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Creating health awareness: a social media enabled collaboration

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Abstract Social media has been an enabler of information dissemination, collaboration and coordination for reasons ranging from personal to political. In healthcare, the context we study here, information dissemination is a key mechanism of creating awareness, a crucial factor in the early detection and prevention of diseases. Thus, in this paper, we look at the role of social media in creating cancer awareness. In particular, we use a multiple case study analysis to examine how individuals and organizations use social media to collaborate to promote such awareness. We find that social media is used to create an online community that drives the creation of cancer awareness in many different ways and for multiple purposes. This research has implications for healthcare organizations in particular, who are looking to use social media to promote awareness, as well as other organizations who may want to use social media in this way.

1 Introduction

The social computing phenomenon (e.g. the proliferation of social media tools such as Facebook, YouTube, MySpace, Twitter) is creating a new reality in health care, bringing social media to the forefront of health information generation and dissemination. Patients are changing from consumers of Internet content to generators of information using social media

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sites and Web 2.0 tools. The term health 2.0 or medicine 2.0 is thus now commonly used [1]. Prior literature has examined multiple means of collaboration for creating health awareness through a variety of offline strategies, such as collaboration among clinicians from various countries [2] and collaboration through a network of community and university organizations [3] to develop educational programs and campaigns. Some research has also examined IT-enabled strategies such as web-services [4] for such collaborations. However, social media has characteristics that enable communication, collaboration, consumption and creation in entirely new ways [5], which have not been examined in the current literature. In this paper, we focus on social media as an enabler of collaboration in the context of health care and examine how this collaboration can create greater health awareness for individuals.

Social media are now providing a space to discuss medical conditions outside of the healthcare providers' office [6]. Patients and their families use social media technologies to share their experiences and their findings and educate others with similar conditions. They repackage the information they find for others, creating forums for knowledge discovery and discussion [6]. For example, approximately two-thirds of posts in Facebook communities dedicated to diabetes include unsolicited sharing of diabetes management strategies and over 13 % of posts provide feedback to information requested by other users [7].

Social media provides a forum for reporting personal experiences, asking questions, and receiving direct feedback for people living with a disease. Through social media, support groups have found a new platform for organizing as patients and family caregivers share their experiences, seek consolation online, and connect with others [6, 8]. Indeed, 620 breast cancer groups exist on Facebook, containing a total of 1,090,397 members. 46.7 % of these groups were created for patient/caregiver support [9]. Healthcare professionals are also using social media tools, with a growing number of physicians in this group. For example, individual physicians

can reach their patients through Twitter to update them with therapeutic advancements, to answer disease-related questions, or simply to provide advice or reminders [8].

More broadly, it has been shown that social media tools have enabled collaboration among individuals [10]. This can occur in such contexts as employees who work together within the boundaries of formal organizations, to contexts where dispersed individuals connect with one another through the support of a common cause. In this paper, we seek to understand how social media enables collaboration in the context of healthcare, specifically to increase cancer awareness. Indeed, collaboration is considered essential in promoting cancer awareness [11, 12], as many different actors need to be involved in cancer prevention, detection and care.

Thus, in this study, we develop a model that allows us to understand how collaboration through social media sites can drive increased cancer awareness. We use a multiple case study design, which includes qualitative analysis of documentation, website analysis, and interviews. Our study identifies the multiple ways in which awareness is created: through educating and providing information, sharing testimonies, providing support, raising funds, and advocating. Our results also provide a basis for understanding the process through which social media grassroots communities are built, ultimately allowing the optimal use of social media when collaborating to promote health awareness.

2 Literature review

To understand the role that social media can play in cancer awareness, we look at three relevant streams of literature: (1) literature on cancer and cancer prevention; (2) literature on the role of collaboration in aiding in efforts to promote cancer awareness; and (3) literature examining how social media has been shown to enable collaboration in other contexts.

2.1 Context: the rising tide of cancer

Cancer is a major public health issue in our society. Currently, one in four deaths in the United States is due to cancer [13]. A total of 1,596,670 estimated new cancer cases and 571,950 cancer-related deaths occurred in the United States in 2011 [13]. Early detection of cancer greatly increases the chances for successful treatment. There are two major components of early detection of cancer: 1) education to promote early diagnosis (e.g. education on early signs of cancer such as lumps, sores that fail to heal, abnormal bleeding, persistent indigestion, and chronic hoarseness) and 2) screening, which refers to the use of simple tests across a healthy population to identify individuals who have the disease, but do not yet have symptoms [14].

Even though screening is paramount for early detection of cancer, people remain largely under-screened [15]. This under-screening can be linked to patients' lack of knowledge or awareness of screening tests and their lack of motivation to undergo screening [16, 17]. Thus, increased awareness of possible warning signs of cancer and the existence of and benefits to screening among the general public can have a great impact on the disease trajectory.

There are many decisions that need to be made by both clinicians and patients with regards to screening or cancer treatment options. Many guidelines thus point out the importance of informed decision-making in cancer screening [18]. Since there is no "best" option for everyone, decisions are defined as being of higher quality when they are informed with the latest scientific evidence and are based on patients' informed values associated with outcomes of the treatment options. However, clinicians are not good judges of patients' values, and patients often have inadequate knowledge, unrealistic expectations, and decisional conflicts that interfere with their involvement in decision making [19]. At the same time, it is recognized as important to support patients with day-to-day problems associated with cancer and treatment [20]; this information and support can help friends and relatives cope with different stages of the illness better [21].

2.2 Collaborating to promote cancer awareness

Low cancer awareness contributes to the delay in presentation of cancer symptoms and may lead to delay in cancer diagnosis [22]. Governments, healthcare organizations, and non-for-profit societies thus support a variety of initiatives to raise awareness and understanding for cancer-related issues, with the ultimate goal of engaging the public in important health information. Research has shown that a lack of knowledge and understanding regarding cancer incidence, outcome and risk makes it unlikely that at-risk individuals, their friends and family, and even the general public can make informed decisions on a range of cancer issues [23]. It thus becomes essential to ensure the earliest awareness in terms of cancer screening [24], as well as provide support and coping strategies for cancer patients and their friends and families [25].

For healthcare organizations and clinicians to be fully aware of the needs of individuals and their families and for individuals to become familiar with the tools and resources available in order to obtain the support that they need, it is crucial that channels of communication exist between these different stakeholders. In the recent years, a good number of collaborative efforts have proven to be key in promoting cancer awareness and decreasing health disparities around cancer in various communities [11, 12]. Building on such collaborative efforts will allow linking different communities, which is increasingly seen as a necessary means to ultimately reduce the incidence and mortality of preventable cancers [11].

2.3 The role of social media

2.3.1 Social media use for health awareness

Studies demonstrate that a growing number of educational institutions are emphasizing and training future medical and allied health practitioners on the importance of using social media as an effective means to disseminate information amongst patients and clients [26]. For example, nursing students have been encouraged to move beyond synthesizing pamphlets and flyers as a means of disseminating information to patients, and have instead been equipped with resources to create 3-to-5 min YouTube videos to distribute using various social media platforms [26]. Moreover, a recent study demonstrated that utilizing Twitter and Facebook as supplementary tools for delivering educational content can be an effective way to engage medical trainees [27]. According to a recent study, 89 % of 291 polled continuing medical education course participants reported using social media, with most common platforms being YouTube and Facebook [28].

Professional medical societies such as the American Society of Clinical Oncology (ASCO) have been successfully using social media sites like Twitter to report clinical news from scientific sessions, to discuss treatment issues, and to facilitate a broader dialogue amongst physicians and healthcare professionals [29]. Additionally, studies have indicated that social media can have tremendous value vis-a-vis epidemiological surveillance, allowing for reporting cases in real time and permitting the monitoring of outbreaks around the world [30]. Overall, there is a growing pull amongst physicians to utilize social media as a means of ensuring the proper dissemination of information to their patients in order to counteract scientifically questionable publications and educational videos [31].

2.3.2 Collaborating through social media

Online social media tools ranging from tools such as RSS feeds to social networking sites to healthcare specific tools like WebMD, have enabled communication between individuals and have the potential to enable collaboration between individuals and healthcare organizations. In the IS literature, collaboration, defined as "the action of working with someone to produce or create something," has been studied at the individual level [10, 32] and the organizational level, focusing on the role of information technology in enabling collaboration within organizations [33] and across organizations [34]. At the individual level, these collaboration-enabling technological tools initially encountered much resistance amongst employees within organizations [33]. However, the ongoing adoption of Enterprise 2.0 tools—the use of Web 2.0 tools within the organization—demonstrates a changing attitude about such technology [35].

Indeed, such tools have garnered attention for their use as a means for individuals to collaborate outside the boundaries of traditional institutions [36]. While, in the past, we typically observed this through crowdsourcing endeavors such as Wikipedia, Threadless, and TopCoder, we have seen social media tools used to enable more grassroots collaboration as well. The study of social media in the information systems (IS) research is nascent, though growing, and the enabling nature of Web 2.0 technologies speaks to fundamental questions of communication and collaboration that are deeply embedded in the endeavors of IS researchers.

2.3.3 Using social media for grassroots community building

Individuals have used social media tools as a mechanism for organizing dispersed individuals in contexts ranging from political elections to times of crisis. Social media-enabled grassroots or citizen-driven organization played a large role in the election of Barack Obama as the President of the United States in 2008 [37] and enabled coordination and grassroots collaboration after such disasters as the October 2007 California Wildfires [38] and the 2008 Sichuan Earthquake [39]. In such disasters, social media proved to be a source of information, which was otherwise difficult to obtain using traditional sources. In the Arab Spring protests of 2011, social media played a key role in coordination. Indeed, in these protests "the input of the social media networks was critical in performing two overlapping functions: (a) organizing the protests and (b) disseminating information about them…" [40]. Without the existence of social media as the organizing tool, information dissemination and coordination of both the protests and for the disaster recovery efforts would have suffered.

2.4 This paper

The literature review suggests that social media enables connection, communication and collaboration amongst individuals; three activities that used to be considered very challenging to achieve. In this study, we look at how social media can enable this collaboration in the context of creating cancer awareness, given our knowledge that collaboration across stakeholders serves an important role in promoting cancer awareness and that cancer awareness is key in cancer prevention.

3 Methods

As our objective is to develop a framework to explain how collaboration, through the adoption and use of social media (here, Facebook) can play a role in cancer awareness, an explanation-building approach was deemed appropriate [41, 42]. We use a grounded theory analytic approach [43] that provides a set of flexible analytic guidelines enabling iterative

data analysis and conceptual development [44]. We conduct a multiple-case study and analyze six organizations whose mission is related to cancer prevention [45, 46], which allows us to identify the social media collaborative efforts, the identity of the partners involved in such collaboration, and the underlying rationales for their Facebook usage. To be able to compare and contrast our cases and to offer some theoretical generalization, cases were purposefully selected using a maximum variation sampling strategy [47]: the six cases we selected varied in terms of disease type (breast vs. prostate[1]), country (Canada or USA), year founded, size (no. of employees) (see Table 1).

To support and enhance our understanding and to strengthen the research findings and conclusions, we triangulate our data sources [47]: analysis of the documentation (e.g. documentation describing the aims and means of the organization, annual reports, newsletters); qualitative content analysis of the website and IT and social media tools used (e.g. Website, Facebook, Twitter etc.) and interviews. We examine the content of the Facebook pages that were used by these organizations using a standardized template. For each organization, we identified the content of the Facebook posts and recorded data in order to develop a data record file for each case. To provide a good overview of the yearly activities, our analysis of the content of the Facebook pages was conducted for four months (March, June, September, and December 2012) for a total of 1,407 activities (395 posts and 1,012 comments). The same strategy was used to extract the content of the documentation.

Interviews provided additional evidence. In each organization, we conducted semi-structured interviews with the CEO and/or person responsible for the social media development and use, i.e. the key informants [47]. Given that in two organizations, there were two respondents, we had a total of eight respondents. These respondents had a thorough knowledge of the origins, implementation, use, barriers and enabling factors of traditional IT and social media usages in their respective organizations. Our interview guide was validated and refined using four pilot interviews with experts from different domains: marketing, information systems, public health and qualitative methods. All interviews, which lasted 1 h on average, were recorded and transcribed verbatim in their entirety.

Following the data collection process, we analyzed the data in two stages. We first performed a within-case analysis of the resulting several hundred pages of transcripts and Facebook content data. The within-case analysis allowed us to focus on the particularities of each case, which permitted us to clearly identify how and why collaboration was enacted. We then proceeded to a cross-case analysis in order to contrast and compare data and to allow for common patterns to emerge. For the cross-case analysis, we followed a grounded theory

Table 1 Cases

Cases	Characteristics
Breast Cancer Action (BCA)	*Type of organization*: a grassroots organization for women with breast cancer and their supporters, at the forefront of the breast cancer activist movement. *Country*: USA; *Disease type*: Breast cancer; *Year founded*: 1990; *no of employees*: 8
Breast Cancer Society (BCS)	*Type of organization*: a registered, national, not-for-profit, grassroots charitable organization dedicated to raising funds. *Country*: Canada; *Disease type*: Breast cancer; *Year founded*: 1991; *no of employees*: 5
Breast Cancer Foundation (BCF)	*Type of organization*: a leading national volunteer-based organization dedicated to creating a future without breast cancer. *Country*: Canada; *Disease type*: Breast Cancer; *Year Founded*: 1986; *no of employees*: 197
Us Too International (UsT)	*Type of organization*: non-profit Cancer Education & Support international support network *Country*: USA; *Disease type*: Prostate Cancer; *Year founded*: 1990; *no of employees*: 5
Prostate Cancer Foundation (PCF)	*Type of organization*: a very large philanthropic source of support for prostate cancer research to discover better treatments and a cure for prostate cancer. *Country*: USA; *Disease type*: Prostate Cancer; *Year founded*: 1993; *no of employees*: 30
Pints for Prostates (PFP)	*Type of organization*: not-for-profit organization aimed at raising awareness and fundraising by making appearances at beer festivals, social networking and pro bono advertising. *Country*: USA; *Disease type*: Prostate Cancer; *Year founded*: 2008; *no of employees*: 2

approach [48]. The analysis of the documentation and the Facebook content was used to provide additional information and to corroborate and validate the information gathered via the interviews. We used N'Vivo 8 to support coding and analysis of the transcripts.[2]

4 Findings

4.1 Within-case analysis

As detailed in Tables 2, 3, 4, 5, 6, and 7, our within-case analysis of the interviews, content of the tools, and documentation provides, for each case, a short description of the organization and the tools used. The tables also present a summary of the drivers of social media use and the main

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[1] Prostate cancer is the most common cancer in men and breast cancer is the most common cancer in women (Siegel 2011).

[2] QSR International. *NVivo 8* software.

Table 2 Breast Cancer Action

Traditional IT tools:	Evidence
• Website	http://bcaction.org/
• e-newletter	
• e-mail alert	
Social media tools:	**Evidence**
• Facebook	http://www.facebook.com/BCAction
• Twitter	http://twitter.com/#!/BCAction
• YouTube	http://www.youtube.com/watch?v= 2lT6sV_z5eg
• Blog	
• LinkedIn	http://www.thinkbeforeyoupink
Main drivers of social media use:	**Evidence**
• Provide a voice for breast cancer victims • Awareness and advocacy tool • Promoting campaigns • Build connections with other organizations • Education	Initially it was kind of—you know, we've been historically a kind of an angry organization. People, you know, the organization was formed from women who were frustrated and angry about the lack of attention that breast cancer was receiving amongst all the cancers and particularly, feeling it was a gendered disease and so, it was—patients should be quieter and more passive and more complacent about women's responses to it and their diagnosis and it shouldn't be talked about and so our initial kind of Facebook and tweets were—were kind of in that vein, and they have now become still kind of—and viewed with that sense of anger but that anger is now more urgent—more an urgency
Impacts of social media use:	**Evidence**
• Increase in number of 'signatures' they get • Increased awareness • Broader reach	And when we've done that, we have had, you know—we have had a vast increase in the number—it vastly increases the number of signatures we can get because our alternative is to hit the streets, send e-mails out and have people e-mail responses. So what we can now do is partner it with an e-mail campaign and a Facebook campaign and we've got a double-whammy component. I see Facebook as a waiting mouthpiece to be grasped and we need to access that—that's what we need to tap into.

Table 3 Breast Cancer Society

Traditional IT tools:	Evidence
• Website-blog	www.bcsc.ca
• e-newletters	
• e-mail (email campaigns)	
• Online coupons	
Social media tools:	**Evidence**
• Facebook	http://www.facebook.com/ breastcancersocietyofcanada
• Twitter	http://twitter.com/#!/bcsctweet
• LinkedIn	http://www.youtube.com/watch?v= 2GPOVCzNb_c
• YouTube	
• Jumo	
Main drivers of social media use:	**Evidence**
• Create awareness about the organization itself at a low cost • Post/re-post online information for readers who access information in different ways • Fundraising • Inform about how the money raised is spent • Imitation (natural evolution of an organization in the modern world) • Be responsive, sensitive • Create a social community that is connected more to their cause and their brand • Reach a target population (young) • Provide information about alternative—complementary treatment • Reach people who are in remote regions • Inform people about specific events	I think it opens up many doors, myself. It keeps us very modern, it keeps us—it allows us to be very nimble, too, in communicating to people. It allows us to—we quite often will say, "Hey, did you hear about this study today?" And we'll post it so people get information right away. So, I think it's a fabulous tool and as far as a cost effective, it's a very cost effective way to communicate with people too.
Impacts of social media use:	**Evidence**
• Increased awareness about the organization (word of mouth) • Reached larger audiences (remote region) • Allowed to fundraise money • By knowing the behavior of people, it is possible to target the strategy (e.g. donation) • Allow to know what people want to know	…we track our visits. So, when one of our newsletters goes out there is a definite spike in visits to our website and it's definitely working. I would say that we are moving forward.

perceived impacts associated with the use of social media in that organization.

4.1.1 Case 1: Breast Cancer Action

Breast Cancer Action (BCA) is a grassroots organization for women with breast cancer and their supporters; it was founded in 1990 (Table 2). BCA was born from the initiative of Elenore Pred, a victim of breast cancer, who felt that government agencies and organizations provided inadequate and superficial information rather than scientific evidence about breast cancer. The three strategic priority areas identified by BCA are: 1) the need to advocate for more effective and less toxic breast cancer treatments; 2) the need to decrease involuntary environmental exposures that put people at risk for breast cancer and 3) the need to create awareness that not just genes, but social injustices—political, economic, and racial inequities—lead to disparities in breast cancer outcomes. BCA works in coalition with other organizations to bring about important policy changes on the local, state, and federal levels; it is now a national organization at the forefront of the breast cancer activist movement. They have a staff of eight full and part-time employees. Apart from the use of traditional IT such

Table 4 Breast Cancer Foundation

Traditional IT tools:	Evidence
• Website • e-newsletters	http://www.cbcf.org
Social media tools: • Facebook • YouTube • Twitter • LinkedIn • Flickr • Blog	Evidence http://www.facebook.com/CanadianBreastCancerFoundation http://twitter.com/#!/cbcf_bcyukon http://www.youtube.com/watch?v=-RWh2Ag4u08 http://findinghope.cbcf.org/
Main drivers of social media use: • Create awareness, bring attention to events • To get involved in the "space" where people were having relevant conversations • Provide a forum for individuals to share stories/contribute to a community • Provide information about events; communicate with individuals who have participated in events • Engage with corporate partners • Complement traditional media efforts in creating brand awareness, etc. • Reach a large number of people at once • Flexible; easy to modify programs/plans	Evidence So, within 2008 we addressed social media and said, 'This is something that we think is an important area to be involved in, and from there we built out a stronger program.' So, we started including Facebook, and YouTube, and Blog information in all of our communications, mostly to the Run for the Cure which is our national title event.
Impacts of social media use: • Reached new audiences • Increase online giving • Increased engagement with public • Share a range of information • Opportunity to share compelling and engaging stories	Evidence Last year we added a little badge to our Run for the Cure website off of our main website to Facebook, and by adding that connection from Facebook to the participant or the person getting involved with the run, we know we garner to about 70 %. The people that participated or donated through that button, 70 % of them are new donors and new participants. So, we know that we're reaching a new audience that way.

as the development of a website, the organization began to use social media in 2009.

4.1.2 Case 2: Breast Cancer Society

The Breast Cancer Society of Canada (BCS) is a registered, national, not-for-profit, charitable organization dedicated to funding Canadian breast cancer research into the detection, prevention, treatment and to ultimately finding a cure for the disease that women fear most (Table 3). BCS was founded by Lawrence and Kay Greenway in 1991 after their daughter passed away from breast cancer. They started as a grassroots charity and have evolved into a national organization whose goal is to raise funds for cancer research dedicated to discovering "the causes of breast cancer, better methods to prevent and detect it, treatments that are more effective and improving the quality of life for survivors" (www.bcsc.ca). This organization began to use social media in 2009.

4.1.3 Case 3: Breast Cancer Foundation

The Canadian Breast Cancer Foundation (BCF) was founded in 1986 and is a national volunteer-based organization dedicated to supporting a variety of activities around funding cancer research and providing education and awareness program, with the ultimate goal of "creating a future without breast cancer." (http://www.cbcf.org) (Table 4). Their focus is on raising funds to help research on risk reduction and prevention and the psychosocial aspects of breast cancer. They promote early screening and more effective treatment and participate in outreach, education and awareness. This organization began to use social media in 2008.

4.1.4 Case 4: Us Too International

Us Too International (UsT) is a non-profit prostate cancer education and support network that was founded in 1990 (Table 5). Their mission is "to help men and their families make informed decisions about prostate cancer detection and treatment through support, education and advocacy" (www.ustoo.org). To do this, Us Too provides men and their families with free information, materials and peer-to-peer support so they can make informed choices on detection, treatment options and coping with ongoing survivorship. One specific goal of this organization is to provide peer to peer education and support to patients and families who suffer from prostate cancer. Us Too began to have online discussion communities seven years ago and in began to use social media in 2008.

Table 5 Us Too International

Traditional IT tools:	Evidence
• Website	www.ustoo.org/About_UsTOO.asp
• e-mail (e.g. e-blast, e-mail campaign)	

Social media tools:	Evidence
• Facebook	http://www.facebook.com/UsTOOInternational
• Twitter	http://twitter.com/#!/USTOOHQ
• LinkedIn	http://www.youtube.com/user/UsTOOInternational
• YouTube	
• Wikis	https://www.inspire.com/groups/us-too-prostate-cancer/discussion/personal-journey-blog-join-me-in-the-discussion/?follow
• Online discussion communities	
• Groupon	
• Blog	

Main drivers of social media use:	Evidence
• Create awareness about the organization itself at a low cost	… we've never really had a budget for marketing or ads or things like that, so as social media came up, you know, we've tried to take advantage of it.
• Post/re-post online information for readers who access information in different ways	
• Inform people about specific events (repertory of events)	
• Fundraising	
• Imitation (natural evolution of an organization in the modern world)	
• Constitute an advocacy group	
• Organize online-discussion communities and support group for people who live in remote regions (territory coverage)	
• Address specific concerns for both patients and families depending on area of interest, stage of disease, or preferred treatment.	

Impacts of social media use:	Evidence
• Increased awareness about the organization (word of mouth)	Well, we're hoping that we'll get some of those people through our Facebook page, for example, or YouTube as they are, you know, perusing around and maybe their friends have liked us or forwarded a link or something like that.
• Reached new audiences (remote region, minorities)	
• Increased engagement with target audiences	
• Co-create information (e.g. how to cope with)	
• Connect people with the same experience	
• Share questions and answers	
• Did not necessarily drive attendance to events	
• Mobilize the prostate cancer community	

Table 6 Prostate Cancer Foundation

Traditional IT tools:	Evidence
• Website	http://www.pcf.org/site/c.leJRIROrEpH/b.5699537/k.BEF4/Home.htm
• e-newsletter	
• e-mail	

Social media tools:	Evidence
• Facebook	http://www.facebook.com/PCF.org
• Twitter	http://twitter.com/#!/pcfnews
• LinkedIn	http://www.youtube.com/watch?v=hZpvVw55vtE
• YouTube	http://mynewyorkminute.org/
• Blog	

Main drivers of social media use:	Evidence
• Post/re-post online information for readers who access information in different ways	And that's one thing social media is good—I mean—it is reaching us into the younger group, which is a target for us.
• Provide online support & connections to others at a low Cost	
• Engage individuals through more personal interaction	
• Platform for having a voice/ talking about issues	
• Reach a different demographic	

Impacts of social media use:	Evidence
• Reached new audiences	I think it's brought in some—new audiences from what we can see. It's a little hard to measure and it takes a lot of time to measure; but, it definitely helps us—it helped me gauge what—have a quick gauge of what people are interested in, topic wise or maybe to be able to see—to kind of see what kind of news really—really catches people's attention and like, what kind of questions they have in a very dynamic way.
• Understand information the individuals are interested in	
• Increased engagement with target audiences	
• Increase in online giving	
• Humanized/given a voice to engage with target audiences	

4.1.5 Case 5: Prostate Cancer Foundation

The Prostate Cancer Foundation (PCF) is the world's largest philanthropic source of support for prostate cancer research to discover better treatments and a cure for prostate cancer (Table 6). At the time PCF was founded in 1993, despite its common occurrence, prostate cancer was still the "hidden" cancer and it received little attention from researchers. To give men and their families hope, PCF set out to harness resources—both financial and human—to accelerate the development of new breakthroughs and find a cure as quickly as possible. Their mission is ambitious but very clear: to eliminate prostate cancer as a life-threatening illness for men and their families. This organization began to use social media in 2009.

4.1.6 Case 6: Pints for Prostates

Pints for Prostates (P4P) is a not-for-profit organization founded by prostate cancer survivor Rick Lyke in 2008 (Table 7). It aims at raising awareness among men about the need for regular health screenings to increase the likelihood of

Table 7 Pints for Prostates

Traditional IT tools:	Evidence
• Website	pintsforprostate.org
• e-mail	
Social media tools:	**Evidence**
• Facebook	http://www.facebook.com/group.php?gid=105465930295
• Twitter	http://twitter.com/#!/pints4prostates
• Flickr	
• Vimeo	
Main drivers of social media use:	**Evidence**
• Awareness tool	So, we were—we were just sort of like a little bit of a movement and, you know, just knowing where the world is going these days as far as media goes and how—how people consume media. That just meant that social media was—was almost a given for us. It wasn't like we had to be convinced about it or had to discover it. It was—it was all around us when we launched.
• Promote events (Bulletin Board for events)	
• Build connections with other organizations	
• Education	
• Build a community of volunteers	
Impacts of social media use:	**Evidence**
• Increased reach	…the other thing that, you know, about it is that if you're not constantly feeding it, you know, it's sort of like this ticker tape, you know, running—you know, if you have been in Times Square where, you know, some the new sites have, you know, have this—this kind of moving digital billboard kind of ticker tape—if you don't keep feeding this ticker tape thing, somebody could get there 10 min later and they don't see your message. So we've—we've spent more time there probably than most other things. But we get a return for it, so we keep doing it.
• Increased donations	
• Focused on one person at a time—if one more person gets tested, it's successful.	

Table 8 Analysis of Facebook pages

Activity	Gender	N (%)
Posts & comments		
Individuals	Female	708 (50.3)
	Male	171 (12.2)
	Unknown	5 (0.4)
Organization		523(37.2)
Total number of posts/comments		1,407 (100)
Number of posts		
Individuals	Female	43 (10.9)
	Male	23 (5.8)
	Unknown	0 (0)
Organization		329 (83.3)
Total number of posts		395(100)
Number of comments		
Individuals	Female	665 (65.7)
	Male	148 (14.6)
	Unknown	5 (0.5)
Organization		194 (19.2)
Total number of comments		1,012 (100)
"Like" activity		
Number of posts/comments with a like		750
Mean number of likes per post		23.7
Mean number of likes per comment		1.8
"Share" activity		
Mean number of shares per post		7.5
Mean number of shares per comment		0.0

earlier detection and PSA (prostate-specific Antigen) testing by making appearances at beer festivals, social networking, and pro bono advertising. All funds raised by P4P go to fighting prostate cancer and assisting men with the disease. All of their activities focus on assisting men and their families in understanding the critical importance of early detection in fighting prostate cancer. P4P cooperates with organizations that works with men on awareness, offers support following treatment, or conducts research aimed at improving care or finding a cure for prostate cancer. This organization began to use social media in 2008 (with the beginning of the organization).

Analysis of the Facebook activities for each of these organizations reveals that the majority of the 1,407 posts and comments (combined) are from individuals; only 523 (out of 1,407) are posted by the organizations (Table 8). A close examination of the data shows while most posts are initiated by the organizations, the comments are primarily posted by individuals. Overall, these posts/comments are associated with a large number of likes (average number of likes is almost twenty-four per post and two per comment) and are shared often (average number of shares is almost 7.5 per post).

4.2 Cross-case analysis

Though in doing the within-case analysis (presented above) we noted some idiosyncrasies for each case, due to space limitations, we will focus on the cross-case analysis results, which mainly focus on commonalities in the activities that these organizations engage in through social media. While there are commonalities, we do want to point out that some organizations are more oriented towards a specific type of activity. It is the case for BCA, for example, whose main activities are educating and advocating that they focus on themes such as cancer screening, prevention and treatment. The main focus of BCS is providing support, especially in terms of providing and sharing coping strategies. In the case of P4P, one of the main activities is raising funds, mainly through the

promotion of various events. Other organizations—BCF, PCF, UST—support a variety of activities, from the sharing of testimonies to fundraising.

Despite these differences, the analysis of the posts reveals that overall, in all six cases, Facebook allows for the creation of a community whose overarching goal is creating cancer awareness. In this context, social media becomes both an enabler and a tool for collaboration. Interview data supports the analysis of the postings, as illustrated by the following quotes:

Our mission is awareness, so the money raised is really secondary. And I always say, when we go to an event or I hear from that one guy who says, "I got tested because of your message"—that's—that's really what it really comes down to that one to one connection where somebody actually says, "Yeah, I got tested". That's our biggest measure of success. PFP

For Facebook, it's a mechanism to—number one—let people know that our organization exists. Sometimes we'll hear, "Oh, I wish I would have heard of your organization 6 months ago when my husband was diagnosed," you know, because we have a network of support group chapters. It's more of an awareness thing. UST

As part of this need to create awareness, social media are seen as particularly useful to reach a wider audience, be it to reach a different demographic or to reach out to people who are not purposefully seeking cancer awareness information.

Facebook, it seemed as a way to reach a broader segment of the population. There is the opportunity through Facebook to reach a broader demographic. BCA

Well, we're hoping that we'll get some of those people through our Facebook page, for example, or YouTube as they are, you know, perusing around and maybe their friends have liked us or forwarded a link or something like that. UST

You know, yes—we see more 50 and 60 year olds tweeting, perhaps, and Facebooking; but, we also need to reach the younger demographic in terms of they're the ones who are assuming caretaker roles and they are the ones who are being more proactive and understand the need to (a) be proactive about a prostate health plan and (2) are open to talking about as a group. PCF

Based on our data analysis, we were able to identify the salient types of activities that were undertaken by the participants to create such awareness. Data reveal that Facebook is used in a way that creates value, above and beyond creating or sustaining a community. Many different actions such as expressing gratitude, making remarks or requesting information, were noted. We here focus on five key activities that seemed to play a critical role in grassroots

community building and cancer awareness: informing and educating, supporting, sharing testimonies, advocating, and raising funds.

4.2.1 Informing and educating

Our analysis of the posts and comments aimed at informing or educating reveals that the majority of the information is provided by the organizations (122/208). The use of Facebook to inform and/or educate is primarily oriented towards cancer screening and prevention (69), which shows how these organizations do provide a forum for public health message:

A majority of Canadian women believe benefits of breast cancer screening in their 40s outweigh risks. Check out the link to learn more. CBCF—September 14, 2011

Keep talking about prostate cancer awareness until you can speak about it no more!!! David Emerson—June 8, 2011

These posts also address the different treatment options available, for example with regards to surgery, chemotherapy, etc. These often provide links to external sites (52/208):

This is kind of interesting! A Machine That Sniffs Out Cancer: www.businessweek.com BCS—March 8, 2012

Finally, another group of topics is related providing information to promote different events, such as Movember[3] activities, galas or "Run for the cure" (52/208):

"Here's a little taste of what we have coming up for you at the 2012 Canadian Breast Cancer Foundation CIBC Run for the Cure! Who's excited? CBCF—March 30, 2012

Have you seen Pink Ribbons, Inc.? The Toronto International Film Festival called it "powerful and incendiary." This documentary is a potential game-changer, showing just how much the shiny pink status quo has cost us—and how little we've gained from it. We're proud to partner with First Run Features in the 2012 release of the movie in the U.S. BCA—March 29, 2012

The Pints for Prostates European Beer Tour gets underway officially in about 45 min with a walking tour of Prague followed by dinner at the Strahov Monastery Brewery. http://prague-stay.com/lifestyle/review/403-strahov-monastery-brewery/. PFP—September 10, 2011

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[3] Movember is a moustache growing charity event held during November each year to raise funds and awareness and increase early cancer detection, diagnosis and effective treatments.

Interview data provide additional insight about these activities. An interesting observation is that social media allows organizations to tailor messages depending on who they are trying to reach. Indeed, organizations felt that social media provided tools that could facilitate a user's ability to make informed decisions:

But now, you know, in the last couple of months I've also started trying to—to just educate guys with some quick factoids and so we'll, you know, one of the more recent ones that I've used, posted on Facebook and it's been re-tweeted by some other folks is the, you know, is men are 33 % more likely to have prostate cancer than women are to have breast cancer. And that's a real shocker to most people when it gets out there because they hear and see so much about the pink ribbon campaign and breast cancer that I think everybody naturally assumes that a lot more women have breast cancer than men have prostate cancer. PFP

So, one of our kind of missions is to provide women with the information that they need to make informed decisions for themselves. BCA

Through Facebook she's addressing questions and even things that people might not think to ask, but it's good to know. Like why are there so many breast cancer organizations? It's a great way to address concerns or to throw the facts out there or get people thinking in a very easy way. BCS

We're funding those researchers often, or we'll share information from them to our social media audiences, we will feature their stories or stories of our funding through a block or newsletter and we'll send it out on Facebook or Twitter. That would be sort of from us on behalf of them. That would be something from one of our researchers or something we funded or some news from the breast cancer research community, but it would come through us. BCF

4.2.2 Supporting

Our analysis revealed that many people contribute to a Facebook page for the purpose of supporting. In our analysis, there were 467 posts and comments aimed at supporting, mainly made by lay individuals. This suggests that Facebook is the platform that enables the development of a peer-to-peer support community. Support is mainly oriented towards coping strategies (218/467) and supporting events (194/467).

"The Breast Cancer Society's online breast cancer support community is available for you, fellow cancer patients, survivors, loved ones, and supporters! We understand that at times you may need more than medical assistance. Emotional support and strength is

mandatory. Good friendships are essential in a time like this…please allow us to reach out to you and lend a heart. Follow the link below to create your own free page." BCS—March 15, 2012

"New support group in Southwestern Ontario for BRCA1 and BRCA2 gene mutation carriers. Bevin Sandercock carries the BRCA2 and considers herself a "PREVIVOR"! She has recently taken on the role of the Ontario outreach co-ordinator for FORCE (Facing Our Risk of Cancer Empowered). Please join her for the first meeting scheduled to take place at the BCSC office on October 26th at 7 pm. Please read article below for more information." BCS—September 29, 2011

In addition to providing a conduit to support groups, these organizations advertised events that they were organizing in support of individuals and the cause as a whole.

"If you live in the Charlotte, N.C. area stop by Common Market tonight for Brewery Alleyway Rumble, a Charlotte Craft Beer Week event! Check out our events tab for more information. Proceeds benefit Pints for Prostates." PFP—March 21, 2012

We also found many examples of individuals supporting each other using the Facebook Platform. For example, one post on June 17, 2011 by the Canadian Breast Cancer Foundation was written in support of one family:

"We are thinking of the Terry Fox family during this time. Betty Fox was an inspiration to millions, and created a legacy."

The results from the analysis of the interviews also demonstrate that social media is often used as a platform for providing and seeking support. All these organizations feel that they had to provide support to their users. In all our cases, organizations were using different social media tools to allow users to interact with them as well as with each other, enabling users to create groups of interest and share experiences with one another.

We have had people ask for certain things because we let everyone comment? So, that for us is wonderful, because that's what we want. We want to know what they need from us and if we can't help them how we can direct them and we have a lot of really valuable resources available to anyone looking for information. BCS

So, for instance on a blog our goal or main objective is to share stories and contribute to a community of information about, mostly about survivors or participation in our events, or sharing in that space. BCF

We also have a listing of all of our support groups everywhere, so that's great if there's one in your city, but if there's not one in your city we have, you know, virtual supports groups, if you will, through our online discussion groups. UST

4.2.3 Sharing testimonies

Our analysis of the 173 posts and comments that share testimonies reveals that the majority of them are provided by lay individuals, including, e.g., patients and family members. These posts show how social media offers a platform to share personal experiences and testimonies between individuals who are directly affected by the disease. Testimonies are about a variety of individual experiences such as uptake of screening test (39) and experience with treatment (41).

Susan shares her experience with breast cancer over the past 2 years, and tells us how she is looking to the future. [posted with a link to Susan's story] CBCF—March 22, 2012

My grandfather was recently diagnosed with a fast-growing prostate cancer and was advised to fight it aggressively with the Proton, the HDR and shots every 6 months. Our only problem is funding for the procedures. Facebbok User 1—March 7, 2012

(…) I think you also need to add to your call of action is self examination I read 70 % of breast cancer is detected this way. Facebook User 2—September 14, 2011

Other testimonies are of a very personal nature and discuss issues related to coping/facing the disease (49) and end-of-life experiences (31).

I have pledged to start a conversation in memory of my father who passed due to PC years ago and in support of myself and my brother both diagnosed last year. Facebook User 3—June 17, 2011

Thanks, Adrienne. I've been sliced & diced and poisoned. Just finally got feeling back in my heretofore dumb feet for the first time in about 6 months Monday (due to neuropathy caused by chemo). Facebook User 4—September 16, 2011

The interviews have revealed that sharing testimonies is sometimes a goal in itself for the organizations who are offering social media platform. Indeed, they are viewed as a vital part of social media activities in a way that increases participants' engagement.

We have some testimonials from breast cancer survivors. BCS

Our goal or main objective is to share stories and contribute to a community of information about, mostly

about survivors or participation in our events, or sharing in that space. BCF

We found that people do like to see the news but they are much more engaged, of course, if you make it personal to them—either through a personal story or ask a question that they can respond to. PCF

4.2.4 Advocating

Our analysis of the posts and comments aimed at advocating (50) reveals that the discussion is shared between the organization and individuals. The use of Facebook to advocate is primarily oriented towards governmental policies and health programs (21) (e.g. patent cases), availability of specific treatment options (16) and increasing screening access or prevention (12) (e.g. make available prostate or breast screening for younger patients).

A few examples of this advocacy can be seen below with examples on the topics of research funding, patents on a medical test and access to health care for those with chronic diseases and disabilities.

"The National Institutes of Health (NIH) is testifying in front of the House Appropriations Committee as we speak in an effort to secure 2013 funding. Though we have to wait until tomorrow for a full recap, there is something you can do today to help secure cancer research funding for 2013. Please sign the online petition!" PCF—March 20, 2012

"Breast Cancer Action, as plaintiffs in the case Association for Molecular Pathology v. Myriad Genetics, opposes gene patents because they harm women's health. Today we learned that the U.S. Supreme Court set aside a 2011 Court of Appeals ruling that allowed Myriad to patent the BRCA1 and BRCA2 genes. The Federal Circuit will reconsider the case in light of the Supreme Court's decision last week in Mayo Collaborative Services v. Prometheus, where it ruled unanimously that a patent on a medical test was invalid because it covered a "law of nature." http://www.aclu.org/free-speech-womens-rights/supreme-court-remands-aclu-gene-patenting-case-appeals-court". BCA—March 26, 2012

"Us TOO's President & CEO, Tom Kirk, along with 25 of the nation's leading patient advocacy organizations, have issued a statement in support of the Affordable Care Act (ACA). The statement was signed by leading patient advocacy organizations that serve people with chronic diseases and disabilities. Us TOO is a proud member of the National Health Council and meets their Standards of Excellence." UST—March 27, 2012

Our interviews demonstrated that social media tools did indeed enable organizations to play an activist role

in relation to their core mission, though the interviewees did not necessarily refer to specific policies or legislation that would be advocated for as we saw in the Facebook posts. Some of these organizations also felt that they had a responsibility to represent the users and defend them; they felt that social media could help them doing so.

We've been historically a kind of an angry organization. People, you know, the organization was formed from women who were frustrated and angry about the lack of attention that breast cancer was receiving amongst all the cancers and particularly, feeling it was a gendered disease. And so, it was—patients should be quieter and more passive and more complacent about women's responses to it and their diagnosis and it shouldn't be talked about and so our initial kind of Facebook and tweets were—were kind of in that vein, and they have now become still kind of—and viewed with that sense of anger but that anger is now more urgent—more an urgency. And it's more directed and specific. BCA

We're not a, you know, we advocate—we want guys—our advocacy is for guys to get tested and, you know, the challenges that have kind of come to us from social media is—is that we're out there in a world where when you are talking about subjects like prostate cancer—there's a lot of different treatments for it. There's a ton of misinformation about it. PFP

4.2.5 Raising funds

Our analysis of the 180 posts and comments that are aimed at raising funds revealed that these posts are almost equally initiated by the organization or by individuals demonstrating that the organizations and individuals are both committed to raising funds for research or support activities. Activities of fund raising are mainly done through promotion of events or sale of products (142); the events that are promoted are events that either the organization themselves are putting on or events that the organization is advertising for other organizations.

"The MAC Rally of Hope has raised $75,000 so far for the Canadian Breast Cancer Foundation and it hasn't even started!!!! Get involved and help us reach our $100,000 goal. Check out www.macrallyofhope.ca *for all the details*." June 17, 2011 by MAC Rally of Hope on CBCF

"We're sending out a huge thank you to all of our wonderful volunteers who raised over $700 to support the Canadian Breast Cancer Foundation by baking more than 250 "pink" cupcakes at the Annual Aurora Street Sale on Sunday! We had many visitors from this family event passing by our booth, and we provided a pedometer for them to count their steps to get moving and stay healthy!" June 7, 2011 CBCF

"Oh Charlotte Craft Beer Week how we love you! Tonight, the party continues at Common Market Beer with NC Brewery Alleyway Rumble. We are bringing a special, one-off secret beer for a blind taste testing in the alleyway. You vote for your favorite! $20 for unlimited pours all night until the kegs are gone. $15 of each ticket sold goes to Pints for Prostates." March 21, 2012 by NoDa Brewing Company on PFP

A similar theme emerged from our interview data. That is, for some of the organizations we interviewed, fund raising was identified as an important rationale for social media use. For three organizations, fund raising was one of their key activities and they felt that social media tools would allow them to perform better in that area.

One day we're all excited that we raised so much money, because our mandate here is to raise funds for research. So, we're all excited that we've done this great job raising these funds and we're trying to figure out what's the best way to promote and event through marketing. BCS

Last year we added a little badge to our Run for the Cure website off of our main website to Facebook, and by adding that connection from Facebook to the participant or the person getting involved with the run, we know we garner to about 70 %. The people that participated or donated through that button, 70 % of them are new donors and new participants. So, we know that we're reaching a new audience that way. BCF

While, as we pointed out previously, some of the organizations we examined are committed to specific topics or activities, our data analysis shows that all the organizations truly share the same objective: cancer awareness. To some degree, they each participate in the five activities identified above. These results suggest that these six organizations compensate, up to a point, for a lack in the current programs and policies on cancer prevention in terms of the five areas identified—informing/educating, supporting, sharing testimonies, advocating and raising funds. Social media users play an important role in filling this gap and increasing cancer awareness.

5 Discussion and conclusion

Our results suggest a number of essential elements that play a major role in shaping collaboration through social media communities. In turn, this collaboration translates into key activities that support the objective of these communities.
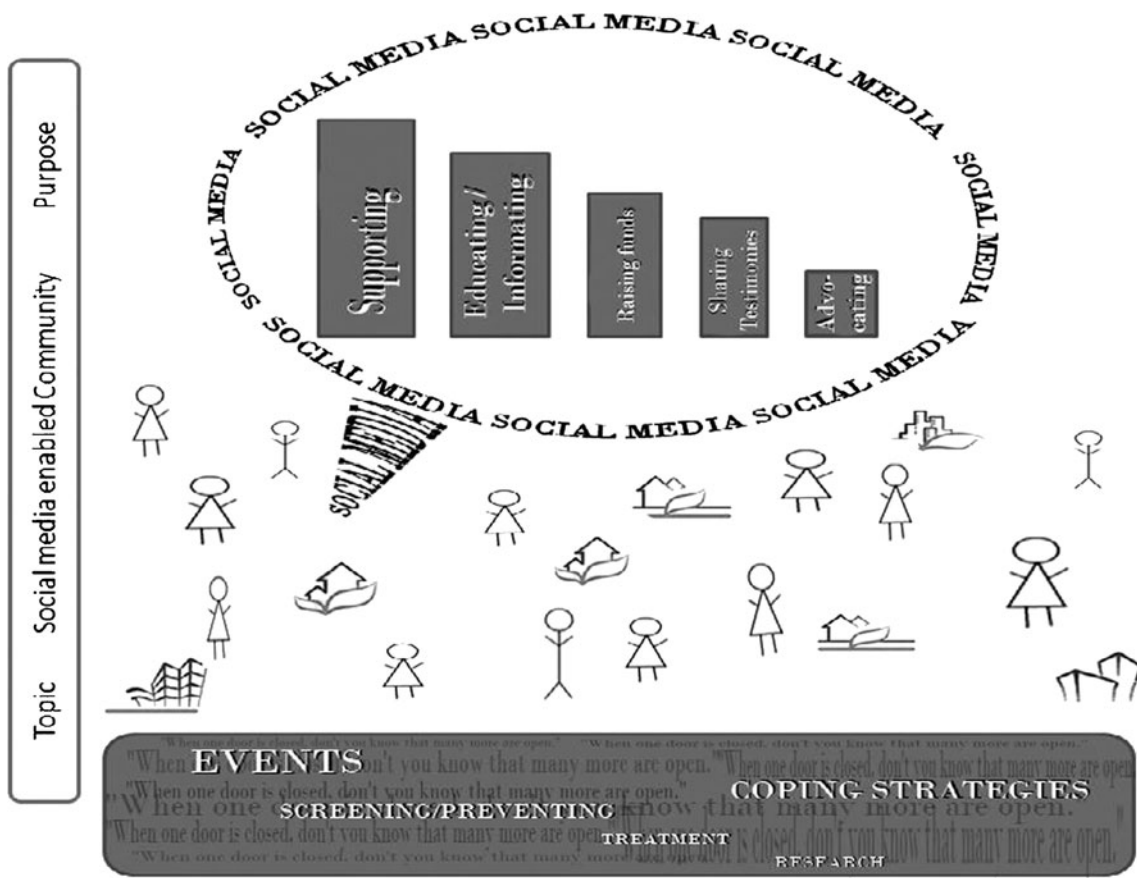
Fig. 1 Social media use to create health awareness

Figure 1 illustrates how organizations and individuals interact and engage with each other to create a community around cancer awareness through social media. By addressing the different topics that are critical for the community—such as screening, prevention, treatment, research and coping strategies—it becomes possible for the members of this community to collaborate to reach their common goals. In the six cases that we studied, the overall objective was to promote

Fig. 2 The users and functions of social media to create health awareness
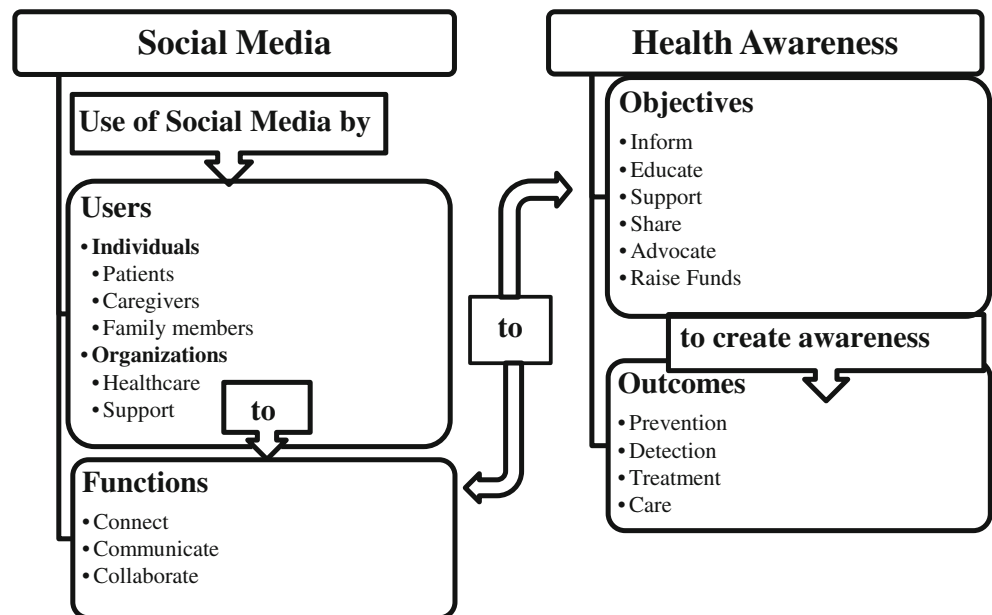
cancer awareness. In line with this general objective, the specific purposes of the social media activities were (1) supporting, (2) educating/informing, (3) raising funds, (4) sharing testimonies and (5) advocating.

Some of these activities have a basic role in creating and shaping the community; this is the case for example when users simply comment on others' posts without adding any additional information, which forms a 'bubble of comments' that maintain the life of the community. Other activities add value above and beyond the creation of a community when they bring about new and pertinent information that truly makes a difference for the community members, for example when they bring about new information or when they share coping strategies that increase the uptake of screening or improve the patient experience. We find that prevalence of these activities in the six communities we study enable the creation a major platform for cancer awareness.

Figure 2 provides a broad overview of the role of social media-enabled collaboration and its impacts on creating awareness.[4] In this paper, we examine the use of social media by organizations to collaborate with individuals for the purposes described above. While the scope of this study was to explore collaboration through social media first from the organization's perspective, there are opportunities to conduct a study focusing on the individual's use of social media not just to collaborate, but also to connect and communicate. Our findings show that organizations that use social media do incite collaboration for health awareness through connecting individuals to each other and even to organizations.

In this way, understanding collaboration through social media from individual's perspective appears to be a powerful tool for creating cancer awareness. In our study, we see this through individuals using social media to interact with one another by, for example, sharing testimonies and providing support for one another. As described above, we find that organizations use social media to accomplish a variety of objectives—from educating to fund-raising—which creates awareness of the need for screening (detection), options for treatment and care. Future research can further explore the mechanism and impact of these social media enabled collaborations, an understanding of which is essential for creating cancer awareness.

The findings in this study go beyond cancer awareness. Creating awareness and providing a platform for a community to form around many such diseases can aid in not only early detection, but also prevention, as well as support through the process of diagnosis and beyond. Our results suggest that these kinds of activities would be particularly important for "orphan" diseases. For such rare diseases, information and a support community is often difficult to find. Thus, the creation

of such a social media-enabled community would allow for patients and caregivers to find each other, connect with one another, and share otherwise dispersed information, which may be difficult to do in the offline world.

The role of these communities seems to be to fill a need that is not addressed by other organizations. Indeed, healthcare organizations do not have the time or the resources to provide such community support and information. Social media thus contributes to informed decision making and, ultimately, to patient-centered care. In the case of other health oriented organizations, such as research centers, patient support is not part of their core mission and they do not have the expertise or the time to create a community around patients and care providers.

At a broader level, social media enables the creation of communities that can link individuals and organizations around a common center of interest. These community members communicate and participate in a truly interactive manner, where organizations play a role of facilitators in enabling the activities that are at the heart of social media communities. These activities allow reducing barriers of time and space and multiple memberships, which might not be possible in other types of organizations. Thus, while the organization creates the platform for interaction, the actual community cannot exist without the individuals who actively participate in it, akin to the notion of grassroots community building. Indeed, we can see, that "if you build it, they will come"—while an organization often facilitates the conversation through creating the platform and initiating posts, the conversations, interactions, and community-building—the community is built when the individuals join in and interact.

The field of Information Systems has, until recently, focused on issues that were considered key for business and organizations; given its pervasive role in our societies, it becomes increasingly important to address issues that affect our society as a whole [49]. With the emergence of Web 2.0 technologies, we have observed more than ever before, that individuals' actions can play a significant role in organizations' actions. When looking at this in the context of health care and cancer prevention, the implications of this are enormous.

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[4] We thank an anonymous reviewer for generously suggesting and conceptualizing Figure 2.

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