Collaborating through Social Media to Create Health Awareness

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Abstract
This paper examines the role that individuals and organizations can play in creating awareness through the use of social media. In the healthcare context, creating cancer awareness is key in early detection of cancer as well as cancer prevention altogether. Using a multiple case study analysis, we are able to understand how collaboration through social media is used 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. This research has implications for organizations looking to use social media to promote awareness as it explains the building process and role of social media grassroots communities.

1. Introduction
Web 2.0 and the social computing phenomena (such as Facebook, YouTube, MySpace, Twitter) are creating a new reality in health care. Patients are changing from consumers of Internet content to generators of information using these Web 2.0 tools. The term health 2.0 or medicine 2.0 is thus now commonly used [1].

Social media (SM) is now providing a space to discuss medical conditions outside of the healthcare providers’ office [2]. Patients and their families use SM technologies to share their experiences and their findings and educate others with similar conditions. They repackaged the information they find for others, creating forums for knowledge discovery and discussion [2]. As an 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 [3].

Social media provides a forum for reporting personal experiences, asking questions, and receiving direct feedback for people living with a disease. Support groups have found a new platform for organizing as patients and family caregivers share their experiences, seek online consoling and connect with others [2, 4]. 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 [5].

Healthcare professionals are also using SM 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 [4].

More broadly, it has been shown that SM tools have enabled collaboration among individuals [6]. 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 SM enables collaboration in the context of healthcare, specifically to increase cancer awareness. Indeed, collaboration is considered essential in promoting cancer awareness [7, 8], as many different actors need to be involved in cancer prevention, detection and care.

Thus, in this study, we develop a model that allows understanding how collaboration through SM 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 this awareness is promoted: educating and providing information, sharing testimonials, providing support, raising funds, and advocating. Our results also provide a basis to understand the process through which SM grassroots communities are built, ultimately allowing the optimal use of SM when collaborating to promote health awareness.

2. Literature Review
To understand the role that SM can play in cancer awareness, we look at three relevant streams of literature: (1) we examine literature on cancer and cancer prevention; (2) we look at the literature on the role of collaboration in aiding in efforts to promote cancer awareness and (3) we look at how SM 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 4 deaths in the United States is due to cancer [9]. A total of 1,596,670 estimated new cancer cases and 571,950 deaths
occurred in the United States in 2011 [9]. 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 in order to identify individuals who have disease, but do not yet have symptoms [10].

Even though screening is paramount for early detection of cancer, people remain largely underscreened [11]. Many barriers are linked to patients’ lack of knowledge or awareness of screening tests and their lack of motivation to undergo screening [12, 13]. Thus, increased awareness of possible warning signs of cancer and 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. Since there is no “best” option for everyone, decisions are defined as being of higher quality when informed with the latest scientific evidence and based on patients’ informed values associated with outcomes of options. However, clinicians are not good judges of patients’ values, and patients often have inadequate knowledge, unrealistic expectations, and decisional conflict that interfere with their involvement in decision making [14]. Many guidelines thus point out the importance of informed decision making in cancer screening [15]. In addition, it is recognized as important to support patients with day-to-day problems associated with cancer and treatment [16]; this information and support can help friends and relatives cope with different stages of the illness better [17].

2.2 Collaborating to promote cancer awareness

Low cancer awareness contributes to delay in presentation for cancer symptoms and may lead to delay in cancer diagnosis [18]. Governments, healthcare organizations, and non-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 incidence, outcome and risk makes it unlikely that at-risk individuals, their friends and family, and even the general public could make informed decisions on a range of cancer issues [19]. It thus becomes essential to ensure the earliest awareness in terms of cancer screening [20] but also for providing support and coping strategies for cancer patients and their close ones [21].

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, it is crucial that channels of communication exist between these different stakeholders. In the past years, a good number of collaborative efforts have proven to be key in promoting cancer awareness and decreasing cancer health disparities in various communities [7, 8]. 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 [7].

2.3 The role of social media

2.3.1 Collaborating through social media. Online SM 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 [6, 22] and the organizational level, focusing on the role of information technology in enabling collaboration within organizations [23] and across organizations [24]. At the individual level, these collaboration-enabling technological tools initially encountered much resistance amongst employees within organizations [23]. 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 [25].

Indeed, such tools have garnered attention for their use as a means for individuals to collaborate outside the boundaries of traditional institutions [26]. While we typically observed this through crowdsourcing endeavors such as Wikipedia, Threadless and TopCoder, we have seen SM tools used to enable more grassroots collaboration as well. While the study of SM in the information systems (IS) research is nascent, 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.

2.3.2 Using social media for grassroots community building. Social media tools have been used by individuals 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 [27] and enabled coordination and grassroots collaboration after such disasters as the October 2007 California Wildfires [28] and the 2008 Sichuan Earthquake [29]. In such disasters, SM provided to be a source of information that was otherwise difficult to obtain using traditional sources. In the Arab Spring protests of 2011, SM played a key role in coordination. Indeed, in these protests “the input of the SM networks was critical in performing two overlapping functions: (a) organizing the protests and (b) disseminating information about them…” [30]. Without the existence of SM as the organizing tool, information dissemination and coordination of both the protests and for disaster recovery efforts would suffer.

3. Methods

The literature review suggests that SM enables connection, communication and collaboration amongst individuals, which used to be considered very challenging. In this study, we look at how SM can enable this collaboration in the context of 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.

As our objective was to develop a framework to explain how collaboration, through the adoption and use of SM (here Facebook) can play a role in cancer awareness, an explanation-building approach was deemed appropriate [31, 32]. We used a grounded theory analytic approach [33] that provides a set of flexible analytic guidelines enabling iterative data analysis and conceptual development [34].

We conducted a multiple-case study and analyzed six organizations whose mission was related to cancer prevention [35, 36], which allowed us to identify the SM 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 [37]: the six cases we selected varied in terms of disease type (breast vs. prostate¹), country (Canada or USA), year founded, size (number of employees) (see Table 1).

To support and enhance our understanding and to strengthen the research findings and conclusions, we triangulated our data sources [37]: 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 SM 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 thus 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 the months of June and September of 2011 and March 2012 for a total of 1352 activities (368 posts and 984 comments). The same strategy was used to extract the content of the documentation.

Interviews provided additional evidence. Given that in two organizations, there were two respondents, we had a total of 8 respondents. In each organization, we thus conducted semi-structured interviews with the CEO and/or person responsible for the SM development and use – i.e. the key informants [37]. These respondents had a thorough knowledge of the origins, implementation, use, barriers and enabling factors of traditional IT and SM 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 – that lasted one hour 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 approach [38]. 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 transcripts².

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. N’Vivo 8 software.
**4. Findings**

Analysis reveals that the majority of the 1352 posts/comments are from individuals; only 375 (out of 1352) are posted by the organizations. A close examination of the data shows that most posts are initiated by the organizations while comments are posted primarily by individual. Overall, these posts/comments are associated with a large number of likes (average number of likes is 24 per post and 2 per comment) and are widely shared, with a total of 8382 “shares”.

Though 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. However, we 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 and that focuses on themes such as cancer screening, prevention and treatment. The main focus of BCS is providing support, especially in terms of promoting and sharing coping strategies. In the case of PFP, 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, SM 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 six 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, SM are seen as particularly useful to reach a wider audience, be it to reach a different demographics 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 fifty and sixty 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**

<table>
<thead>
<tr>
<th>Cases</th>
<th>Characteristics</th>
<th>Country</th>
<th>Disease type</th>
<th>Year founded</th>
<th>no of employees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer Action (BCA)</td>
<td>Type of organization: a grassroots organization for women with breast cancer and their supporters, at the forefront of the breast cancer activist movement.</td>
<td>USA</td>
<td>Breast cancer</td>
<td>1990</td>
<td>8</td>
</tr>
<tr>
<td>Breast Cancer Society (BCS)</td>
<td>Type of organization: a registered, national, not-for-profit, grassroots charitable organization dedicated to raising funds.</td>
<td>Canada</td>
<td>Breast cancer</td>
<td>1991</td>
<td>5</td>
</tr>
<tr>
<td>Breast Cancer Foundation (BCF)</td>
<td>Type of organization: a leading national volunteer-based organization dedicated to creating a future without breast cancer.</td>
<td>Canada</td>
<td>Breast cancer</td>
<td>1986</td>
<td>197</td>
</tr>
<tr>
<td>Us Too International (UST)</td>
<td>Type of organization: non-profit Cancer Education &amp; Support international support network</td>
<td>USA</td>
<td>Prostate Cancer</td>
<td>1990</td>
<td>5</td>
</tr>
<tr>
<td>Prostate Cancer Foundation (PCF)</td>
<td>Type of organization: A very large philanthropic source of support for prostate cancer research to discover better treatments and a cure for prostate cancer.</td>
<td>USA</td>
<td>Prostate Cancer</td>
<td>1993</td>
<td>30</td>
</tr>
<tr>
<td>Pints for prostate (PFP)</td>
<td>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.</td>
<td>USA</td>
<td>Prostate Cancer</td>
<td>2008</td>
<td>2</td>
</tr>
</tbody>
</table>
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, raising funds:

4.1 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 to the promotion of different events, such as Movember activities, galas or “Run for the cure” (52/208):

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


Interview data provide additional insight about these activities. An interesting observation is that SM allows organizations to tailor messages depending on who they are trying to reach. Indeed, organizations felt that SM 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

4.2 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.” March 15, 2012 BCS Inc.

“New support group in Southwestern Ontario for BRCA1 and BRCA2 gene mutation carriers. Bevin Sandercoc caries the BRCA2 and considers herself a "PREVIVOR"! She has recently taken on the role of the Ontario outreach

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1 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.
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 7pm. Please read article below for more information.” September 29, 2011 BCS

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.” March 21, 2012 Pints for Prostates

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 SM 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 SM tools 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

4.3 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 for examples patients and family members. These posts show how SM 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).

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. Felicia ODonnell – 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. Cherie Mathews – 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. Brian Lauther – 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). – Mary Coverdale September 16, 2011

The interviews have revealed that sharing testimonies is sometimes a goal in itself for the organizations who are offering SM platform. Indeed, they are viewed as a vital part of SM 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

4.4 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.
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 SM 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

4.5 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.macryallyofhope.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 SM use. For three organizations, fund raising was one of their key activities and they felt that SM 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 SM communities. In turn, this collaboration translates into key activities that support the objective of these communities.

Figure 1 illustrates how organizations and individuals create a community around cancer awareness through SM. By addressing the different topics that were critical for the community, it became possible to the members of this community to collaborate to reach their common goals. In the cases that we studied, the overall objective was to promote cancer awareness. In line with this general objective, the specific purposes of the SM 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 found that prevalence of these activities in the six communities we studied create a major platform for cancer awareness. Our results suggest that this kind 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 and 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. SM thus contributes to informed decision making and, ultimately, to patient-centered care. In the case of other organizations, such as research centers, patient support is not part of their mission and they do not have the expertise or the time to create a community around patients and care providers.

Overall, social media enables the creation of communities that truly 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 SM 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.

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 (Wattal et al., p. 680)“39 . 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.
References


Acknowledgement: We would like to sincerely thank Samuel Perreault for his help in coding the social media data and for his assistance in developing Figure 1.