condition ($N = 11$), five explore cancer [28,30,32,33,37] (two specifically breast cancer), three examine chronic pain related conditions [22,24,27], one HIV/AIDS [36], one diabetes [21] and one rheumatoid arthritis [26]. The remaining studies ($N = 8$), either explored multiple chronic disease groups or examined chronic disease in the broader sense of the word [20,23,25,29,31,34,35,38]. Even in those multi-disease studies, the most common reported conditions included breast cancer, then arthritis and fibromyalgia.

3.4. Participants utilizing

A general breakdown of the papers included in this review by research location is as follows: USA (10); Europe (6); Asia/Pacific (3).

Participant demographics showed considerable variation, however, the general breakdown is as follows.

Whilst four studies [21–24] did not report gender of participants, the majority were female (in 12 of 19 studies). Only three studies investigated more males [32,34,36], however, in one of those studies the ratio of males to females was nearly 1:1 [34]. Of the seven studies to highlight race or ethnicity of their samples, most participants were white [27,29,30,33,34]. Age range showed the most variation with ages reported from 20 years, through to 65; the mean age of participants could be located in a narrower band, typically between 42 and 53 years. Nine of 19 studies mentioned relationship status, indicating some of their samples were either married or living with a partner. Education level was also reported: 11 of 19 indicated a high level of education with nine studies indicating at least some college [25–27,29,33–37] and the remaining two divided between both higher educated participants and high school educated or lower [28,32]. Level of employment and its relationship to the condition under investigation was more difficult to infer, as there was a mix between studies commenting on employment status and those that did not. There was considerable variation between the percentage of employed versus unemployed and full-time versus part-time employed participants. Competence in internet usage was explicitly stated or alluded to in three studies [9,11,15], and whilst not stating competence, a large number of studies investigated participants of pre-existing OSG [20,21,25,31,35–38].

3.5. Forms of social media utilization

More than 60% of the studies fall into the category of Predecessor studies ($N = 12$). There is a dearth of studies that report on health outcomes and other effects of social media (web 2.0) among chronic disease sufferers. Whilst in existence, robust work into the effect of social media on chronic disease sufferers is largely missing and represents a significant gap in knowledge of the effects of social media on chronic disease sufferers.

3.5.1. Predecessors

3.5.1.1. Online support groups (OSG), discussion forums, bulletin boards and chat ($N = 12$). This review highlights that OSG appear to be the most widely used and popular early social platform in chronic disease management. Cancer sufferers are largely reported, however, a range of chronic diseases are represented. Like SNS, the OSG that feature in this review were either custom created for the purposes of delivering an intervention or pre-existing. Whether custom created or otherwise, use of OSG fits into several categories: social support, information retrieval/insight, exchanging information/experiences, finding positive meaning, comparison/recognition and helping others [25,28,31,35–38]. According to van Uden-Kraan et al., OSG use leads to ‘empowered’ patients [25,35]. Users could either be quite active or passive (those who mainly absorb, rather than actively participate) [37].

Websites incorporating social functionality, such as bulletin boards, discussion forums and chat features have also been employed in chronic disease management [22–24,29]. Primarily, websites such as these were created as adjuncts to traditional care. Social features, such as a discussion board, were incorporated into an interactive website in a 2009 study to enhance chronic pain self-management. Emphasis was on individualized care and fostering integrative knowledge through interaction with others with a similar condition [22]. A similar intervention was also utilized in the design of a website in a 2008 study featuring a bulletin board for arthritis and fibromyalgia patients [29]. Use of a bulletin board for complex regional pain syndrome sufferers also indicated that participants used the board for encouragement, venting and to give advice. However, support provision was the main purpose [24]. The aforementioned studies showed that websites integrating earlier social functionality improve intervention attrition rates and lead to better patient engagement/participation and health outcomes because they enable care to be more tailored to the individual.

3.5.2. Social media

3.5.2.1. Social Network Sites (SNS) ($N = 5$). Three of five SNS were created specifically for the purpose of an intervention [26,27,32], the others utilizing the existing platforms of Facebook [21] and DailyStrength [20]. The purpose of enhancing self-management of disease was present in [27], however, constructing a SNS with the objective of driving support and social interaction was more of a factor for determining purpose [26,32]. The specific make-up and features of the intervention were outlined as user-centric profile, discussion posts, chat and private messaging [26,27]. ‘Friending’ other participants was also a feature in one instance [27]. A video-sharing service was the core focus in [32] (as well as user profile creation, photos and narratives).

Of the pre-existing SNS, Facebook has the highest number of active users and some of the ways in which it is utilized include: fundraising, awareness, promotions and support [39]. In the case of patients with type 1 diabetes, it appears that group members primarily use the platform to share information, request information from others and offer each other support [21]. DailyStrength

[20], a health-related SNS for patients and carers, centres around the formation of different support groups. Analysis of the conversation content from support groups for breast cancer, diabetes and fibromyalgia found the most common usage patterns centred around 'support'. The authors suggest that in poorly understood and socially stigmatized chronic diseases, support is the main activity or conversation to occur, as well coping and fitting within society [20].

3.5.2.2. Blogs (N = 1). There is literature available regarding the use of blogging as a form of emotional catharsis in chronic disease management [33]. However, few studies exist that report or explain the actual impact of blogging and how they may form an effective part of management. It appears that breast cancer sufferers are one patient population that have most to gain from narrating their experiences. For cancer sufferers, blogging has been used as a means to self-manage emotions, problem-solve, and share information [33].

3.5.2.3. Virtual Worlds (N = 1). Only one such study relevant to this review appears to exist investigating the potential of delivering psychosocial interventions via a virtual world, such as Second Life [34]. It is suggested that virtual environments may provide an ideal platform for the delivery of these interventions for conditions such as depression and other chronic diseases involving significant psychosocial components [34]. This may be especially true for those patients who find access to healthcare more difficult or whose conditions limit their ability to attend face–face interventions regularly. Second Life has been used to custom create a virtual environment for the provision of relaxation and stress alleviation. The participant can log on and attend the session through their 'avatar' and the clinician runs this session through the virtual world.

3.6. Reported effects/outcomes

Effects and health outcomes presented in this review were arranged into the following categories:

- Engagement/participation.
- Social interactions.
- Effect on disease-specific knowledge.
- Psychosocial impacts.
- Physical condition impacts.

Table 2 shows that the reported impacts on actual health status from use of the reported platforms are less evident for 'physical condition'. Conversely, impact on 'psychosocial' health appears more common. Even more apparent, is the general effect social media and predecessors have over variables such as participation, social interaction and knowledge.

3.6.1. Engagement/participation

Measured as the number of times each unique online feature was accessed and average length of time spent engaging with the platform, it was reported that participant interaction was high with a custom social networking intervention for rheumatoid arthritis [26] and that the most utilized feature was the discussion board. Participation was also reported positively amongst young cancer survivors using a custom created mobile based social network program (LIFECommunity). Interestingly, increased engagement with the site was positively correlated to having a lower support network offline [32]. A 2011 review investigating

Table 2
Platforms and reported effects/outcomes.

	OSG	Discussion forum/bulletin board/chat	SNS			Blogs	Virtual Worlds
			Custom	Facebook	Daily Strength		
Engagement/participation		[23]	[32,26]				
Social interactions							
– Peer support	[36–38,35,25]	[24,23]	[32,26]	[21]	[20]		
– Empowerment: (Includes: better informed, social well-being, confidence in treatment, confidence with practitioner, self-esteem, network building, acceptance & belonging, understanding, validation, optimism, control)	[36,38,35,25]	[22,24]	[32]			[33]	
– Information sharing	[36,38,35,25]	[22,24]	[32]	[21]	[20]	[33]	
Disease-specific knowledge		[22]	[27,26]				
Psychosocial impacts							
– Emotional burden							
– Catastrophizing							
– Pain-induced fear			[27]				
– Depression	[37,38,35,25]		[27]			[33]	[34]
– Anxiety	[30,37,31,28]		[27]				[34]
– Stress	[37,38]		[27]				[34]
– Emotional expression & distress	[37]	[29]	[27]				[34]
– Coping	[36]		[27]				
– Self-efficacy	[36]	[29]					
– QOL (psychosocial)	[36]	[29]					
Physical condition impacts		[29,23]	[27]				
– Pain severity		[23]	[27]				
– Pain-related interference/limitation			[27]				
– Perceived disability			[27]				
– Functional limitation		[23]					
– QOL (physical)	[36]						

what factors influence user engagement in online interventions proposed that incorporating social tools and support functions better tailors intervention to the patient. This resulted in better user engagement in the intervention [23].

3.6.2. Social interactions

Social interaction was frequently investigated and covered a wide range of themes (especially in those studies of OSG). These can include: peer support, empowerment (e.g. network building, acceptance and belonging in society, understanding and validation) and information sharing amongst online community members.

Via analysis of posts on LIFECommunity, it was revealed that participants felt a strong sense of support offered by the online environment. This was also found to be the case on Facebook for diabetes sufferers [21]. Activity on DailyStrength as a platform for breast cancer, diabetes and fibromyalgia communities to congregate also showed that support appeared to be the key focus of interaction on this platform [20]. LIFECommunity also fostered acceptance & belonging, as well as understanding & validation of the condition [26]. As reported above, it appears that social support is also positively linked to engagement/participation, as indicated whereby those with poorer support networks were shown to engage in the online intervention more in order to fulfil needs not being met offline [32]. Apart from emotional catharsis, blogging was found to be most useful for information sharing. Also, patients mentioned that problem solving was improved by blogging as well [33].

Similarly, social interactions were also frequently examined in those studies of OSG, discussion forums and bulletin boards. Particularly, the notion of empowerment is presented by van Uden-Kraan [25,35]. Study of complex regional pain syndrome sufferers suggests that online message board use is a great outlet to allow members to accept and validate their condition and attempt to focus on the positive [24]. In a similar fashion to the study on blogging, OSG use was seen as place to deal with emotions [37]. Study of empowering processes and psychosocial outcomes from OSG use in HIV/AIDS showed a statistically significant improvement in adaptive coping from use. This result was intimately linked to social interaction occurring via peer support, positivity and information exchange [36]. Similar functions/processes were reported for Japanese breast cancer OSG participants, whereby support was the most common feature [37]. An interpretative study of message board posts for complex regional pain syndrome sufferers also indicated that support is an obvious benefit of discussion board set-ups. This occurs via giving advice, sharing and receiving information and sharing experiences [24]. In line with van Uden-Kraan's [25,35] work on empowerment, one of the only other studies to sample participants of OSG across a range of chronic diseases also showed that OSG use was positively correlated to the empowerment outcomes of feeling better informed, improved well-being, greater confidence with treatment, better self-esteem and acceptance of their illness [38]. These were significantly correlated to comparison to other members, helping each other/support and sharing of information. However, van Uden-Kraan was only able to find a modest correlation [35]. Interestingly, all three studies were also the only ones to investigate and support that OSG use improved patient relations with their physician. Mainly because participants felt that using an OSG made them better prepared for consultations and more confident in discussing the information they had found online [22,38].

3.6.3. Effect on disease-specific knowledge

Disease-specific knowledge, accepted as an important factor for successful chronic disease self-management is also discussed. After participating in the online chronic pain self management program, significantly improved disease specific knowledge was reported by participants, thus allowing them to better self-manage [27]. This notion of disease-specific insight was similarly highlighted in [37]. Of the discussion themes analysed for diabetes Facebook groups, both providing information and requesting information were the highest reported uses [21]. Similarly, discussions surrounding experiential knowledge were also amongst the themes to emerge from interaction on DailyStrength [20]. It was also stated that participating in online self-management programs is a good place to find useful disease specific resources and lessons learnt from the environment can be meaningful or beneficial to sufferers [26]. Improved disease-specific knowledge was best highlighted in the conceptual design of an interactive social website for chronic pain sufferers, whereby users seek information to build both declarative and factual knowledge. This then allowed them to apply it within the context of their own illness management [22].

3.6.4. Psychosocial impacts

Impact on psychosocial wellbeing was widely reported. Given the often long-standing burden that chronic disease can place on an individual's mental state, a large percentage of interventions have focussed on improving psychosocial wellbeing. Emotional burden, catastrophizing, pain induced fear, depression, anxiety and stress were all seen to statistically improve via use of a custom social network site intervention for chronic pain suffers [27]. Only one study conducted in 2012 investigated the potential virtual worlds such as Second Life might hold for psychosocial management. It presented a general trend towards less perceived stress, distress, depression and anxiety after intervention, highlighting the potential benefits it may hold. However, only improvement on the Global Severity Index (measure of overall psychological distress) was seen to be statistically significant [34]. Despite seemingly positive results, it is prudent to note that this was a pilot study and individuals were healthy. Carry over to chronic disease sufferers is merely suggested. It will not be until intervention is tested on a specific chronic disease population that results can be confidently interpreted [34]. Study of the use of blogging amongst cancer patients also tended to target psychosocial health management as the primary focus. It was found most useful for alleviating emotional distress [33]. A 2008 study utilizing an online bulletin board for arthritis sufferers also found significant psychosocial improvements, seen via improved health-related distress and self-efficacy [29].

The benefits of peer support in the 2011 study of Japanese breast cancer sufferers also reported significant improvement in depressive symptoms, as well as anxiety (especially for 'active' participants) [37]. The only systematic review [31] strengthened the argument for OSG use to improve depression. They investigated both stand-alone OSG interventions and those parts of multicomponent online interventions in cancer (majority had breast cancer). Whilst both showed improvements in depressive symptoms, they reported that 60% of stand-alone interventions showed improved depression, compared to just 12% in multi-component. This was statistically significant [31]. Participation in another OSG intervention for breast cancer sufferers was also suggested to improve depressive symptoms in a peer led setting, however, this was not statistically significant [30]. Self-efficacy, as well as quality of life (QOL) (a broader measure of health status),[1] were both examined in one 2012 paper and found to be statistically significant, with QOL positively correlated to adaptive coping [36]. This study of OSG use for HIV/AIDS positively linked these two variables to social interaction.

---

[1] *Note:* QOL measurement encompasses both physical and psychosocial health. Therefore, positive results seen in this paper also apply to physical condition impacts (as noted in Table 2).

3.6.5. Physical condition impacts

Physical condition changes were the least reported from social media use. Few studies investigated the effects and uses of such sites on physical condition status. Compared to treatment as usual, participants undertaking an online chronic pain management program showed statistically significant improvements in pain severity, pain-related interference and perceived disability [27]. The same 2011 review that studied what factors influence user engagement in online interventions indicated that a tailored intervention to the needs of the patient led to positive improvements in instances of pain and activity limitation [23]. An RCT utilizing an online bulletin board as part of an online arthritis self-management program found that participants in the intervention group displayed significant improvements in pain severity and functional limitation at both 6 months and 1-year follow-up [29].

3.7. Evidence of the role of affordances

Of specific interest to this review is ‘how’ social media use may influence outcomes. Specifically, what is it about these social platforms that enable the aforementioned processes to occur? What are their affordances to the individual in health self-management?

While Table 2 highlights the relationship between the examined platforms and the effects/outcomes seen from use, what the patterns do not demonstrate is any relationship that considers outcomes in relation to the underlying mechanisms of social media use. In a second cycle of analysis of the literature selected for the review, it was possible to identify a selection of affordances that we have termed: *identity, flexibility, structure, narration and adaptation.*

When approaching social media from an affordance perspective it is important to understand that it is not the features of social media (such as profiles, walls, video sharing, commenting and tagging) that are most important. The tools and functionalities are important in so far as they afford participants different ways to interact and behave.

3.7.1. Identity

The papers in this review suggest that social media afford chronic disease sufferers more choice and control over how they present and assert themselves, as well as how much about their condition they disclose and share. This affordance surrounds ‘self-presentation’ and has implications for the norms of patient identity protection and patient records ownership. Depending on sufferers’ individual needs, individuals can chose to make their behaviours and personal information visible or chose to interact in a more discreet manner [14].

Despite some ability to control profile visibility on popular SNS such as Facebook, profile information, networks and pictures are more visible and more readily identifiable using this type of social media over others. It has been suggested that this may improve perceived credibility and reach and enhance networking capabilities, but it may also suggest certain SNS are less suitable for support in socially stigmatizing conditions [39].

Other social media such as blogs and virtual worlds allow for a much more anonymous interaction, which may be preferable to some people. Participants of OSG and users of online message boards have responded positively to anonymity, suggesting that the privacy allowed by not disclosing a full profile means they can discuss potentially taboo topics otherwise not discussed in more transparent environments, face to face or offline [24]. Similarly, social media platforms such as Second Life (virtual environments) may provide another means to deliver chronic disease interventions, as interaction occurs via ‘avatars’ or online representations of the user. Second Life users have suggested that the relative anonymity offered in the virtual environment made participation more comforting and approachable [34]. Inherently, anonymity is a means for sufferers to discuss their concerns and share sensitive health information in a seemingly confidential manner and has been suggested to create a cyber buffer zone for participants to feel safe and comfortable in their online environment [1]. Stigmatized patients or those less likely to attend face–face interventions due to self-consciousness are thus provided with another avenue to participate without the fear of judgement [1]. However, one of the possible negatives surrounding anonymous interaction can be potential to be subject to spam, recruitment notifications and promotional content. This is particularly true of environments where it is difficult to fully verify the identity of others. Despite one Facebook study [21] on social networking in diabetes discussing the potential problem of unsolicited advertising and authenticity, no reports of adverse effects have been found in the present review.

3.7.2. Flexibility

Whilst ‘identity’ refers to ‘who’ and ‘what’, ‘flexibility’ for the purposes of this review refers to ‘when’ and where’. Cohort size, number of members belonging to a group, time of day and geographic location are all factors and potential barriers affecting the effectiveness of social interaction in chronic disease. Social media affords chronic disease sufferers some ‘flexibility’ in regards to the timing and location of communication. It provides a sense of time–space freedom enabling chronic disease sufferers some choice to decide when and where they interact.

Clinicians may need to consider that unlike synchronous communication, which requires users to be online at the same time and in some cases similar time zones, asynchronous communication is a possible effective means for chronic disease sufferers to communicate [26]. As was the case in two particular instances in the present study, rheumatoid arthritis and complex regional pain sufferers indicated that wall, board and message posting were more engaging compared to online chat because of the asynchrony offered [24,26]. In both cases, users were able to follow posts and interact at a time that suited them. Therefore, when faced with a dispersed, small and/or time poor community, asynchronous communication using social media may be better suited to meet the needs of chronic disease patients [26].

3.7.3. Structure

Structure refers to the architecture of participation and framework that social media affords to chronic disease sufferers. Whilst traditional web 1.0 Internet search opened users up to a wealth of health information, the boundaries around this online health information seeking were undefined. Conversely, the ability of social media to connect individuals, enhance information sharing and collaboration, has helped facilitate and guide chronic disease sufferers with their self-management and given online management more direction [6,40]. This same idea is highlighted in research describing social media as a form of ‘apomediary’ or filter, guiding sufferers to relevant and accurate information to self-manage their condition [40].

This idea of facilitation or guidance via social media occurs at different levels. As can be seen via the included studies in this review, use of social media in chronic disease management can either be self-guided (an example of this is seen in the process of emotional catharsis from blogging [33]), fostered through peer to peer interaction ($N = 2$) [27,28], or guided by an external source (facilitator or health professional) ($N = 6$) [22,23,26,29,31,32]. One particular study [30] actually compared peer to peer interaction with external facilitation. Despite these contrasts, positive outcomes have been reported in all instances.

Use of a facilitator or health professional input continues to be debated. Those advocating in favour suggest that this minimises the risk of poor quality and/or misleading information ending up in the hands of patients [1]. Further suggestions in favour of external facilitation include:

- To prompt participants into action [29,32].
- Data safety [32].
- Monitoring activity and information for appropriateness/screening [22,26,29].
- Guide participants with their management [22,23].
- To address specific topics/act as a contact point [29].
- To ensure the website functions properly [22].

Whether social media use in chronic disease should be formally facilitated or not is a prudent question. The findings of this review suggest that it might not actually matter. Authors of the 2009 systematic review on OSG use for depression reinforce this view, however, results were not statistically significant [31]. Similarly, one study from 2012 [30] formally investigated the difference in outcomes seen between participants undergoing a professionally facilitated intervention compared to a peer to peer only support group intervention. Participants suffering depression were randomized to either group. The authors found that both groups' depressive symptoms improved but there were no significant differences in depression as a result of undergoing intervention in either group. Study size was suggested as one possible reason for no significant difference ($N = 50$). Notably, they did suggest that group members in the professionally led group were more active in terms of reading and posting [30]. This is augmented by a further suggestion that professional input is important to improve an intervention's effectiveness and decrease attrition rates [19]. Given that greater 'engagement' or 'participation' is a reported positive effect in this review, it may be plausible to suggest that if involving a health professional leads to greater participation, then this is clinically significant and relevant. This theory supports the work of van Uden-Kraan et al. who suggest that, active and engaged patients are indeed more empowered, which in turn correlates to improved well being [25,35].

Debate concerning the level of facilitation or guidance of social media use continues and further study regarding which circumstances lead to optimal outcomes for different types of patients is required.

3.7.4. Narration

Narratives have been explored as a means to tell one's story, express and manage emotions and share information in chronic disease [33]. Social media provide chronic disease sufferers with the opportunity to narrate their experiences through a variety of channels.

Within the present review, narration was highlighted most visibly through blogging. The included 2008 study examining blogging amongst cancer sufferers not only highlighted that participants believed blogs to be a relatively reputable source of information but that the platform is well suited as a way to problem solve and manage emotions [33]. Similarly, a 2012 study also suggested that blogs may be an appropriate platform for narratives to be created and shared for emotional expressive and support needs [41]. This is reiterated by a 2011 study that thematically coded the content of a selection of cancer narratives sourced from the video-sharing service, YouTube [42]. The authors found similarly that emotional engagement was high as sufferers detailed their own story. Whilst only two specific outlets are explored here (blogging and video narratives), social media warrant further investigation for their narrative potential, as they appear positive for emotional catharsis. Additional research is needed to investigate whether positive emotional management and/or engagement via narratives lead to improved psychosocial health status among certain types of sufferers.

3.7.5. Adaptation

Chronic disease sufferers need variety in their management as their needs are seen to change over time and over the course of disease [25]. Information needs, support needs and overall management need to be adaptable. Social media afford sufferers the ability to adapt self-management behaviour over time.

It was proposed in a 2010 study of HIV/AIDS sufferers, that those early in their disease have the most to gain from social media because they benefit from being better informed at this early stage [8]. During the early stages of disease, information needs are relatively high, therefore sharing and building networks are important. However, as disease progresses and information needs diminish, social media appears to have a stronger role in consolidating existing relationships and using it for support. Hence, its role adapts to suit the needs of the patient at that point in time. Drop-off in social media usage can be seen over time as patients come to terms with their condition and turn to the medium less frequently [26].

The ability of social media to accommodate evolving patient needs and behaviours is a key influence over attrition rates and warrants consideration as social media purpose and intervention design is contemplated.

4. Discussion

This review has examined ways in which social media has been used in the management of various chronic diseases but the limited amount of literature available highlights substantial gaps in knowledge. Thus, it is difficult to make any definitive conclusions regarding the best approach to social media use under different circumstances and for different individual needs. The findings presented in Table 2 are simply associations between platform and outcomes. They are also skewed, highlighting a greater propensity of the literature to examine non-health effects over health effects, suggesting that social media foster support, information sharing, empowerment and improved disease-specific knowledge. In terms of actual health outcomes, there has been more literature in support of psychosocial outcomes, as opposed to physical health outcomes. However, of special attention at this present time is that the literature predominantly represents studies involving predecessors of social media such as OSG and discussion forums, as opposed to social media, such as SNS, blogs, wikis and virtual worlds. It could be expected that as time progresses more papers examining the effects and health outcomes from social media use will appear.

The gaps in knowledge surrounding social media use and patient outcomes have been a key motivation behind the affordance approach to closer examination. This is because the concept of interactions and behaviours enabled by various social media may help to improve understanding of they can be used to generate different effects for different people. This perspective is a relatively novel approach in healthcare and chronic disease but is established in other fields of social research. A recent 2012 study also approached social media from an affordance perspective in looking at the ways social media can influence organizational processes and communications [14]. The theory behind this approach is that a better understanding of the behaviours social media enable may provide a more efficient avenue to improve organizational processes as compared to a technology centred approach (i.e. focusing on the functionality of individual platforms and their features) [14]. As a concept, social media's affordances may not only aid researchers to overcome barriers hindering evidence-based practice of social media use in chronic disease but may also be a more insightful approach to the study of social media in health management in general.

Whilst this review has thematically identified a series of affordances social media may enable in a chronic disease context (identity, flexibility, structure, narration and adaptation), it acknowledges other perspectives on social media affordances outside the health context. For example, [14] proposes affordances of visibility, persistence, editability and association. Visibility refers to social media's ability to make user behaviour, knowledge, personal information and networks visible to others (in some ways this aligns itself with 'identity'). Persistence pertains to the lingering availability of information communicated through social media even after it has occurred. Editability refers to the ability to refine and craft communications before and even after it is viewed by others ('asynchrony' as discussed is a key feature that enables editability to occur). Finally, association is the connections between/among individuals and individuals to content. Whilst these affordances are discussed in a workflow and communication context, their potential applicability to chronic disease management may be worthy of further investigation.

It is important to mention that earlier social platforms such as discussion forums and bulletin boards, web 1.0 applications, as well as other forms of offline chronic disease management may also offer some of the same affordances [14]. For example: posting on a SNS or, discussion forum, blogging, emailing and filling in a survey, all afford flexibility in terms of timing of interaction. However, as a group, social media may provide the scope to allow for a more efficient and consistent combination of these affordances.

It is also noted that studies of the effects of offline social support networks on people with chronic diseases predate online technology. Such studies indicate that social support networks are a key component of chronic disease management, for example to help with coping and driving lifestyle change [43]. Extending social support networks can now be achieved via current trends in Internet technology such as social media. Further theorising about the health outcomes of social media use may uncover similarities and possibly differences in the underlying mechanisms of social networking in technological and non-technological settings. However, a comparative study of offline versus online social support is out of scope in the present review.

4.1. Limitations/challenges

Traditionally there has been a trend in technology literature to focus on benefits and positive research findings. The studies examined in this review have also shown an affinity to report positively. Notably however, these results contained a mix of both statistically and non-statistically significant findings. Small sample sizes are one possible explanation, with the smallest being just $N = 14$ and five studies sampling less than fifty participants. Confounding this, attrition rates were infrequently reported, nor were intention-to-treat analyses discussed. This review also highlights biases in participant selection. Paramount was the tendency to sample female, Caucasian, college educated, employed and competent Internet users. Whilst these findings are in line with previous public health work describing trends in Internet usage [3], they do not correspond to the profile of the average chronic disease sufferer, typically (in the USA) described as African American, less educated and lower income earning. Whilst highlighting issues pertinent to e-health literacy, the report does however, suggest that if demographic variables are controlled, chronic disease sufferers are likely to be active and positive about social media [3].

5. Conclusion

The present review has aimed not only to explore the effects of social media on chronic disease sufferers but to better understand the mechanisms underlying these effects via exploring different ways that chronic disease sufferers use social media. Understanding the personal choices and behaviours afforded to chronic disease sufferers by social media may improve understanding of how to better tailor these online interventions to the specific and individualized needs of people in this group.

The effects and health outcomes described in this review from using social media appear positive from the limited studies that have investigated their use in this area. However, given the large representation in the literature of OSG, discussion forums and bulletin boards, there remains a significant gap in knowledge of the effects of more specific social media.

Identifying affordances of social media has been one approach that aims to overcome a lack of understanding informing effective social media use chronic disease management. It is hypothesized that they may influence the ways in which social media impact different sub-groups of patients. The affordances presented in this review are all significant to healthcare as online modalities continue to shape participatory care and self-management. It is clear that research into social media usage in chronic disease management is still in its early stages. The literature in this domain is still dominated by studies of early web-based technology and studies of individual social platforms with little consideration of theory surrounding social media. It is for this reason that attention and refinement to the affordances of social media in an illness context must be considered alongside or in place of platform specific studies. This may have a more significant impact on the rigor, theory and evidence-based approach to social media usage in chronic disease management in years to come. Further research is thus suggested using systematic and thoughtful study designs to investigate how the particular affordances of social media are best suited to addressing different patient needs. If this can be achieved, social media may play a more important role and be used more effectively in patients' clinical management and self-management, thus leading to better health outcomes.

Acknowledgments

A sincere thank you to Mr. Patrick Condron, Liaison Librarian at Melbourne Medical School for his valuable assistance during the early stage of undertaking this review and to Mr. Stephen Thurlow, Advisor at the Melbourne School of Design for his advice in the preparation of this manuscript.

Appendix A. Search terms used

(a) Social media/ Internet related	(b) Chronic disease related	(c) Effects/health outcomes
"social media"	chronic	"quality of life"
"social network"	chronic disease	QOL
"social networks"	chronic illness	autonomy
"social networking"	cancer	"self-efficacy"
"social network site"	depression	"self efficacy"
"social network sites"	anxiety	"pain intensity"
"web 2.0"	arthirits	"pain management"
"medicine 2.0"	diabetes	"patient management"
"med 2.0"	"chronic pain"	"quality of care"

(*continued on next page*)

Appendix A (*continued*)

(a) Social media/ Internet related	(b) Chronic disease related	(c) Effects/health outcomes
“health 2.0”	pain	“care team”
“web 3.0”	“complex regional pain”	“cognitive behavioural therapy”
“medicine 3.0”	CRPS	“cognitive behavioral therapy”
“med 3.0”	CRP	CBT
“health 3.0”	“chronic regional pain”	“pain level”
“semantic web”	“reflex sympathetic dystrophy”	“pain levels”
“discussion board”	RSD	distress
“discussion boards”	fibromyalgia	anxiety
“discussion forum”		depression
“discussion forums”		“self-management”
“online support group”		“self management”
“online support groups”		utilisation
“electronic support group”		utilization
“electronic support groups”		visits
online		appointments
internet		morbidity
“web-based”		engagement
“web based”		participation
“internet-based”		management
“internet based”		empowerment
emailing		behaviour
Facebook		behavior
Twitter		mood
Youtube		use
blog		usage
blogs		activity
blogging		“physical function”
Myspace		“physical activity”
“Patients Like Me”		adherence
“PatientsLikeMe”		
“Second Life”		
SecondLife		

References

[1] Seeman N. Web 2.0 and chronic illness: new horizons new opportunities. Healthc Q 2008;11:104–8. 10, 4.

[2] Fox S. The social life of health information. Pew Internet & American Life Project. Washington, DC, USA: Pew Research Center Publications; 2011. p. 12/9/2011.

[3] Fox S. Chronic disease and the internet. Pew Internet & American Life Project. Washington, DC: Pew Research Centre; 2010. p. 53.

[4] Hesse BW, O’Connell M, Augustson EM, Chou WY, Shaikh AR, Rutten LJ. Realizing the promise of Web 2.0: engaging community intelligence. J Health Commun 2011;16(Suppl 1):10–31.

[5] Kamel Boulos MN, Wheeler S. The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. Health Info Libr J 2007;24:2–23.

[6] Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of social media. Bus Horizons 2010;53:59–68.

[7] Boyd DM, Ellison NB. Social network sites: definition, history, and scholarship. J Comput Mediated Commun 2008;13:210–30.

[8] Mo PKH, Coulson NS. Living with HIV/AIDS and use of online support groups. J Health Psychol 2010;15:339–50.

[9] Chong E, Xie B. The use of theory in social studies of Web 2.0. In: Proceedings of the 2011 44th Hawaii international conference on system sciences. IEEE Computer Society; 2011. p. 1–10.

[10] Cormode G, Krishnamurthy B. Key differences between Web 1.0 and Web 2.0; 2008.

[11] O’Reily T, Battelle J. Web squared: Web 2.0 five years on. San Francisco: O’Reily Media; 2009.

[12] Van De Belt TH, Engelen LJ, Berben SA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. J Med Internet Res 2010;12:e18.

[13] Schein R, Wilson K, Keelan J. Literature review on effectiveness of the use of social media. A report for Peel Public Health. Ontario, Canada; 2010. p. 63.

[14] Treem JW, Leonardi PM. Social media use in organizations: exploring the affordances of visibility, editability, persistence, and association. Commun Yearbook 2012;36:143–89.

[15] Gibson J. The ecological approach to visual perception. 2nd ed. New Jersey, USA: Lawrence Erlbaum Associates Inc; 1986.

[16] Norman D. The design of everyday things. Basic Books; 2002.

[17] Phillips JL, Currow DC. Cancer as a chronic disease. Collegian 2010;17:47–50.

[18] Brattberg G. Internet-based rehabilitation for individuals with chronic pain and burnout: a randomized trial. Int J Rehabil Res 2006;29:221–7.

[19] Nordfeldt S. Patient and parent views on a Web 2.0 diabetes portal – the management. J Med Internet Res 2010:12.

[20] Chen AT. Exploring online support spaces: using cluster analysis to examine breast cancer diabetes and fibromyalgia support groups. Patient Educ Couns 2011.

[21] Greene JA. Online social networking by patients with diabetes: a qualitative. J Gen Intern Med 2011;26:287–92.

[22] Schulz PJ, Rubinelli S, Mariotti G, Keller N. Meeting the ranging of informational needs of chronic low back pain sufferers: conceptual design and rationale of the interactive website ONESELF. Disabil Rehabil 2009;31:2118–24.

[23] Schubart JR, Stuckey HL, Ganeshamoorthy A, Sciamanna CN. Chronic health conditions and internet behavioral interventions: a review of factors to enhance user engagement. Comput Inform Nurs 2011;29:81–92.

[24] Rodham K. Seeking support: an interpretative phenomenological analysis of an Internet message board for people with Complex Regional Pain Syndrome. Psychol Health 2009;24:619–34.

[25] van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. Qual Health Res 2008;18:405–17.

[26] Shigaki CL, Smarr KL, Yang G, Donovan-Hanson K, Siva C, Johnson RA, et al. Social interactions in an online self-management program for rheumatoid arthritis. Chronic Illness 2008;4:239–46.

[27] Ruehlman LS, Karoly P, Enders C. A randomized controlled evaluation of an online chronic pain self management program. Pain 2012;153:319–30.

[28] Hoybye MT, Dalton SO, Bidstrup PE, Frederiksen K, Johansen C. Effect of Internet peer-support groups on psychosocial adjustment to cancer: a randomised study. Br J Cancer 2010;9:1348–54.

[29] Lorig KR, Ritter PL, Laurent DD, Plant K. The internet-based arthritis self-management program: a one-year randomized trial for patients with arthritis or fibromyalgia. Arthritis Rheum 2008;59:1009–17.

[30] Klemm P. Effects of online support group format (moderated vs peer-led) on depressive symptoms and extent of participation in women with breast cancer. Comput Inform Nurs 2012;30:9–18.

[31] Griffiths KM, Calear AL, Banfield M. Systematic review on internet support groups (ISGs) and depression (1): do ISGs reduce depressive symptoms? J Med Internet Res 2009:11.

[32] McLaughlin M, Nam Y, Gould J, Pade C, Meeske KA, Ruccione KS, et al. A videosharing social networking intervention for young adult cancer survivors. Comput Human Behav 2012;28:631–41.

[33] Chung DS, Kim S. Blogging activity among cancer patients and their companions: uses, gratifications, and predictors of outcomes. J Am Soc Inf Sci Technol 2008;59:297–306.

[34] Hoch DB, Watson AJ, Linton DA, Bello HE, Senelly M, Milik MT, et al. The feasibility and impact of delivering a mind–body intervention in a virtual world. PLoS One 2012:7.

[35] van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, van de Laar MA. Participation in online patient support groups endorses patients’ empowerment. Patient Educ Couns 2009;74:61–9.

[36] Mo PKH, Coulson NS. Developing a model for online support group use, empowering processes and psychosocial outcomes for individuals living with HIV/AIDS. Psychol Health 2012;27:445–59.

[37] Setoyama Y, Yamazaki Y, Namayama K. Benefits of peer support in online Japanese breast cancer communities: differences between lurkers and posters. J Med Internet Res 2011:13.

[38] Bartlett YK, Coulson NS. An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. Patient Educ Couns 2011;83:113–9.

[39] Bender JL, Jimenez-Marroquin M-C, Jadad AR. Seeking support on facebook: a content analysis of breast cancer groups. J Med Internet Res 2011;13. e16-e.

[40] Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10:e22.

[41] Keim-Malpass J, Steeves RH. Talking with death at a diner: young women's online narratives of cancer. Oncol Nurs Forum 2012;39:373–8.

[42] Chou W-YS, Hunt Y, Folkers A, Augustson E. Cancer survivorship in the age of YouTube and social media: a narrative analysis. J Med Internet Res 2011;13. e7-e.

[43] Funnell MM. Peer-based behavioural strategies to improve chronic disease self-management and clinical outcomes: evidence logistics evaluation considerations and needs for future research. Fam Pract 2010:17–22.