

## Social Media in Healthcare

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### Abstract

*Despite its significant potential there has been limited analysis of the use of interactive social media in a healthcare setting. This paper considers important feedback and advice from cancer patients at a large Canadian academic health science centre, along with a review of Social Media literature, Information Seeking Theory, Virtual Communities literature, Social Theory, Adaptive Structuration Theory (AST), and technology evolution to propose a high-level, theoretical interactive-dynamic social media platform for cancer patients. Further, it puts forward a research question and four propositions to guide future empirical research to assess whether this type of social media platform positively influences patient and provider satisfaction, health outcomes and value for money in the treatment of cancer patients.*

### 1. Introduction

In an effort to make substantial improvements, a Canadian academic health science centre cancer program reached out to current and former patients to learn firsthand about their true experience. Its final report summarizes the following approach and findings [1]. Over the course of a year, a patients' reference panel comprised of 36 members chosen from 15,000 cancer patients and their families worked with administrative and medical leaders through a series of focus group sessions and interviews. Over 100 recommendations were then drafted to address gaps in information including limited access to personalized information and educational material, poor communication, and lack of coordination. Issues which unnecessarily lead to confusion about treatment plans, not knowing who the care team is, poor coordination of appointments, and the need to seek information from external sources and engage advocates to help manage their journey. Other issues such as financial strain, unnecessary visits, difficulty managing drug regimens, and the need for psycho-social support were also raised. Acting on the recommendations, program leaders initiated a large scale transformation to enhance the patient experience with a "more patient-and family-

centred approach to care" [1, p. 11]. The transformation agenda considered the possibility of using innovative technology such as social media to simplify communication between patients, families and their care team.

This paper considers this important patient feedback and advice, along with a review of Social Media literature, Information Seeking Theory, Virtual Communities literature, Social Theory, Adaptive Structuration Theory (AST), and technology evolution to craft a high-level, theoretical interactive-dynamic social media platform to address these largely communication related issues. Further, it puts forward a research question and four propositions to guide future empirical research to assess whether this type of social media platform positively influences patient and provider satisfaction, health outcomes and value for money in the treatment of cancer patients. Finally, it contributes to the literature by responding to calls, first to extend information systems theory to include social computing, and second to examine social computing using other social science theory and frameworks.

### 2. Technology evolution

As far back as 2011, over 6 billion people globally were using mobile phones, with more than 80% of the world's population spending upwards of two and a half hours on devices per day [2]. By 2020, some researchers predict that there will be 7 trillion wireless devices serving 7 billion people [3]; drastically more mobile devices than people on the earth. These advances are so compelling and accessible that they have infiltrated virtually all aspects of business and social culture, changing the way knowledge is generated and communicated [4]–[8], and "profoundly changing the way society operates" [9, p. 3]. Social computing is beginning to shift power from organizations to people [4]–[6], [10]–[13] as "...billions of people contribute knowledge and opinions...[and] build collective intelligence" online [14, p. 14]. It supplies the environment for personalization of goods and services and the creation of information that is responsive to people's preferences [5]. As a result, people are choosing to interact with each other [15] to get information because

it is immediate and authentic, rather than enduring a long lag time [16] to receive sanitized information from companies, governments and other public and private organizations [11]. Contrary to what many executive leaders may have initially thought, the Internet and social media is unstoppable [11], [17]–[19]. The public who benefit from these innovations in their personal and social lives are now demanding the same level of functionality from the businesses and organizations they interact with [6]. Even older generations embrace social computing because of its tremendous value [16], [20]. Thus, this radical shift behooves organizations to incorporate these technical advances into their practices to meet client expectations [6].

Fueled by these technical innovations, information and knowledge creation is proliferating exponentially. According to IBM, “...90% of the world’s data was generated in the last two years”, and on the healthcare front, medical information is doubling every five years [21, p. 6]. This explosion of content stretches human cognitive powers to their limits and makes it difficult for anyone to stay current [11]. Therefore, in the face of this extraordinary growth it is not surprising that patients are adopting social computing to manage information overload and augment knowledge so they can play a more empowered and active role in managing their health [9], [13], [15], [20], [22]–[25]. Uptake of social computing for health is reflected in the numbers. For example, of the 85% of U.S. adults who use the Internet [20], 80% search for health related information, which “...influences [their] healthcare decisions and interactions with healthcare providers [25, p. 209], [26]. This is true particularly for older people who are the majority of those who actively seek healthcare information online and participate in healthcare related virtual communities [16]. This online engagement has “...a positive effect on [their] perceived quality of life and well-being” [20, p. 146]. Twenty percent of those U.S. users also create health-related content [15], [20], [23], [25]–[27]. Finally, IBM further projects that by 2016 one billion health-related apps will be downloaded per year [21].

Certainly, there is no doubt that patient expectations of both healthcare institutions and physicians are being shaped by the rapid evolution of knowledge and information on the broader Internet [1]. By way of example, “...patients are increasingly demanding access to services such as online appointments, appointment reminders and referral to specialists....one third of respondents...are willing to have their social medial conversations monitored if it [helps] them to improve their health and better coordinate care” [20, p. 149]. Like other businesses, healthcare institutions have been caught off guard.

Individual healthcare professionals are slow to adapt, either due to a genuine lack of knowledge, or a fear of potential consequences, such as lost productivity and legal problems [15]. Regardless, healthcare organizations cannot ignore the inevitable arrival of social media and the accompanying increase in patient expectations. Rather, they should welcome the opportunity to rethink information systems strategies to incorporate simple but sophisticated patient facing social media to improve relationships with patients and families [6], [28]. Speeding up and enriching communication with and between patients using social media platforms that facilitates access to information and clinicians, intuitively infers higher patient and provider satisfaction, better health outcomes, and reasonable value for money as a byproduct.

### **3. Theory and literature review**

#### **3.1. Social media research**

Despite online communities becoming essential to both businesses and society in general, there is yet very little extant theory on the subject [29]. Rapid cultural changes related to the massive assimilation of social computing are so profound that Parameswaran and Whinston [4] suggest that existing information Systems (IS) theoretical frameworks may not be comprehensive enough to explain the phenomena. They suggest that IS theory, as well as theoretical frameworks from reference disciplines such as sociology, social psychology, economics and history, be reworked and extended to incorporate the impact of this new social and technological phenomenon. Other researchers abandoned IS theory altogether and opt instead to use reference discipline theory directly to analyze and explain the implications of social media. For example, Ren et al. [29, p. 859] take credit for “...[showing] the value of mining social science theories to gain new insights into understanding online communities”. Moser, Ganley and Groenewegen’s [30] study of online communities was guided by social capital, social network, organizing structure and social media communicative genres theory. While Weiss et al., [7] advocate use of social psychological theories including ecological systems theory, community-based participatory research, and social network and social capital theory to study virtual communities.

#### **3.2. Social media defined**

A review of social computing literature reveals a struggle to define social media, online social networks, and Web 2.0 or “the social web” in this nascent field of

study [4], [16], [26, p. 5], [31]–[33]. Some researchers and early Internet or Web 1.0 proponents argue that Internet websites were first to provide the infrastructure and opportunity for users to consume, create and share information in the form of virtual communities from the start, even though the tools to do so were limited [4], [23], [32], [33]. Others argue that ARPANET, the pre-Internet network used by researchers is a form of virtual community [23]. Still others make the case that Web 2.0, which rose to prominence around 2005, added net new rich functionality that did not exist before, or evolved initial rudimentary attempts [32]. Functionality such as blogs, microblogs, wikis, podcasts, instant messaging, tagging, commenting, rating, social bookmarking, and the ability to chat, create and share content, and set up highly interactive “peer-to-peer communities” [34, p. 2] that allows users to connect with each other real-time, distinguishes modern social computing from earlier more static websites [4], [16], [19], [32], [35].

Social media or online social networks are not mere technical artifacts, but rather make up a dynamic ecosystem, “...replete with content, connections, technology enablers and constraints, and social norms of behavior...[and] require engagement of community members willing to share their time, energy and expertise...” [36, p. 526]. “Underlying features emphasized flexibility of access, interaction, mobility, multimedia, participation, informality and feedback” [26, p. 5]. This platform openness is a differentiator, which facilitates and engenders individual participation on a large scale without encumbrance, completely bypassing old paradigms of editorial control. Given the “hands-off” stance toward the Internet, it has essentially remained an open information commons that enables everyone to participate in society through digital platforms [5]. Although many have attempted to bring clarity to the definition, there remains widespread confusion about what characterizes social media, to the point that some “...studies [have described] a social media intervention without considering what social media and Web 2.0 actually are or do” [7], [32, p. 959]. This has prompted some researchers to encourage further study to more precisely define social media, social networks and Web 2.0 [31], [32]. Despite gray areas which seem to imply that Web 2.0 is more of a philosophy than a specific set of technical components, social media literature does, for the most part, integrate three essential concepts: “open sharing, interactivity and collaboration” [33, p. 335] that allows users to create and share content and forge online relationships with minimal editorial control or oversight [5]–[7], [19], [33], [37].

With this in mind, social media in healthcare, for the purposes of this paper, is defined as an open and

interactive, mobile platform with social networking features and functions that enables: (1) easy patient-to-provider, and patient-to-patient formal and informal synchronous communication and unencumbered collaboration; (2) providers to easily create and moderate high-quality, multimedia, personalized clinical content for patients; (3) patients to easily create and consume content; (4) patients to forge online relationships with minimal editorial control or oversight; and, (5) patients to easily keep family and friends informed using their device of choice.

### 3.3. Internet information quality

Although social media and the Internet have many benefits and facilitate online relationships and opportunities to create and share content, it is crucial that users approach with a healthy degree of skepticism and caution. One of the biggest downsides of the Internet is questionable information quality [15], [22], [23], [26], [32], [35], [37]–[39]. Sorting through the overwhelming volumes of information served up by search engines and proliferated by a wide variety of professional and amateur users to find valid, hidden gems can be difficult and time-consuming for laypeople [26]. This is especially true for healthcare where there is major concern about information quality generated by virtual communities; “in particular, the ones that are not moderated by health professionals [15], [23]. “The real problem [is] finding the good stuff,” [26, p. 8] without the guidance of subject matter experts. For those seeking healthcare information online to inform their health-related decisions, this equivocality can obviously have serious consequences. That said there are many who believe that it is possible to generate high-quality information without deliberate, professional governance [4], [32], which can be a bottleneck that restricts whether and how quickly information is made available. They argue that patients who have lived with disease have valid information to share; information that covers different aspects of health management not typically covered by more clinical health professionals. It is also offered through a more informal, friendly exchange, which satisfies not only the need for information, but the innate desire to connect with others for emotional support [10], [32], [38]. They argue that high-quality healthcare virtual communities have their own built-in formal or informal policing, either provided by a small group of leaders who monitor and update the site or by members self-managing to group norms [4], [14], [37]. Most often informal leaders “get promoted” based on reputation and on how other members assess the quality of their work [4], [37].

This crowdsourcing model has been successfully used across the Internet, for example with Wikipedia and open-source programming sites [4], [37]. In healthcare, "...patients crowd source opinions on diagnosis, options for treatment, and experiences with providers" [39, p. 177]. It has been shown that "as the reputation of a social software site grows, the quality of the collectively generated content also improves, possibly due to more high-value participation and refinement" [4, p. 343]. Ideally, virtual communities should strike a balance, bringing professionals and patients together, while maintaining patient-to-patient contact, and ensuring quality by providing professionally authored and reviewed content [4].

### 3.4. Information seeking theory

Information seeking, defined as "the purposive acquisition of information from selective information carriers,"—a well-known coping strategy for patients [40]—is a complex activity that has received limited research attention in the healthcare space [22]. Perpetuating what is arguably a "rationalized myth" [41, p. 344], the proliferation of online healthcare information is held out as having significant benefits. This implies that patients are able to navigate and synthesize information to make informed decisions about their health [22]. However, "...the huge amount of...information available does not automatically mean that information is useful to those who seek it, or even particularly easy to find" [22, p. 389].

Although it has been empirically shown in the emerging research that patients value information from face-to-face visits with their care team members over what they can glean from secondary sources [20], [22], [40], use of the Internet as a source of healthcare information by the general population is growing rapidly [24]. "Healthcare information seeking is second only to email communication, search engine utilization and maps browsing" [23, p. 87]. In addition to the intuitive benefits such as "...convenience, coverage and anonymity" [20, p. 141], one possible explanation is that the face time patients have with their physicians and other caregivers is limited, hence they often come away from appointments with lingering questions and uncertainty. Another may be that the information the care team does impart is more likely to be clinical in nature, dealing with specifics about their disease state, practicalities of treatment, surgical procedures, and/or test results, delivered in an aloof, professional manner. Although crucial, this information does not always satisfy a patient's need to understand what they are going to personally experience on a day-to-day basis, or address their psycho-social needs [22], which leads to uncertainty. In other cases, in particular with serious

diseases such as cancer, physicians, given the complexities of the disease, cannot always give patients definitive answers about their personal prognosis, leading to sometimes protracted uncertainty. Finally, another complicating factor that contributes to the information void and uncertainty can be the lack of coordination between siloed clinical specialties each separately providing crucial aspects of care to the patient [42], [43]. This fragmentation can sometimes lead to communication breakdowns that inadvertently leave the patient in a state of uncertainty while they are transferred from one clinical discipline to another [43]. "Because uncertainty is positively correlated with stress" [44, p. 324], it seems reasonable that patients, driven by an innate need to get some sense of control and reduce uncertainty, are highly motivated to leverage the Internet to seek the information and support they need to cope with their disease [24]. Some research studies infer that this information seeking behavior can indeed reduce uncertainty and translate to positive health outcomes [44]; however, it does not come without a large time and emotional investment on the part of the patient.

In addition to the challenge of getting information through traditional sources, other motivation for leveraging social networking for health include seeking social support, getting second opinions, learning what comes next, and obtaining supplementary information to help make health-related decisions [20], [22]. It is also used as a source to prepare for discussions with physicians and validate information received from them. The Comprehensive Model of Information Seeking (CMIS) suggests that differences in demographics, disease state and degree of social support, factor into information seeking behavior [40]. Other literature suggests that patient information seeking behavior is complementary [9], [20], rather than substitutive. That is patients do, for the most part, trust the medical system and their providers, but seek to augment or complement the information they receive from them and other traditional sources, such as books, friends and family, with information from the Internet. Patients rarely dismiss the information they get from their professional care providers and substitute it outright with information they receive online. Rather, they tend to use different sources to triangulate and validate information. One potential concern raised in the literature is the possibility of developing an "Internet addiction" [23, p. 93] or manic information seeking behavior, which has been empirically shown to increase stress levels and depression [44]. However, more recent research suggests that the benefits of the Internet and social media use outweigh these risks [44]. As such, health organizations are advised to consider the factors that

drive information seeking behavior, from demographics to the need for social support and ability to access up to date, personalized information, when designing patient facing social media for health platforms [22]. Having readily available professionally moderated content may also reduce the odds of unhealthy information seeking behaviors.

### 3.6. Virtual community literature

The definition of ‘community’, a long standing sociological construct on which the definition of virtual communities is based, in and of itself remains elusive [23]. Despite that, some common elements of traditional communities include social interaction, common geographic area, and strong, long-standing relationships among members [23]. Early definitions of virtual communities emphasized computer mediation of communication, but modern definitions are more comprehensive and highlight the importance of social connections [23]. Virtual communities are essentially ‘social structures’ made up of a network of virtual relationships where the first contact takes place online, and are most often formed around a topic of interest [23], [24]. Rather than geographic boundaries, virtual communities are defined by shared interests and self-identification [23], [38]. A study by Kordzadeh and Warren [35] provides a valuable overview of the topology of virtual communities, citing separate studies that span from 2001 through 2011. Some highlights include observations that virtual communities can be member-initiated or organization-initiated, and social or professional. They typically share five key attributes (Porter’s p-attributes): “purpose, place, platform, population interaction structure, and profit model” [35]. Successful virtual communities are commonly led by a few highly engaged, motivated individuals [23].

Health related virtual communities come together to share information and support around various health issues. Some can have a power hierarchy if professional healthcare providers are involved. This power differential can impede the freedom typical of virtual communities; however, professionals lend credibility and improve information quality [23]. That does not imply that patient only healthcare virtual communities cannot be credible. Indeed, there are many led by experienced patients who take great pains in ensuring high-quality content [23]. Empirical virtual community studies contend, counter to early computer mediated communication findings [45]–[47], that strong relationships can be forged online, and often these relationships extend beyond the Internet. Further, cancer patients have been shown to benefit from supportive virtual relationships with fellow cancer patients and cancer survivors [24], with whom they can

share practical and experiential knowledge [22], [43], [44]. Eysenbach, Powell, Englesakis, Rizo and Stern et al., [38] found that online relationships not only provide an outlet for getting support and information, they actually positively impact patients’ long-term prognosis [24]. Participation in online communities is associated with “positive emotional attachment...to the community” [6, p. 596]. A recent study that examines how online communities form, suggests that affirmation, sharing, advice, and social glue organizing structures are “recognizable and distinct patterns of behavior that are implicitly understood” [30, p. 554] by four types of participants: team players, storytellers, utility posters and all-round talents” [30, p. 553].

Given cancer patients’ growing reliance on the Internet, some researchers maintain that cancer-related virtual communities should be tailored to meet patients’ emotional and informational needs, and suggests that their model could be used as a guide by practitioners to inform designs [24]. Practitioners should also look at ways of limiting information to respected and credible sources. Success of virtual community endeavors can be measured by four success factors, namely, “a critical mass of users, an attitude of contribution, business needs that are matched by community needs, and dedicated organizational resources” [12]. Given the potential benefits, healthcare organizations should seriously consider implementing social media platforms that enable the formation of virtual communities for their cancer patients.

### 3.7. Social theory

Social network theory (SNT) seeks to explain network connections or the pattern of ties and interactions between people [48], [49]. It empirically shows that individuals with high network centrality accumulate benefits such as early access to information and a higher share of available resources, which positively correlates to enhanced performance [48]–[52]. As a result, these individuals have considerable influence, often greater than that of formal leaders [52]. Within SNT there are several disparate theories, such as structural holes theory [49], where an individual benefits from bridging otherwise disconnected networks, and weak tie theory that argues individuals benefit from having several casual connections, which exposes them to a higher variety of information sources [44], [48], [49], [53]. It includes various constructs, e.g., advice networks, and in-group and out-group ties [54]. Social capital is made up of various resources embedded in social relations, along with a sense of obligation [44]. This imbued ‘reciprocity’ makes it possible to call in social capital

or accumulated favors or potential resources when they are needed [44], [55]. Social capital studies and diffusion and influence studies consider different aspects of network ties; the former focuses on the benefits, the latter on how the network changes or influences individuals [48]. These social theory constructs also manifest themselves in online networks and virtual communities. “Online social capital is measured in terms of interpersonal trust, social interaction and social support” [44, p. 328]. Population interaction structure, one of the five p-attributes of virtual communities referred to previously, describes community structure in terms of weak and strong ties [35]. The Internet is the perfect channel through which to create extended weak ties [44]. These weak peer-to-peer relationships, in addition to meeting informational needs, build social capital. One example of accumulated capital is searchable online content [10] built through ongoing interactions amongst network members, another is virtual relationships that offer emotional support.

On the healthcare front, particularly with cancer patients, social capital, in the form of social interaction and social support, accumulated through online relationships has been shown to help alleviate stress and depression, “overcome social isolation” [20, p. 140] and positively affect health outcomes [44]. An interesting observation is that virtual communities created for clinical purposes are often formed around the typical healthcare hierarchical structure, where individuals with high network centrality, usually professionals, determine the areas of focus for the group [23]. Given that having broad social networks of weak ties and virtual relationships has been shown to positively affect well-being and health outcomes, and building social networks is facilitated by social media, healthcare organizations should consider embedding social networking features into their social media platforms.

### **3.8. Adaptive structuration theory (AST)**

AST “provides a dynamic picture of the process by which people incorporate advanced technologies into their work practices” [56, p. 122]. It includes two types of social structures, first, structures intended by technology use, and second, structures that evolve as users learn the technology and its affordances. Simply put, it describes how use of technology artifacts evolves over time as users become more familiar with their potential and begin to use them in innovative ways to change work practices to maximize benefits for themselves and the organization [12]. AST “considers how a system changes, how use of a system changes, and how an organization changes as a result

of using the system” [12, p. 304]. This interplay between technology and human action or social processes is iterative. New uses generate new ideas in a “recursive relationship” that result in multiple different uses for the same technology artifacts [12], [56, p. 125]. Effective use is demonstrated by how close actual use is to intended use, how standardized it is amongst users, and how positive user attitudes are towards it. The more “...faithful adaption, team consensus, and positive attitudes...” the stronger the technology [57, p. 117].

Healthcare, as an information intense industry, depends heavily on well-practiced, repetitive, core operational routines to disseminate information and trigger actions to achieve high degrees of patient safety and quality in care delivery. In this context, even well-planned automation projects will disrupt routine operations, at least temporarily. Recognizing this from field observations, Goh, Gao, & Agarwal [58, p. 580], propose a “Dynamic Process Model of Adaptive Routinization of Health Information Technology (HIT)”, an iterative, adaptive model, grounded in AST. This model formally documents an approach to manage initial negative sentiment, suggesting mechanisms to turn around negative symbolic expression and steer the narrative path towards technology acceptance and realization of anticipated performance gains. Their findings and model emphasize the importance of agency in the form of leadership, and highlights the importance of support for ongoing workflow, technology enhancements and training to mitigate unforeseen workflow issues. This support encourages uptake amongst users because the more comfortable they become, the more they recognize functional affordances that can help them to deliver safer, more efficient care. This in turn engenders agency in the form of personal innovativeness, which inspires others and helps to further propagate positive attitudes about the technology artifact. The researchers claim that an iterative cycle that continually recognizes and addresses system and routine glitches leads to high compliance and realization of initially anticipated performance gains [58]. Introduction of social media in the healthcare space will cause some degree of organizational change, therefore, healthcare organizations can draw on the suggested implementation constructs and ongoing, iterative sustainment approaches of AST to better inform design and implementation of both social media platforms technology artifacts and work practices to engender high levels of adoption. Doing so will help to ensure that the required social structures and organizational support resources are both appropriate and available [12], [32]. Social media researchers suggest paying

particular attention to four affordances: “visibility, persistence, editability, and association” [32, p. 967]. Finally, given the seeming lack of empirical research, future research should consider conducting a field study of social media implementation in healthcare to add to the AST body of knowledge.

## 4. Interactive-dynamic social media platform for cancer patients

### 4.1. Discussion

Some researchers believe that the future of healthcare is partly dependent on improvements in online communication with patients facilitated by social media [20]. They suggest that social media is an important lever to improve patient health and well-being by making information and support ubiquitously available [15]. Others highly recommend social technologies be integrated with provider processes and content [6]. “Organizations can coordinate the information from social media space and connect with customers in more meaningful ways that provide value and increase trust” [20]. To attract a critical mass of users, design of these platforms should be guided by the theory outlined herein, and tailored to patients’ emotional and informational needs and user participation dynamics. With this in mind, officially sanctioned healthcare social media platforms could be developed to provide value-creating social features and functions, and rich content, typical of high-traffic sites on the open Internet, to encourage participation [6]. All this with the added benefit of healthcare professional oversight and the opportunity to connect virtually with other similar patients without doing a broad search across all Internet cancer related websites. “To maximize the potential of these online [healthcare] communities, it is thus preferable to have guidance from health professionals, who can lead, moderate, and bring into the discussion the expertise required in their off-line world” [23]. A sophisticated, professionally designed social media platform could go a long way to empowering patients [16], and potentially improving their satisfaction, well-being and health outcomes [24]. One recommendation that practitioners should consider is selecting site moderators from amongst participants [30]. In healthcare, those moderators could be drawn from clinical staff.

### 4.1. Interactive-dynamic social media platform for cancer patients

Firsthand feedback from cancer patients coupled with the theory and literature reviewed above informs the following proposed high-level design for an interactive, dynamic social media platform. Theoretically, if the desired features, functions and content drawn from these sources are faithfully embedded into a platform supported by clinical and administrative resources, and seamlessly integrated into clinical workflow, it follows that patients and



**Figure 1: Interactive–dynamic social media platform**

providers will accrue the associated benefits.

First, drawing from information seeking theory, patient facing social media platform designs should include elements to increase the quality and availability of professionally moderated personalized information in such a way that it reduces uncertainty, for example:

- a visual, dynamic treatment plan showing key milestones [22] with links to related clinical or educational related information and appointment details
- decision aids powered by an online content library of pre-vetted, personalized sources of high-quality information and links to organization sanctioned healthcare content sources to inform decision-making
- ability to organize, filter and tag content [22]
- tailored clinical education and clinical trial information
- online appointments, electronic referral and alerts and reminders available on mobile phones
- a personalized view of electronic health record content, such as test results, medication profiles, instructions, and other clinical documentation
- online journaling that can be optionally shared with physicians, family and other members of the care team [15]
- streaming educational video, webinars, and podcasts

Second, drawing from virtual community literature and social theory designs should include:

- a view of and means to connect to the patient's care team
- an ability "... to ask questions online and keep a log of the dialogue..." [15]
- mechanisms to create patient-to-patient networks for patients with the same disease
- virtual communities with assigned professionals from the care team for more synchronous informal dialogue [15]
- patient only private virtual communities to encourage unfettered dialogue aimed at connecting patients so they can build social support
- an ability to self-select into groups [29]
- a collaboration space similar to Facebook, so patients can keep family and friends up-to-date
- chatting, blogging, microblogging, wiki, and instant messaging capabilities

Third, drawing from adaptive structuration theory, designs should consider how to seamlessly integrate social media platforms into existing organizational routines. Physician, nurse and other care provider workflows must be reengineered to ensure the social media platform has the required support to attract and retain patients and ensure their needs are consistently met. Internal and external champions should be identified to promote the platform, and iterative feedback and development cycles should be resourced on an ongoing basis so that patient and provider feedback can be built into future versions.

## 4.2. Research question and propositions

Based on the feedback from cancer patients and the theory and literature reviewed above, the following research question and propositions are put forward to guide future research of social media platforms for cancer patients:

**Research Question:** Will the use of an interactive-dynamic social media platform with rich content and social networking features have a positive effect on cancer patient satisfaction, provider satisfaction, health outcomes, and value for money?

**Proposition 1:** Cancer patient use of a dynamic-interactive social media platform will improve patient satisfaction as measured by: (a) user counts, (b) volume of patient activity, (c) content contributions, (d) how close actual use is to intended use, (e) patient feedback, and (f) standard patient satisfaction metrics.

**Proposition 2:** Cancer patient use of a dynamic-interactive social media platform will improve provider satisfaction as measured by (a) user counts, (b) volume of provider activity, (c) content contributions, (d) how

close actual use is to intended use, (e) provider feedback, and (f) standard provider satisfaction metrics.

**Proposition 3:** Cancer patient use of a dynamic-interactive social media platform will improve health outcomes as measured by: (a) pre- and post- patient adherence to prescribe medication and treatment regimes, and (b) expected prognosis versus actual prognosis.

**Proposition 4:** Cancer patient use of a dynamic-interactive social media platform will increase value for money as measured by: (a) quality and patient safety metrics, and (b) financial return on investment.

## 5. Conclusion

This paper reviews social media and virtual community literature and considers social media through the lens of information seeking theory, social theory, and adaptive structuration theory to get an appreciation of the benefits and drawbacks for cancer patients. General user and patient use and interaction on the Internet was examined to get some sense of the challenges with finding information and establishing supportive relationships. This knowledge was in turn used to create a feature and function set, and content mix for a high-level patient-centric, interactive-dynamic social media platform aimed at improving patient and provider satisfaction, patient health outcomes, and achieving a reasonable level of value for money in the treatment of cancer patients.

The theory and literature review, though limited, also confirms that social media is a nascent area of information systems research [30], [31]. Although interest is growing given its exponential adoption across the globe [31], [35], the field still offers many rich opportunities for future study. Both theory development [4], [24] and further empirical studies are required to demonstrate the potential benefits and drawbacks of social media. This conclusion is also supported by a 2013 study that reports that the "...limited amount of literature available highlights substantial gaps in knowledge [making it] difficult to draw any definitive conclusions..." [32, p. 966]. Social media research in healthcare is even sparser, which lends support to pursuing further study of healthcare social media implementations. As such, this paper puts forward a preliminary research question and four propositions by which to empirically test the impact of social media in care and treatment of cancer patients. Finally, with regard to future research, in addition to considering the theories explored herein, researchers are encouraged to consider different avenues to respond to calls to extend IS and frameworks, and



empirically test the societal changes brought on by the exponential expansion of the Internet and social media [4], [7], [29], [30].

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