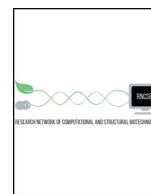




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# The “Real World”? Effects of Online Communication about Prostate Cancer on Offline Communication

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## ARTICLE INFO

### Article history:

Received 21 August 2018

Received in revised form 28 September 2018

Accepted 1 October 2018

Available online 12 October 2018

### Keywords:

Prostate cancer

Online communities

Social networks

Interpersonal communication

Social media

## ABSTRACT

**Introduction:** Online peer-to-peer social support programs are based on the premise that support from others who have been through a similar experience can help reduce the negative impacts of disease. Such support programs are increasingly found online, but how these conversations translate into real world interactions about health concerns is currently not well understood.

**Methods:** Grounded in social network theory, this formative study explored how participants in an online prostate cancer community comprised of patients and their families translate their online conversations into offline ones. A survey was designed and fielded, and received 157 complete responses.

**Results:** Results support prior research findings that these offline conversations are primarily information-oriented ( $n = 105$ ) and extend them by the finding that members of online prostate cancer social support communities do, in fact, share information obtained online with others offline ( $n = 103$ ). Family members appear to be primary receivers of this information ( $n = 121$ ) while health care providers are not, which may impact treatment and care.

**Conclusions:** The opportunity to tie more concretely online messages with offline conversations is of critical importance and interest. Recommendations are presented for future research.

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## 1. Introduction and Review of the Literature

Prostate cancer (PCa) is the third most common type of cancer in the U.S., and as of 2012, there were an estimated 2,800,000 men living with PCa in the United States [1]. While PCa has excellent survival rates when caught early, it is ranked as the fifth leading cause of cancer death in the United States. In fact, death rates are higher in African American men, men who have advanced stage cancer, and men ages 75–84 [2].

While there are a number of different types of treatment options available for patients with PCa, they come with side effects, e.g. erectile dysfunction, incontinence [2]. The empirical literature has well documented how unfamiliar and challenging the treatment of PCa can be for men, challenging men's confidence and perceived self-efficacy [3–7]. Helgeson and Cohen [8] contest that cancer patients' ability to live with their illness may be impacted by certain side-effects of PCa treatment including a weakened sense of self-confidence, perceived self-efficacy, and depression [3–7,9–25]. Massie et al.'s work also suggests that depression is a prevalent psychiatric syndrome in the cancer population [13].

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Helgeson and Cohen suggest further that the social environment of cancer patients is a powerful determinant of this [8]. Two primary reasons for this is because first, both structural and functional elements of one's social environment may promote well-being [26,27], and second, the stress of cancer may influence interpersonal relationships which can lead to patient withdrawal from these relationships [8]. Evincing this is Boehm et al.'s work, which tested a church-based intervention with African American men diagnosed with PCa found that, post-intervention, the study's sample had improved knowledge and self-efficacy scores [4]. As well, McQuellon et al. found that anxiety, depressive symptoms, and overall distress in cancer patients can be reduced through the use of interventions such as receiving a clinic tour and information about clinic operations and providing question and answer sessions with an oncology counselor [18].

This evidence helps to lay the foundation for the role of interpersonal communication within social networks in the study of cancer communication [8,26]. Social network theory (SNT) suggests that people access personal communication networks in order to access relevant information and support from others [28]. From a networking perspective, a social network involves a set of actors and connections between them that allow for such exchanges to take place [29]. These resources may include data, information, goods and services, social support, and financial support [30]. Recent research findings support this, suggesting that

there can be numerous types of actors and interactions within an online social network [31,32]. Practically, however, personal network relationships can help members access social cues, provide people with a sense of belonging, form their identity, and gain a sense of protection from being around others like them [28,33]. This can be particularly salient for men and women who are making health decisions for themselves and/or friends/family members.

How and to what extent an individual engages with another person about a topic – whether online or off – varies depending on the relationship with that person [34]. In terms of understanding levels of influence within relationships, the literature points out that not all relationships are created equal [34–44]. Granovetter first conceptualized the idea that there are varying levels of connection between two people in a social network with his “tie strength” construct [37]. Granovetter differentiates between strong and weak ties, suggesting that while strong ties are those ties with others most similar to an individual, weak ties are those ties with individuals who are less close and less similar, and it is most often between weak ties where innovation and new ideas are spread [37].

The advent of the Internet has resulted in new and different channels for these peer-to-peer social networks and relationships. Seventy percent of Americans now use social media to connect with one another, to engage with news content, and to share information, and use of the Internet appears to be increasing [45]. Further, data suggests that this increased activity includes accessing health information [46]. Moreover, these use statistics do not appear to shift across racial and ethnic lines [47]. Ultimately, this signals an expansion of the peer-to-peer network opportunities, as increased interpersonal interactions take place online in virtual communities and social media.

Online support groups, as a form of health-related online social networks, offer numerous benefits, such as 24-7 access, access at times most convenient to users, the ability to take the time to carefully develop responses at one's own speed, the removal of geographic and transportation barriers, ease of use for patients with mobility problems, speech and hearing difficulties or caregiving responsibilities, and anonymity for users with stigmatizing disorders like AIDS or persons recovering from sexual abuse [48–50]. Specifically, they are particularly useful for connecting individuals to others with similar health concerns [51].

Moreover, families of patients may also receive benefits from participating in these types of online communities. Coulson, Buchanan and Aubeeluck's work on online social networks in support of patients with Huntington's disease and their families found that a main function of these online social networks appeared to be to provide emotional support to all members including the families of patients [52]. The authors' work is based on prior research, which found that caretakers often subordinate their own needs and quality of life to the needs of their sick loved ones [53–58]. Given caretakers' behaviors of subordinating their own quality of life because of sick loved ones, Coulson, Buchanan and Aubeeluck suggest that participating in such online groups can typically help family members feel acknowledged and validated by other members' similar experiences and viewpoints [52].

Moreover, the concept of tie strength has been studied in relation to these online social networks. Recent studies found links between weak-tie support preference and lower perceived stress, as well as weak-tie preference and objective utility – or the degree to which individuals are perceived able to communicate about illness objectively – in computer-mediated environments [59]. Despite prior work on understanding relationships within online and offline social networks, little research has looked at how relationships transcend these spaces [60–63]. While understudied, there is some initial evidence that relationships that are initially formed in the online world can promote interactions and relationships in the offline world [60–62]. Moreover, Carter found that “rather than being exotic and removed from real life, [these relationships] are actually being assimilated into everyday life” (p. 148) [60].

Ultimately, online peer-to-peer social networks have an important role to play in the treatment and management of PCa – for both patients and their families. Moreover, online PCa communities are considered to be one of the most promising aspects of e-Health with, “evidence [that suggests] that relationships that are initially formed in the online world can promote interactions and relationships in the offline world [60–62]” (p. 1) [63]. Despite this, how such online interpersonal communication impacts offline interpersonal communication has not been well studied. Xie states, “It remains under-examined in the general literature how and why online interactions and relationships lead to offline interactions and relationships, the transition from online to offline and vice versa and how, together, online and offline interactions affect the quality of overall relationships” (p. 2) [63]. Therefore, further understanding how these online interactions and conversations translate into real world conversations and behaviors is worthy of discussion.

This study aimed to understand how interpersonal conversations in an online PCa community comprised of patients and their families result in offline conversations. Specifically, it looked at whether members of an online PCa community talk with people who are not members of that community about topics discussed in the community, with whom those conversations happen, how comfortable members are with these kinds of conversations, what barriers there are to these conversations, and which topics are discussed. It builds on prior research that looks at the use of online health-related social networks by specifically focusing on PCa. It expands on this work by looking at how participation by both patients and their families in online communities leads to offline interactions, which has not been well-studied to-date. This paper reviews the foundational literature supporting this study, the study design and methods, the findings and future research opportunities. Finally, it acknowledges the limitations of this study.

## 2. Research Questions

The aim of this exploratory study was to explore how participants in an online PCa community comprised of patients and their families translate their online conversations into offline conversations, specifically the topics they discuss and with whom they have these discussions. In pursuit of these goals, the following research questions were posited:

RQ1: How do conversations that take place in an online prostate cancer community translate into conversations had by those members offline?

RQ1a: What barriers exist to the sharing of information learned in these online communities offline?

RQ2: With whom do online community members have offline conversations?

RQ2a: What are those conversation experiences like?

RQ2b: What topics do online community members choose to discuss with offline receivers?

RQ3: What do members of an online prostate cancer community find valuable about using the community?

RQ4: Do individuals who share information offline differ from those who do not share information offline based on the perceived value of the community?

While an exploratory study, the researcher hopes to glean some insights that may serve to expand research in this area and inform a larger study and possibly future health communication campaigns.

## 3. Methods

This pilot study utilized an inductive approach and convenience sample whereby, a non-probability sample was obtained based on the characteristics of the population studied and the objective of the study [64] to explore how conversations that take place within one online PCa community comprised of patients and their families translate into offline conversations had by those same members.

### 3.1. Recruitment

Institutional Review Board (IRB) approval was obtained through George Mason University's Office of Research Integrity and Assurance. Following IRB approval, participant recruitment started. Respondents were recruited via the online PCa community, The "New" Prostate Cancer InfoLink Social Network (InfoLink). As of December 2016, InfoLink has 6527 members [65]. InfoLink is an online social network focused specifically on "bringing together patients, family members, physicians, researchers, and anyone else who is seeking information about PCa" [65]. It is a service of Prostate Cancer International (PCI) and is closely associated with the core information and daily news made available through PCI [65].

To invite the sample of users to be part of this study, messages promoting the survey and inviting members of the online community to participate were sent via the online community manager. This was done by the community manager posting a message via the online community forum. Two messages were posted including the original announcement and one follow up message to remind members to take the survey.

### 3.2. Sample

The study analyzed survey responses by members of an online PCa community, InfoLink. The sample for this study was a convenience sample, thereby letting anyone who is a member of the online community respond to the survey. Three hundred and forty-three participants initiated the online survey. In reviewing the data set, the researchers found that some responses that were duplicative (IP addresses were the same) and that some responses were only partially completed (and thus unusable for data analysis). Therefore, 186 participants were removed from the data set. As a result, 157 eligible participants completed the survey.

### 3.3. Measures

To collect data and evaluate the outcomes of this study, a survey was developed. All recruitment materials and messages included the link to the online survey via Qualtrics. The first page of the survey contained informed consent materials. Participants clicked "agree" to provide consent. Participants answered sociodemographic questions and responded to a scale adapted from another published survey on the technology acceptance model [66]. Reliability of the scale was assessed using Cronbach's alpha.

**3.3.1.1. Perceived Value.** A validated scale from previous research was used to operationalize this study's concept of "Perceived Value", or the value users of the online community perceive getting from participating in the community. Four items from Malhotra and Galletta's Psychological Attachment scale were adapted for the online community context. This measure uses a Likert-type scale ranging from 1 (Strongly agree) to 4 (Strongly disagree) [66]. Items from this scale included: 1) The use of the "New" Prostate Cancer InfoLink Social Network is important to me; 2) I feel a sense of personal ownership about the use of the "New" Prostate Cancer InfoLink Social Network; 3) I talk up the use of the "New" Prostate Cancer InfoLink Social Network to my friends and family; and 4) I am proud about using the "New" Prostate Cancer InfoLink Social Network. This measure had a Cronbach's alpha reliability coefficient of 0.87.

**3.3.1.2. Have Shared.** This measure assessed whether respondents have shared information they have learned in the online community with people offline using a Yes/No dichotomous scale.

**3.3.1.3. Will Share.** This measure assessed whether respondents planned to share information they have learned in the online community with people offline in the future using a Yes/No dichotomous scale.

**3.3.1.4. Education.** Because of the low representation from less well-educated online community members, the level of education categories "College Degree" and "Graduate Degree" were combined and "Some College", "High School Degree" and "High School or Less" were combined.

**3.3.1.5. Race/Ethnicity.** Because of the low representation of non-White respondents, all other ethnicities were grouped into an "Other" category and Whites and non-Whites were compared for this analysis.

### 3.4. Analytical Process

The survey was developed and fielded using Qualtrics software. The survey was conducted from October 1–28, 2016. Frequencies and t-tests were run using SPSS Statistical Software Version 20 to answer research questions 1 and 3a. As well, a number of questions had open-ended responses. For this, themes were identified through both inductive and deductive processes [67,68], with themes and patterns from prior research with this community identified [69,70], and additional themes that emerged from the interview data captured. All these themes were collated in a code frame that was used throughout the data analysis process. Themes from the literature included value of participation, e.g. emotional versus informational support types; themes that emerged from the coding process included topics of conversation, e.g., treatment and personal connection, and perceptions of conversations. Open-coding of the content was conducted on a random sample of 20% of the total number of responses [71]. Content coding was used to answer questions 1a, 2, 2a, 2b, and 3.

## 4. Results

The final sample size for this study was 157 respondents. Among the respondent sample, the average age of the respondents was 65 years old. 58% of respondents were over the age of 65 ( $n = 90$ ) with the lowest age in the sample being 40. The sample skewed male (91%,  $n = 143$ ), with females representing only 9% ( $n = 14$ ) of respondents. In terms of education, the majority of respondents had college/graduate degrees (96%,  $n = 151$ ). In terms of race, the majority of respondents 93% were Caucasian/White ( $n = 146$ ), with the rest of the sample reporting being non-White (7%,  $n = 11$ ). Only 37% of respondents ( $n = 58$ ) reported having a family history of prostate cancer; while the majority (63%,  $n = 99$ ) reported not having a family history of prostate cancer. 89% of respondents ( $n = 140$ ) reported that they have children; while 11% ( $n = 17$ ) reported that they did not. See Table 1.

**Table 1**  
Frequency distributions for variables in sample ( $N = 157$ ).

Variable	Category	N	%
Age <sup>a</sup>	18–44	1	<1%
	45–64	65	42%
	65+	90	58%
Gender	Male	143	91%
	Female	14	9%
Education	Less than College	6	4%
	College/Graduate Degree	151	96%
Race	White	146	93%
	Non-white	11	7%
Have Children	Yes	140	89%
	No	17	11%
Family History of PCa	Yes	58	37%
	No	99	63%
Have Shared Information	Yes	103	66%
	No	54	34%
Likelihood to Share in the Future	Yes	134	85%
	No	23	15%

<sup>a</sup> Individual ages were grouped in this chart based on U.S. Census age groups (U.S. Census, 2010).

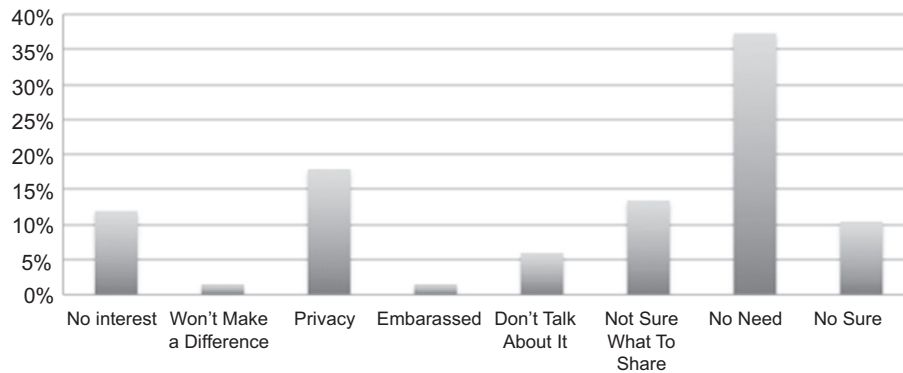


Fig. 1. Why Members Do Not Share Information

#### 4.1. RQ1: How Do Conversations that Take Place in an Online Prostate Cancer Community Translate into Conversations had by those Members in Offline?

The first research question for this study explored how information shared within an online prostate cancer community affected offline interpersonal communication. In order to assess this question, basic frequencies tests were run on two questions in the survey – first, whether respondents have shared information they have learned in the online community with people offline, and second, whether they planned to do so in the future. To the first question, results from the analysis indicate that the majority of respondents (66%,  $n = 103$ ) have shared information obtained in the online community with someone offline. Only 34% ( $n = 54$ ) reported not having shared. To the second question, results from the analysis of the sample data indicate that the majority of respondents are likely to share information from the online community with others offline (85%,  $n = 134$ ). Only 15% reported not planning to do so ( $n = 23$ ).

#### 4.2. RQ1a: What Barriers Exist to the Sharing of Information Learned in These Online Communities Offline?

A sub-question to the first research question focused on barriers to offline information sharing. For this question, open-ended responses were analyzed using the code frame developed for this study. Results suggest that for respondents who reported that they did not share information with others offline, the majority reported that they had no need to talk about the information shared online with others offline (37%,  $n = 25$ ). As well, a primary driver of this lack of conversation was “Privacy” (18%,  $n = 12$ ). Fig. 1 depicts these data.

#### 4.3. RQ2: With Whom Do Online Community Members Have Offline Conversations?

The second research question focused on the people with whom online community members share information offline. For this question, open-ended responses were analyzed using the code frame developed

for this study. Results suggest that by far, members of the online community share information obtained online with their family offline (57%,  $n = 121$ ). Broken out, spouses are primary receivers of this information (26%,  $n = 55$ ), followed first by other family members (17%,  $n = 35$ ), and then by children (15%,  $n = 31$ ). Friends (21%,  $n = 44$ ) and other patients (16%,  $n = 11$ ) are also main receivers of this information. Health care providers (HCPs) only represented 5% ( $n = 11$ ) of responses about with whom this information is shared. Fig. 2 displays these data.

#### 4.4. RQ2a: What are those Conversation Experiences Like?

Related to this study's second research question, a sub-question was posed which aimed to understand respondents' perceptions about how comfortable those offline conversations are. For this question, open-ended responses were analyzed using the code frame developed for this study. To assess this, a number of aspects of their feedback about their experiences with these conversations were considered. First, the results suggest that the majority of these offline conversations are positive (60%,  $n = 71$ ). 12% ( $n = 14$ ) reported that they felt that they were being helpful and 10% ( $n = 12$ ) reported that it felt normal to have these conversations. 15% of respondents ( $n = 18$ ) reported that they were not able to assess how the conversation went. For these respondents, they also reported that this information was shared via email so there was no response or evaluation of how the information was received. Only a few reported negative experiences (3%,  $n = 4$ ). Fig. 3 details these data.

#### 4.5. RQ2b: What Topics Do Online Community Members Choose to Discuss with Offline Receivers?

A second sub-question to the study's second research question focused on the topics that are talked about with others offline. For this question, open-ended responses were analyzed using the code frame developed for this study. Results suggest that “Research and Up-To-Date Data” is the most frequently shared type of information (23%,  $n = 39$ ). This is followed by information about “Treatment Options” (22%,  $n = 38$ ) and “General Information and Resources” (17%,  $n = 28$ ). Noteworthy is the low frequency of “Personal Stories” (8%,  $n = 14$ ) and “Emotional Support

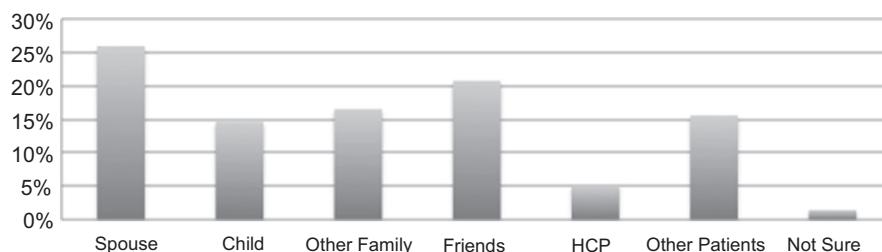


Fig. 2. With Whom Information is Shared

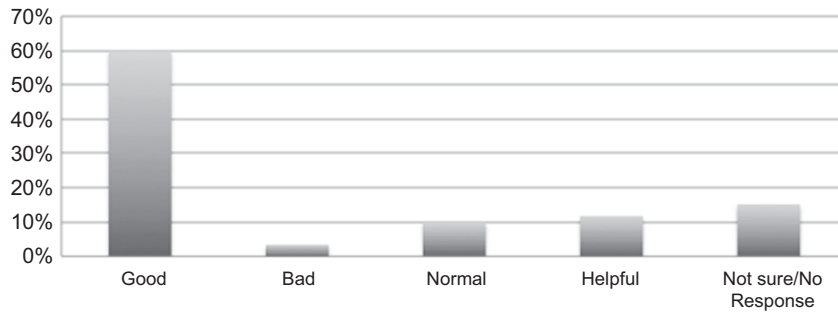


Fig. 3. Conversation Experience

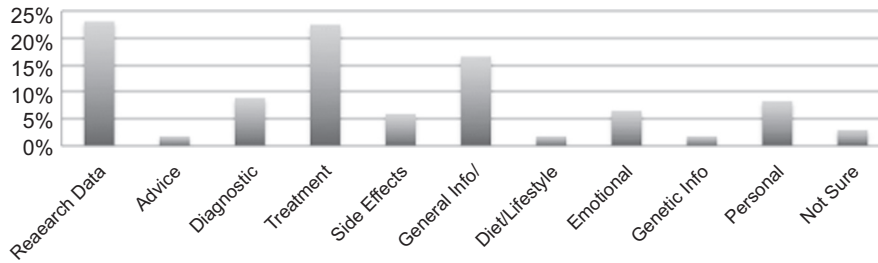


Fig. 4. What Information is Shared

and Coping”- related information (7%, n = 11) that is shared. Fig. 4 details these data.

4.6. RQ3: What Do Members of an Online Prostate Cancer Community Find Valuable about using it?

The study’s third, and final, research question focused on online community members’ perception of the utility of the online community. For this question, open-ended responses were analyzed using the code frame developed for this study. Results suggest that the information shared within the online community was the most valuable aspect of being a member of the online community (43%, n = 123). Second to this was the ability to connect with others (22%, n = 64). Fig. 5 details these data.

4.7. RQ4 Do Individuals who Share Information Offline Differ from those who do not Share Information Offline Based on the Perceived Value of the Community?

The fourth question focused on understanding whether individuals who share information offline differ from those who do not share information offline based on the perceived value of the community. To assess this, the relationship between the variables, “Perceived Value” and

whether one shares information offline were assessed. This relationship was found to be statistically significant. Using a *t*-test, data were analyzed to understand whether people who share information offline differ from those, who do not based on how valuable they perceive the online community to be. For this test, there was a significant difference in the scores for those who do not share (M = 2.63, SD = 0.71) and those who share (M = 1.91, SD = 0.50);  $t(155) = 7.36, p \leq 0.001$ . This indicates that there is a difference between individuals who share information offline and those who do not share based on their perceived value of the community. In short, sharing information offline really does have an effect on the perceived value of the online community.

5. Discussion

This study aimed to understand how interpersonal conversations in an online PCa community comprised of patients and their families result in offline conversations, specifically, whether members of an online PCa community talk with people who are not members of that community about topics discussed in the community, with whom those conversations happen, how comfortable members are with these kinds of conversations, what barriers there are to these conversations, and which topics are discussed. The findings from this study are worthy of some discussion and hold several implications for future work in this area.

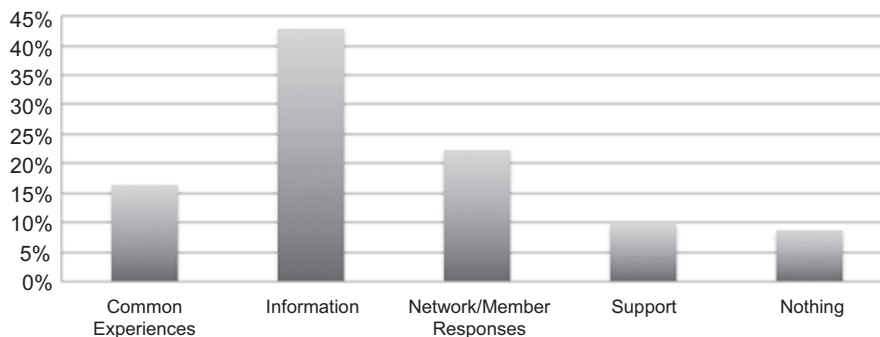


Fig. 5. Utility of Online Community

The following in-depth discussion of the study's results begins an exploration of how this work contributes theoretical and translational insights to the social science literature.

### 5.1. Theoretical Insights

Theoretically, this study contributes to the literature in a number of ways. First, it provides updated data collected from an online support community, specifically one focused on PCa. The current literature on online social networks has demonstrated that they are particularly useful for connecting individuals to others with similar health concerns [51] and while this holds true for patients, families of patients also receive benefits from participating in these types of online communities [52–58]. In providing updated data collected from an online social network focused on PCa patients and their families, it supports prior research findings by suggesting that information, e.g. data, research and treatment options, is a valued aspect of the online community yet emotional support is also highly prized.

Further, it builds on work that has previously focused on offline social networks, extending that research by finding that users of these online networks do indeed share information from online communities with their offline social networks, something not well-studied to-date. Findings suggest that conversations had within the online network do bleed over into the face-to-face world, and that online community members intend to continue sharing this information in this way in the future. Moreover, these findings suggest that participants of the online social network who share are different from those who do not share, and that this sharing of information offline really does have an effect on the perceived value of the online community. These results add to the limited research around online effects on offline behaviors to-date.

This study's findings also provide insight into the qualities of the material that is most frequently shared between online and offline social networks. First, information about PCa is most often discussed. While perhaps the sharing of disease-related information could appear to be a more transactional kind of relationship these conversations are perceived to be positive by users of the online social network.

Such online-to-offline communication also expands our understanding of online social networks and the ties that exist within them. First, it supports Granovetter's work on weak ties by supporting the idea that weak ties are where innovation and new ideas are spread, e.g. the sharing of new information via an online social network [37], but also extends it by providing evidence of how these weak ties circulate this kind of information online.

Finally, this study's findings suggest that while there may be a preference for weak tie support in computer-mediated environments, as the prior cited literature found, the online conversations had between weak ties can have effects on offline strong tie relationships as well. This is evinced by the finding that information is most commonly shared with family including spouses and children. These findings further suggest that online and offline social networks are not separate, but rather, interwoven, which allows for flows of information to move freely between the online and offline worlds. This is an important finding that emerged from this study that greatly advances our understanding of how online interactions may impact offline ones. There is a dearth of literature on this topic and this study's preliminary data is, therefore, some of the first of this kind.

### 5.2. Translational Insights

The preliminary results of this study are also promising for future translational communication efforts, especially in the area of PCa communication. Clearly information is a primary reason members engage in the online community and it is primarily what members share with others offline. Therefore, the role and need of quality PCa information is paramount. However, the social network itself, as a secondary driver

of engagement in the online community, suggests that information without a personal network may not be as valuable. Moreover, the finding that respondents reported sharing information gathered in the online community with their HCPs only minimally suggests that there could be a barrier between information gathering online and how that information translates into actual prevention and treatment discussions.

Another translational implication of this study's findings is related to the finding noted previously that weak tie relationships online may effect offline strong tie relationships. If online weak ties do, in fact, effect offline strong ties, this relationship holds much promise for future PCa and other health-related research and communication initiatives where interventions are implemented online with the aim of affecting real-world behaviors. This is an area that, indeed, requires subsequent exploration.

Social network participants' reported mode of offline communication is worthy of some discussion. While not a question included in the survey itself, respondents did share that some of the information collected in the online community was shared offline via email. This suggests a few things. First, that "offline" may have different definitions for online community members. Despite the fact that email is still "online", respondents counted email conversations among the conversations that took place outside of the online community. Second, it suggests that there are different modes of information sharing that PCa patients and their families engage in. Finally, the use of email ultimately limited respondents' ability to share how this information was received and evaluate further impact of this information dissemination. This is another area worthy of further investigation.

A final point for discussion is that the study's findings revealed that there is little potential for online social network members to stop sharing or not share information obtained in the online network with others offline moving forward. This bodes well for health communicators who are seeking broader information dissemination about PCa and wishing to have an impact beyond the online community itself.

### 5.3. Limitations

A constraint of this study was the time frame for study design, data collection, and analysis. Because of this, this study utilized a convenience sample, which resulted in the sample being relatively homogenous. This sample was both a relatively older group of men, as well as a well-educated one. It skewed Caucasian/White, with only 7% of respondents being non-White. This aligns with prior data that suggest that Caucasians are more active health information seekers than non-Whites – especially when it comes to cancer-related information [72].

While demographic data for the whole community could not be obtained (personal communication by E. Michael Scott, February 1, 2018), there is no way to know if this study's sample is representative of the community as a whole. The high number of Caucasian respondents suggests that the community itself could skew Caucasian, as data shows that, "Latinos, blacks and whites use social media networks about equally, but there are some differences in their preferences" [73].

This underscores the need for future studies to identify other similar online PCa communities that may have a more diverse membership and/or recruit a more diverse sample from this online community. This is particularly important – not just to diversify samples in future research – but as well because non-Whites have higher incidence and mortality rates due to PCa. Understanding their communication patterns is crucial to the development of tailored and culturally appropriate health information dissemination efforts aimed at these groups.

As well, most of the online community member respondents reported having children but only a minority of them reported having had a family history of PCa. This is an interesting finding because despite the high number of respondents who reported having children, children were the smallest group among family members with whom online community members shared information offline. This coupled with

the finding that privacy prevented offline communication may suggest that offline conversations with children may be a sensitive area for men suffering from PCa. Related to this, the low frequency of personal stories being shared may have also been influenced by the fact that privacy restricted certain members from sharing this kind of information offline.

Limitations within the survey instrument may have also limited the data collected. For instance, the survey instrument did not include a question about respondent marital status yet this information would have been helpful to know in order to understand how support and communication vary based on marital status. As well, many of the analyses that were conducted were descriptive and intercoder reliability could not be assessed due to time and resource constraints. Despite this, the findings from this pilot project and exploratory study provide a foundation for future, more sophisticated research methods.

Additionally, this study made use of cross-sectional, self-reported data, among an opt-in sample with the possibility of self-selection bias. This may have skewed how respondents responded to the questions and therefore the data gathered. Finally, because this study was designed for expediency, there was not an opportunity to gain additional insight through interviews with the online community members themselves. This could have helped to triangulate the study's findings as well as provide a deeper understanding of some of the study's findings.

## 6. Conclusions and Future Research

As Serrat and Rheingold note, the world has changed and the information revolution has shifted the way people communicate [62,74]. It now revolves around flows of data, information, and knowledge – and those flows move through social connections. Therefore understanding how these connections operate is critical for communicators to understand in order to be able to get their messages disseminated. Especially for PCa researchers and communicators who are increasingly being required to demonstrate effectiveness of their campaigns on “real world” health behaviors, the opportunity to tie more concretely the communication of messages online with offline conversations – and hopefully, one day, behavior – is of critical importance and interest.

The intention of this study is to understand how conversations that take place in an online PCa community comprised of patients and their families are shared, if at all, offline, and with whom and on which topics. Future research should aim to explore the relationship between online weak ties and offline strong ties more in depth. As well, future work should aim to explore how these conversations translate into actual discussions about treatment with HCPs is critical. Given the low number of respondents who reported sharing information from the online community with their HCP, understand why this is, or barriers that exist to sharing this information with HCPs is worthy of investigation as it could help inform barriers to patient care and/or messaging strategies around discussing PCa treatment options with providers.

As well, this topic should be examined with a more diverse sample including women, more representatives from different race/ethnicities, and less well educated PCa patients and family members who use online social support communities. This is especially important in light of the fact that non-White men have higher mortality from PCa.

As well, this study could be conducted within online communities for other cancers and health issues to explore whether similar online-offline information sharing behaviors are unique to PCa or hold true for other issues as well. Finally, future research should build in more questions about mode of offline communication in order to garner a broader understanding of such offline information sharing.

## References

[1] National Cancer Institute. Cancer stat facts: prostate cancer. Accessed at <http://seer.cancer.gov/statfacts/html/prost.html>; 2015.

- [2] National Cancer Institute. Prostate cancer treatment (PDQ®)–patient version. Accessed at <http://www.cancer.gov/cancertopics/pdq/treatment/prostate/Patient/page4>; 2015.
- [3] Beckham JC, Burker EJ, Burker EJ, Feldman ME, Costakis MJ. Self-efficacy and adjustment in cancer patients: a preliminary report. *Behav Med* 1997;23(3):138–42.
- [4] Boehm S, Coleman-Burns P, Schlenk EA, Funnell MM, Parzuchowski J, Powell IJ. Prostate cancer in African American men: increasing knowledge and self-efficacy. *J Community Health Nurs* 1995;12(3):161–9.
- [5] Cunningham AJ, Lockwood GA, Cunningham JA. A relationship between perceived self-efficacy and quality of life in cancer patients. *Patient Educ Couns* 1991;17(1):71–8.
- [6] Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. *Cancer Nurs* 1997;20(3):187–96.
- [7] Weber BA, Roberts BL, Resnick M, Deimling G, Zauszniewski JA, Musil C, et al. The effect of dyadic intervention on self-efficacy, social support, and depression for men with prostate cancer. *Psychooncology* 2004;13(1):47–60.
- [8] Helgeson VS, Cohen S. Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. *Health Psychol* 1996;15(2):135.
- [9] Cain EN, Kohorn EL, Quinlan DM, Latimer K, Schwartz PE. Psychosocial benefits of a cancer support group. *Cancer* 1986;57(1):183–9.
- [10] Clarke DM. Psychological factors in illness and recovery. *N Z Med J* 1998;111(1076):410–2.
- [11] Frank-Stromborg M, Wright PS, Segalla M, Diekmann J. Psychological impact of the “cancer” diagnosis. *Oncology nursing forum*, Vol. 11. ; 1984. p. 16 No. 3, p.
- [12] Jønler M, Messing EM, Rhodes PR, Bruskewitz RC. Sequelae of radical prostatectomy. *Br J Urol* 1994;74(3):352–8.
- [13] Massie MJ, Gagnon P, Holland JC. Depression and suicide in patients with cancer. *J Pain Symptom Manage* 1994;9(5):325–40.
- [14] Massie MJ, Holland JC. Diagnosis and treatment of depression in the cancer patient. *J Clin Psychiatry* 1984;45(3, Sect 2):25–9.
- [15] Massie MJ, Holland JC. Depression and the cancer patient. *J Clin Psychiatry* 1990 Jul 51 Suppl:12–7; discussion 18–9.
- [16] McDaniel JS, Musselman DL, Porter MR, Reed DA, Nemeroff CB. Depression in patients with cancer: diagnosis, biology, and treatment. *Arch Gen Psychiatry* 1995;52(2):89–99.
- [17] McGarvey EL, Canterbury RJ, Cohen RB. Evidence of acute stress disorder after diagnosis of cancer. *South Med J* 1998;91(9):864–6.
- [18] McQuellon RP, Wells M, Hoffman S, Craven B, Russell G, Cruz J, et al. Reducing distress in cancer patients with an orientation program. *Psychooncology* 1998;7(3):207–17.
- [19] Newport DJ, Nemeroff CB. Assessment and treatment of depression in the cancer patient. *J Psychosom Res* 1998;45(3):215–37.
- [20] Seiegel D. Essentials of psychotherapeutic intervention for cancer patients. *Support Care Cancer* 1995;3(4):252–6.
- [21] Valente SM, Saunders JM, Cohen MZ. Evaluating depression among patients with cancer. *Cancer Pract* 1994;2(1):65–71.
- [22] Van PE, Van DDW, Denis L. Surgery or radiation: is there really a choice for early prostate cancer. *Crit Rev Oncol Hematol* 1998;27(1):11–27.
- [23] van't Spijker A, Trijsburg RW, Duivenvoorden HJ. Psychological sequelae of cancer diagnosis: a meta-analytical review of 58 studies after 1980. *Psychosom Med* 1997;59(3):280–93.
- [24] Weisman AD. Early diagnosis of vulnerability in cancer patients. *Am J Med Sci* 1976; 271(2):187–96.
- [25] Wortman CB. Social support and the cancer patient: conceptual and methodologic issues. *Cancer* 1984;53:2339–60.
- [26] Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985;98(2):310.
- [27] Glanz K, Lerman C. Psychosocial impact of breast cancer: a critical review. *Ann Behav Med* 1992;14(3):204–12.
- [28] Valente TW. Social networks and health: models, methods, and applications. , Vol. 1 New York: Oxford University Press; 2010.
- [29] Ye J. Traditional and online support networks in the cross-cultural adaptation of Chinese international students in the United States. *J Comp Mediated Commun* 2006;11(3):863–76.
- [30] Marsden PV, Campbell KE. Measuring tie strength. *Soc Forces* 1984;63(2):482–501.
- [31] Contractor NS, Whitbred RC, Fonti F, Steglich C. Understanding the ties that bind: a longitudinal investigation of the evolution of a communication network. *Western J Commun* 2012;76(4):333–57.
- [32] Contractor N, Monge P, Leonardi PM. Network Theory| multidimensional networks and the dynamics of sociomateriality: bringing technology inside the network. *Int J Commun* 2011;5:39.
- [33] Heisler JM, Ellis JB. Motherhood and the construction of “mommy identity”: Messages about motherhood and face negotiation. *Commun Q* 2008;56(4):445–67.
- [34] Wilson RE, Gosling SD, Graham LT. A review of Facebook research in the social sciences. *Perspect Psychol Sci* 2012;7(3).
- [35] Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *J Med Internet Res* 2013;15(4).
- [36] Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ* 2004;328(7449):1166.
- [37] Granovetter MS. The strength of weak ties. *Social networks*; 1977. p. 347–67.
- [38] Bakshy E, Karrer B, Adamic LA. Social influence and the diffusion of user-created content. Proceedings of the 10th ACM conference on electronic commerce. ACM; 2009. p. 325–34.

- [39] Cha M, Haddadi H, Benevenuto F, Gummadi PK. Measuring user influence in twitter: The million follower fallacy. *ICWSM 2010*;10(10–17):30.
- [40] Gilbert, E., & Karahalios, K. (2009). Predicting tie strength with social media. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 211–220). ACM.
- [41] Lento T, Welser HT, Gu L, Smith M. The ties that blog: Examining the relationship between social ties and continued participation in the wallop weblogging system. *3rd Annual workshop on the weblogging ecosystem*, Vol. 12. ; 2006, May.
- [42] Lewis K, Kaufman J, Gonzalez M, Wimmer A, Christakis N. Tastes, ties, and time: a new social network dataset using Facebook. *com. Soc Networks 2008*;30(4):330–42.
- [43] Sun T, Youn S, Wu G, Kuntaraporn M. Online word-of-mouth (or mouse): an exploration of its antecedents and consequences. *J Comp Mediated Commun 2006*;11(4):1104–27.
- [44] Valente TW. Network interventions. *Science 2012*;337(6090):49–53.
- [45] Pew Research Center. Social media fact sheet. Accessed at <http://www.pewinternet.org/fact-sheet/social-media/>; 2017.
- [46] Perrin Andrew. Social media usage; 2015; 2005–15.
- [47] IOM.edu. Communicating with today's WIC mom: the millennial generation. Accessed at [https://www.cdph.ca.gov/programs/wicworks/Documents/Millennial%20Generation/WICconnects%20Presentations/Communicating\\_with\\_Todays\\_WIC\\_Mom\\_Meredith\\_10.3.11.pdf](https://www.cdph.ca.gov/programs/wicworks/Documents/Millennial%20Generation/WICconnects%20Presentations/Communicating_with_Todays_WIC_Mom_Meredith_10.3.11.pdf); 2017.
- [48] Finn J. Computer-based self-help groups: a new resource to supplement support groups. *Soc Work Groups 1995*;18(1):109–17.
- [49] Finn J. An exploration of helping processes in an online self-help group focusing on issues of disability. *Health Soc Work 1999*;24(3):220–31.
- [50] Madara EJ. The mutual-aid self-help online revolution. *Soc Policy 1997*;27(3):20–7.
- [51] Walther JB, Boyd S. Attraction to computer-mediated social support. *Communication technology and society: audience adoption and uses*; 2002; 153188.
- [52] Coulson NS, Buchanan H, Aubeeluck A. Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient Educ Couns 2007*;68(2):173–8.
- [53] Aubeeluck A, Buchanan H. Capturing the Huntington's disease spousal carer experience: a preliminary investigation using the 'Photovoice' method. *Dementia 2006*;5(1):95–116.
- [54] Kessler S. Forgotten person in the Huntington disease family. *Am J Med Genet 1993*;48(3):145–50.
- [55] Maslach C, Philip GZ. *Burnout—the cost of caring*. Englewood Cliffs, New Jersey: PrenticeHall, Inc; 1982.
- [56] Flicker L. The effects of caregiving for the demented elderly. *Aust J Ageing 1992*;11(3):9–15.
- [57] Tyler A, Harper PS, Davies K, Newcome RG. Family break-down and stress in Huntington's chorea. *J Biosoc Sci 1983*;15(2):127–38.
- [58] Hans MB, Koeppen AH. Huntington's chorea: its impact on the spouse. *J Nerv Ment Dis 1980 Apr*;168(4) 209–14.
- [59] Wright KB, Rains S, Banas J. Weak-tie support network preference and perceived life stress among participants in health-related, computer-mediated support groups. *J Comp Mediated Commun 2010*;15(4):606–24.
- [60] Carter D. Living in virtual communities: an ethnography of human relationships in cyberspace. *Inf Commun Soc 2005*;8(2):148–67.
- [61] Parks MR, Floyd K. Making friends in cyberspace. *Journal of computer-mediated communication*, 1(4). JCMC144; 1996.
- [62] Rheingold H. *The virtual community: finding connection in a computerized world*. Addison-Wesley Longman Publishing Co., Inc; 1993.
- [63] Xie B. The mutual shaping of online and offline social relationships. *Inflamm Res 2008*(3):13.
- [64] Creswell JW. *Qualitative inquiry and research design. Choosing among five traditions*. Thousand Oaks. Google Scholar; 1998.
- [65] The "New" Prostate Cancer InfoLink Social Network. The "New" prostate cancer infolink social network. Accessed at <http://prostatecancerinfolink.ning.com/>; 2016.
- [66] Malhotra Y, Galletta DF. Extending the technology acceptance model to account for social influence: theoretical bases and empirical validation. *Systems sciences, 1999. HICSS-32. Proceedings of the 32nd annual Hawaii international conference on* (pp. 14–pp). IEEE; 1999.
- [67] Riessman CK. *Narrative methods for the human sciences*. Sage; 2008.
- [68] Bradford A. Deductive reasoning vs. Inductive reasoning. Accessed at <https://www.livescience.com/21569-deduction-vs-induction.html>; 2018.
- [69] Burke-Garcia A, Kreps GL, Wright KB. Perceptions about disseminating health information among mommy bloggers: quantitative study. *JMIR research protocols*, Vol. 7; 2018; 4.
- [70] Keyton J. *Communication research: asking questions, finding answers. Nghiên cứu truyền thông: đặt câu hỏi, tìm câu trả lời* Lon don: McGraw-Hill Higher Education; 2006.
- [71] Tracy SJ. *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. John Wiley & Sons; 2012.
- [72] Nguyen GT, Shungu NP, Niederdeppe J, Barg FK, Holmes JH, Armstrong K, et al. Cancer-related information seeking and scanning behavior of older Vietnamese immigrants. *J Health Commun 2010*;15(7):754–68.
- [73] Krogstad JM. Social media preferences vary by race and ethnicity. *Pew Research Center*; 2015; 3.
- [74] Serrat O. *Social network analysis. Knowledge solutions*. Singapore: Springer; 2017. p. 39–43.