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Social Media for the Promotion of Holistic Self-Participatory Care: An Evidence Based Approach

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Summary

Objectives: As health information is becoming increasingly accessible, social

media offers ample opportunities to track, be informed, share and promote health.

These authors explore how social media and holistic care may work together; more

specifically however, our objective is to document, from different perspectives, how

social networks have impacted, supported and helped sustain holistic self-participatory

care.

Methods: A literature review was performed to investigate the use of

social media for promoting health in general and complementary alternative care in

particular. We also explore a case study of an intervention for improving the health of

Greek senior citizens through digital and other means.

Results: The Health Belief Model provides a framework for assessing the benefits of

social media interventions in promoting comprehensive participatory self-care. Some

interventions are particularly effective when integrating social media with real-world

encounters. Yet not all social media tools are evidence-based and efficacious.

Interestingly, social media is also used to elicit patient ratings of treatments (e.g., for

depression), often demonstrating the effectiveness of complementary treatments, such

as yoga and mindfulness meditation.

Conclusions: To facilitate the use of social media for the promotion of complementary

alternative medicine through self-quantification, social connectedness and sharing of

experiences, exploration of concrete and abstract ideas are presented herewithin. The main mechanisms by which social support may help improve health - emotional support, an ability to share experiences, and non-hierarchal roles, emphasizing reciprocity in giving and receiving support – are integral to social media and provide great hope for its effective use.

Key words: web 2.0, Evidence-Based Health Care, Community-Based Participatory Research, Holistic Health, Self-Management.

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Introduction

The use of contemporary *social media or web 2.0* for the promotion and sustainability of holistic self-management is not well documented. Over the years, individuals have come to increasingly rely on web-based health information. Eighty one percent of U.S. adults use the internet, and 59% say they have looked online for health information in the past year [1]. Today, people are increasingly aware of their health conditions and status [2] as social media offers a spectrum of highly interactive tools, including wikis (e.g., Wikicancer), blogs (e.g., SixUntilMe), Twitter (e.g., @QuitSmoking123), Facebook and thematic patient networks (e.g., PatientsLikeMe and CureTogether) which allow individual engagement and offer health information and patient contributions to create a supportive patient conversation ecosystem.

Increasingly, thanks to advances in sensor technologies and the social web, people are starting to capture personal health-related data in the course of their routine daily activities. This has facilitated the concept of self-quantification [3], concerned with capturing, recording, analyzing and sharing personal health data, thereby rendering the data conveyed through social media richer than ever. Self-quantification applies to diseases, as well as to preventive applications - individuals are able to track symptoms that may be associated with the risk of a having a certain disease or health condition (e.g., metabolic syndrome) and share them with peers or health professionals [4]. This is also a good example of crowd sourcing, where information accumulated from patients (in this case), generates a new body of knowledge and evidence.

In this paper we discuss how social media and holistic care may work together; more specifically however, our objective is to document, from different perspectives,

how social networks have impacted, supported and helped sustain holistic self-participatory care.

Complementary Alternative Medicine (CAM) and Social Media

CAM techniques, including acupuncture, massage, music therapy, yoga, (mindfulness) meditation, guided imagery and deep-breathing exercises are used to "promote physical, mental, emotional and spiritual wellbeing" [5]. These therapies have been used to complement conventional medicine in treating existing physical and mental conditions and, while many perceive these modalities to be "unconventional" compared to traditional medical practices, evidence-based research are being conducted using these techniques with varying results [6]. Social media may provide support and engagement for individuals who choose to integrate CAMs into their treatment and lifestyle. Moreover, both CAMs and social media are under increased scrutiny to support current evidence-based practices.

Social Media Supporting CAMs

The "quantified-self" movement includes applications involving CAM techniques. Such applications as "yoga apps to become a better yogi" are available on "quantified-selfers" phones and desktops [7]. Those interested in meditation may keep track of the number of minutes of meditation and record comments via "i.strive.to" (http://i.strive.to/track/meditation). These apps have links to Facebook, Twitter, and Google for those who wish to share a post of personal experiences and motivate others to do the same. Examples are often inspiring and demonstrative of the benefits conveyed through digital and social interventions. For example, based on the work of Selhub and Logan [8], Hansen is currently exploring whether viewing various nature

scene applications is associated with a decrease in surgical patients' anxiety and pain levels and an increase in patients' self-efficacy in healing [9] (see Figure 1).

Figure 1: Screen shot of nature apps for surgical patients by Salumedia

Other examples involve the active participation of patients in rating the efficacy of interventions, some of which are derived from CAM. The ability to pool information from patients and to aggregate input on patient reported outcomes, lends tremendous power to social media and renders it an important resource for patients and caretakers alike. Cure Together, a social patient network, conducted a novel study including 227 individuals who rated 31 various treatments for bi-polar disorder [10]. The researchers combined patient-reported results from social media with integrated therapy options and

produced a live interactive infographic showing some of the self-assessed and quantified interventions. For example, patients reported modalities, such as sleep regulation and meditation, as alternative treatments that improved their condition. Moreover, Keener points out these modalities "also have been shown elsewhere to result in functional and structural changes in cortical midline regions as well as limbic areas" of the brain [11]. Currently, the live infographic [12] (Figure 2) displays 1,565 treatment effectiveness ratings with regimented sleep, reduction in alcohol consumption, and exercise rated as most effective and popular by participants. (The x-axis displays the fraction of respondents who tried a given treatment; the y-axis displays the average rated effectiveness of a given treatment. The vertical blue line displays the average fraction of respondents who tried each treatment and the horizontal blue line displays average rated effectiveness of all treatments). Yoga and mindfulness meditation were also highly rated for alleviating symptoms. Major bipolar medications were rated as neither effective nor popular among the research respondents. Regardless of the "potential bias in patient self-selection and recall" [10] this study may serve as a model for future patient-based outcomes research surrounding the quantified self and the use of CAMs.

Figure 2: 40 Bipolar Disorder Treatments Compared as Rated by Patients

Health Belief Model

   While the use of social media is relatively new, it dovetails with Rosenstock's [13] Health Belief Model (HBM), one of the first social cognition models to explain health behaviors [14]. Initially the author's aim was to identify how health promotion services were socially received in a community. In 1988 the model was updated to reflect an individual's current perceived personal threat along with a belief in the effectiveness of a suggested health behavior as they predict the actual uptake of the health promoting behavior. Various constructs have been added to relate various human perceptions to a subsequent predictable health behavior. Such factors as demographic, socio-psychological, perceived self-efficacy, promotion of health behaviors and motivation to achieve health, as well as perceived threat and control, are considered when looking at the outcomes. This model may greatly assist with the development of a conceptual framework for research pertaining to the use of social media and CAMs: non-psychologists may easily apply the constructs, the outcomes are based upon attitudes

and beliefs of individuals and human behavior predictions are measurable. Connor and Norman [15] report three areas to which the model may be applied: Preventative health, sick role behavior and clinic use. The Health Belief Model is consistent with the use of social media tools as illustrated in Table 1.

Table 1: Applications of the Health Belief Model within Social Media

	Traditional HBM	**HBM and Social Media**
Concept	Smoking Cessation	Screening for Lung Cancer Education via Social Media
Perceived Susceptibility	Adults believe they may get lung cancer	Adults believe they may have been exposed to harmful nicotine over the years and seek screening and track future exposure via mobile technology
Perceived Benefits	Adults believe the consequences of getting lung cancer are real enough to try and quit smoking	Adults believe the consequences associated with having lung cancer without knowledge or treatment are significant enough to try to avoid smoking and embrace text messaging reminders.
Perceived Barriers	Adults identify personal	Adults identify personal

	barriers to quitting smoking (e.g. weight gain, anxiety, peer pressure, etc.)	barriers to getting tested (e.g. getting to a clinic, fear of the unknown, telling loved ones) via an online support group.
Cues to Action	Adults receive educational material to help quit smoking behaviors	Adults receive educational reminder cues via poster boards at work, Facebook, Linkedin, cell phones or Twitter/Yammer
Self-Efficacy	Adults feel confident they can stop smoking and replace with healthy behaviors, such as meditation and yoga in all circumstances.	Adults receive guidance as to where they may receive lung x-rays if symptomatic cough and shortness-of-breath persist. Wikis and blogs may promote self-efficacy and education.

Evidence for the contribution of social support to health outcomes

A more traditional contribution of social media to health lies in the support it provides to patients. While social media is still in its infancy, social support has repeatedly been shown to improve health outcomes across various diseases. These findings serve as a foundation for establishing evidence-based practice (EBP) for social media.

Importantly, social support has a positive effect on health, regardless of other forms of support. A study using data from the Health Survey for England [16] found, in line with earlier research, personal levels of social support contribute to a better self-reported health status. This holds even when social capital is entered into the equation. A review of 81 studies [17] has shown social support was reliably related to beneficial effects on cardiovascular, endocrine, and immune function. Potential health-related behaviors did not appear to be responsible for these associations, suggesting the effect is driven by emotional support. Some underlying mechanisms for the effect of support, as identified in the studies, include stress-buffering, emotional support, and family support. Later work [18] described two psychological paths through which social support improves health outcomes: a practical one, facilitating healthier activities and behaviors such as exercise, eating healthy, and not smoking; and one related to appraisals, emotions, and feeling of control (e.g., [19]).

A review of the literature from 1948 to 2001 [20] found 122 studies that correlated structural or functional social support with patient adherence to medical regimens. Practical assistance, which had the strongest association with adherence, cannot be applied in the online context. However, emotional support, as mentioned above, is a benefit of social support relevant to social media. Indeed, risk of non-adherence was 1.35 higher in patients who did not receive this support, though the association between adherence and emotional support was stronger in studies involving self-reported adherence.

Other health benefits of social support have been reported. Researchers of male diabetic patients found reciprocal peer support reduced Hemoglobin A1c more

effectively than did nurse support [21]. As the authors note, "Peer support could allow patients to share experiences and receive reinforcement that is not available from time-pressed clinicians, and it may especially benefit patients who are tackling challenging medical tasks, such as insulin management" (p. 507). In this study, social support was delivered over the phone, and patients were not assigned the role of either "helper" or "helpee". This is analogous to social media, where most people do not assume an official role, but rather belong to a community that shares characteristics pertaining to a disease or condition.

While the above highlights the promise of social media in improving health outcomes, recent work suggests there may be important caveats to consider. The first study to examine the effect of Twitter on health outcomes [22] analyzed all 153 user accounts containing the words "quit or stop smoking", or "smoking cessation." Almost half the accounts (48%) were commercially focused, reminding us that, despite its name, *social media,* is not solely used by individuals seeking to connect by one another for personal reasons. Further, only 14% of the 4576 tweets examined were related to US Tobacco Treatment Clinical Practice Guidelines. The scarcity of effective smoking cessation messages on Twitter serves as an important reminder not all social media necessarily provides effective support for healthy behaviors. Another caveat is not all social interaction is supportive and positive: network interactions can set a negative example and/or promote risky health behaviors [18]. For example, parents can help reduce adolescent substance abuse by providing support and monitoring, but they can also contribute to increased use, by setting an example of substance abuse [23]. Social

media may set the stage for individuals to reflect upon personal desire and/or willingness to cease the harmful behaviors as per the illustrated HBM (see Table 1). Thus, the main mechanisms by which social support may help improve health are: emotional support, an ability to share experiences, and non-hierarchal roles, emphasizing reciprocity in giving and receiving support. The content delivered through social media should be aligned with effective health promotion messages.

Integrating physical and cognitive training with social support

The continuous growth of the older population calls for new technological solutions for improving the health, independent living, quality of life, and active ageing of senior citizens [24]. Recent technological advances have shown to be of great potential for meeting the needs of older people too. To do so, contemporary technologies, like the use of social media, should assist seniors in staying healthier, living independently for longer, counteracting age-related cognitive and functional decline, and enabling them to remain active for longer.

Poor physical health due to lack of physical exercise and a healthy diet has repeatedly been shown a risk factor of geriatric depression [25, 26]. Social exclusion, a characteristic of an older person's life profile, is another crucial factor in depression. Social relationships influence many aspects of people's lives, including the achievement and maintenance of good health. Many studies and research on ageing have shown higher levels of social connectedness among older persons, is associated with better health, well-being and even moderates the rate and extent of cognitive decline [27]. Numerous studies have evaluated the effects of activity, learning, personal goals, and

continuing self-development and have found that levels of life satisfaction and meaning are enhanced and positively correlated with feelings of control, self-esteem and self-efficacy [28, 29].

We next highlight a recent study conducted in Europe and funded by the European Commission- the Long Lasting Memories Project, in an effort to provide evidence on the likely application of social networks in promoting and sustaining holistic self-participatory care. These are then discussed in the light of mEducator, in an effort to emphasize important technological developments that combine social media and the semantic web, thereby offering support in managing data collected in various projects, and outlining the importance of semi-automatically collecting evidence for elderly health care.

LLM - the Long Lasting Memories Project and its extensions

The Long Lasting Memories (LLM) service is an integrated solution offering information communication technology-based physical and cognitive training within an assistive smart home environment targeting elderly people [30]. The service followed an earlier clinical trial on cognitive training [31] which was coupled with physical training and was piloted in Austria, Cyprus, Greece and Spain. Specific components of the cognitive training system utilized social media content, namely YouTube videos, accompanied by sets of relevant questions (e.g. memory, observations, attention) targeting at providing brain exercise for the senior user. The physical training system is an exercise-gaming ("exergaming") platform for seniors' physical training [32]. Seniors may interact with the platform through innovative low-cost game peripherals, such as the Nintendo Wii™ Remote and Balance Board. Following user-centered game design principles, the system was designed by accounting for the significant role of affect (stress,

disappointment) when seniors encounter new technologies. Passive affective

components of the platform, along with active affective components, allow users to

maintain their self-esteem by communicating with the system and its dynamic content,

respectively [27, 32]. Trials have already provided evidence the exergaming LLM

platform may alleviate many of the existing deficits of aging, especially those concerning

cognitive and physical decline and geriatric depression, and improve quality of life [33-

35].

During LLM trials, interventions were administered to groups of elderly, depending on

factors such as time of day, geographic location, and personal preferences. Results

obtained so far [27] show strong evidence the entertainment and joy associated with

interaction in a social group impacts the affective state of the user; these, in turn, play a

crucial role in the acceptability of a human-computer interactive system like the

exergaming platform. Initial analysis of the statistical interaction between the results

from an affective survey (i.e. whether the system made users happier) and the dropout

curves confirm there is a relationship between the affect perceived from interaction with

the system, the measured system acceptance (or the recorded non-drop-out system

usage) and the joy perceived through social interaction in the group. The latter seemed

to be an important factor in the success of the interventions. When the training system

is enriched with the "social network" aspect of the intervention, the post-intervention

effect is greater. This suggests the efficacy of digital tools may be enhanced by

integrating them with actual social support.

Evidence shows the main reason for the elder's exclusion from the Information Society

is associated with the inability or unwillingness of most elderly people to use the same

IT and communication technologies used by younger people. This is mostly because these tools are too difficult to be managed or understood by elderly people. The obvious consequence is a rejection of any kind of technology, but also the chance to interact with other people and improve their communication skills and social life as a whole. Indeed, the LLM project demonstrates that older users have a high degree of reciprocity and responsiveness, showing the need to communicate, share and create friendships. LLM has also shown in an indirect way why and how interventions utilizing next generation social gaming and self-participatory activities may become useful and effective after all.

Using contemporary social media to collect interventional evidence

Social Software, and particularly semantic wikis, have increasingly been adopted by many online health related professional and educational services. Semantic wikis further extend the usual notion of a collaborative Wiki by the incorporation of "semantic technologies," like Resource Description Framework, Web Ontology Language (OWL), Topic Maps or Conceptual Graphs, with the idea of exploiting the semantics of the terms, thereby enriching existing navigational links with symbols that describe semantic context/connections [36, 37]. Capitalizing on such technologies, recent research endeavors have allowed for and presented contemporary tools designed to aid physicians and patients in identifying interventions commonly associated with specific nursing diagnoses [38]. In this way, activities needed to implement and document care as provided to the individual patient in a variety of health care settings from acute to community/home care may be entered into a portal through a "Wikipedia-like" web-based tool that provides methods for organizing thought processes for clinical decision

making, or delivery of individualized patient care. Such wikis may also provide end users with a means to retrieve and share data about interventions and diagnoses, and the infograph in Figure 2 provides an example for such use. Moreover, research organizations and other working groups (or any researcher) may use such platforms to publish work in a single semantic (ontological - OWML) format. As data in such formats may be searched by semantic web search engines, the whole approach offers a new channel for data sharing and retrieval that will accelerate scientific discovery as well as increase the researcher's or stakeholder's visibility. Obviously a great deal of such data related to this paper regards evidence from interventions (such as those from social media and self participatory care). Thus, potentially, as it will be shown below, such evidence may be described over the web in a contemporary and useful way.

The mEducator Project and its extensions

The semantic web was developed to provide a "smart" solution for linking and searching resources by linking structured data from an application or from primary sources. These data, called Linked Data, although stemming from an old idea, have only recently begun to be implemented. According to Bizer and colleagues [39], Linked Data basically emphasises upon the use of the Web so as to create formal links between data from different sources, while technically speaking, it refers to Web data that are machine readable, or more explicitly linked to other external data sets, and which can in turn be linked to from external data sets.

The advent of the semantic web and linked data has led to an emphasis on the connectivity of knowledge, information and resources. Indeed resources from different repositories may now be connected and related. However, efforts to apply the semantic

web and linked data principles to share educational resources has been limited. mEducator [40, 41] has filled this gap by adapting resource sharing, retrieving, re-using and repurposing to the era of semantic web, while maintaining key aspects of the social web. mEducator, has effectively compared two alternative solutions for sharing and retrieving educational resources, namely, mEducator2.0 based completely on Web2.0 principles and mEducator3.0, which exploits the richness of Web3.0 approaches. Educational resources may be linked with information from self-participatory care interventions or more formal interventions/trials or even drug trial results (as outlined above). Further, collaborative technologies (Web 2.0) and social media activities, like blogs, wikis, discussion forums, as well as mash-ups of content search and retrieval, have been implemented in these mEducator systems to foster sharing of experience with the system among users. The notion of a social network of users (aka Web2.0 tools) where each user may view educational resources created by other users has been facilitated by the Friend of a Friend Ontology (also used in Facebook to semantify personal information in the user profile). This takes the very personal notion of participatory health-care to its social peak. For instance, in a recent article, Konstantinidis et al [42] have exploited the mEducator technology and highlighted its role in discovering and retrieving YouTube health videos. Moreover, as discussed in the previous section, if evidence from interventions (such as those from SM and self participatory care) may be regarded as educational material, mEducator offers a contemporary but also useful way to capitalize on social media related information. As the latter will soon become semantic social media through the use of 'Big Open (Linked) Data' this point is deemed important.

Harmonizing evidence based medicine and holistic self-participatory care

When evaluated through the lens of the purist, there is an apparent dissonance between the traditional definition of "high-level evidence" [43] and Holistic Self-Participatory Care. In reality however, the two movements are symbiotic, particularly when the medical and research communities work together to provide a platform that supports patient self-quantification with the correct metrics. A noteworthy example of this was published by Wicks and colleagues [44] in a *Nature Biotechnology* study of 149 patients and matched controls to demonstrate the absence of a positive correlation between the prevention of Amyotrophic Lateral Sclerosis (ALS) progression and use of lithium, disputed common, yet controversial treatment for ALS.

Within the Evidence-Based Medicine framework, the self-quantification of holistic self-participatory care may be optimistically regarded as '*N* of 1' trial [45]. However, as Wicks and colleagues [44] have demonstrated, by providing patients with an appropriate platform, patients, medical professionals and researchers may all benefit and, in some cases, work together to discover new knowledge. Indeed, work in this direction represents the future of self-quantification, a topic that deserves urgent attention from the scientific community.

The fragmentation of applications and lack of access to one's data are the most commonly reported frustrations with self-quantification. In order to leverage patient-driven research, the research community needs to acknowledge the opportunity cost of continuing to work in silos [46]. With the exception of the aforementioned article, there are virtually no trials to date that have used social media-based self-reported data to directly impact clinical practice guidelines. However, the potential contribution of

quantified-self data in social networks to research and medical practice is enormous. To leap into the future, we need to help design the data collection process and patient experience in the context of self-quantification.

The need for personalization in social media health interventions

Recently, with the increase in the number of tools available over the Internet, ubiquity of smartphones and increasing broadband access, more virtual communities (i.e. groups of people connecting via the web) relating to disease or illness are beginning to form. However, few have attempted to create a rigorous classification or 'taxonomy' of online social networks. We believe it is time to develop a more easily interpretable classification system of the functionality/services available via these individual social media tools.

To date, there are few examples of interventions or studies that attempt to extrapolate how 'affordances' offered by various social networks are related to the individualized needs of groups of patients. We understand that no matter the health concern, no two patients are identical and that the manifestation of impairments, whether physical, cognitive or both, will vary widely. This most certainly affects the mode of interaction or experience a particular individual may participate. We believe that utilizing social media as a health management tool needs to reflect this. Doubtless, the richness of data available from self-quantification and social media may assist in fine tuning evidence of effectiveness.

Conclusion

Social media have the potential to change medical practice and education, and medical practitioners have the potential to acknowledge the value provided by social networks in

improving patient outcomes and enhancing communication. Providing the right platform to generate high-quality evidence, however, will prove a challenge in the short- and long-term. This paper has presented how social networks promote and sustain holistic self-participatory care at many levels. Future evidence-based triangulated research will be necessary to create sustainable social media interventions that will support people living in a world of evolving technologies and considering a holistic approach to health. Comprehensive books, summarizing extant knowledge and inspiring new progress, help pave the way for organizations adopting social media tools toward improved health [47]. Emerging social media tools, as well as creative non-traditional research ideas, are supporting individuals faced with mental and physical health concerns and, motivating individuals to take a proactive approach in promoting and maintaining a holistic approach to health and well-being. Today, these ever evolving technologies are available to healthcare professionals and patients alike and are a rich pipeline of research opportunities that may expand our knowledge in understanding the factors that influence human behavior to achieve optimal health.

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